

Situation Analysis of Disability Resources and Needs of Shantytowns Near Lima, Peru

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Abstract: Individuals in shantytowns of Lima, Peru experience unique challenges due to socioeconomic status and perceived inabilities. A situation analysis using rapid ethnographic procedures was conducted to explore life with disability in shantytowns of Lima, Peru. Participants and their caregivers expressed ideas to improve social inclusion of individuals with disabilities in their communities.

Keywords: disability in the developing world, social/political discrimination, disability analysis

Introduction

Individuals with a disability experience more discrimination from social and political activities, lower levels of education, higher rates of poverty, and decreased levels of employment in comparison to non-disabled populations. Households with an individual with a disability experience extra costs resulting from disability, and these households are more likely to experience food insecurity, poor housing, lack of access to safe water and sanitation, and inadequate access to health care. Poverty is thought to be both a cause and a consequence of disability. Recent studies indicate that over 80 percent of individuals with a disability live in a developing country (Chandran, Hyder, & Peek-Asa, 2010).

In June of 2011, the World Health Organization (WHO) published the World Report on Disability, the first comprehensive global disability analysis in over 30 years. This document identifies areas for further research, in particular qualitative research to better understand the lived experiences of individuals with a disability, as the understanding of disability is limited in many less developed areas. The purpose of this study is to investigate community resources and needs for individuals with disabilities living in the shantytown communities near Lima, Peru.

Literature Review

Currently there are over 650 million adults living with disabilities in the world, and four-fifths live in developing countries (WHO, 2011). According to the World Health Survey (2004), the disability rate in high-income countries averaged 11.8% and 18.0% in lower income countries (WHO, 2011). Disability can be both a cause and a consequence of poverty. Poverty can lead to disability through health conditions including low-birth weight, malnutrition, poor living conditions, unsafe work environments, and injuries (WHO, 2011). More than one-half of disabilities are preventable and can be directly linked to poverty (Parnes et al., 2009). Likewise, disability can lead to poverty: empirical evidence indicates that families of a disabled individual experience both economic and social disadvantages at a higher rate than families without disabled individuals. Disability often results in lower levels of education, employment, financial earnings, and increased expenditures on health related issues (Parnes et al., 2009; WHO, 2011). The challenges related to disability tend to be greater in developing countries with inadequate

health care systems, poor infrastructure, and limited budget for health care needs of their citizens (Maulik & Darmstadt, 2007; Parnes et al., 2009; Spiegel, Gosselin, Coughlin, Kushner, & Bickler, 2008). In developing areas, vulnerable groups, including women and individuals living in the poorest wealth quintile, have higher rates of disability (WHO, 2011).

Quantitative research related to disability in developing areas is limited; however a few socioeconomic trends are indicated. Children who are raised in poverty and have parents with low levels of education have higher rates of mental retardation (Aly, Taj, & Ibrahim, 2010).

Children with disabilities have lower school attendance rates than non-disabled children (WHO, 2011). A study of 15 developing countries indicates that households with disabled members spend more on healthcare than households without disabled members (WHO, 2011). Households with disabled members have fewer assets and worse living conditions than households without disabled members (WHO, 2011). In an analysis of 13 developing countries, disability is associated with greater chance of poverty when poverty is measured as being in the lower two quintiles of wealth (WHO, 2011).

According to the World Health Organization (2010a), community-based rehabilitation (CBR) is an important strategy to meet the needs of people with disabilities, especially in developing countries. Most disabled individuals, especially those in low- and middle-income countries or in rural areas have no access to institutional rehabilitation services. In low income areas, having a disability carries a social stigma that leads to limited access to health care, education, and livelihood opportunities (WHO, 2010b). CBR is implemented through efforts of individuals with disabilities, their families, organizations, communities, and relevant government and non-government organizations (NGOs) with goals of developing strategies for physical rehabilitation, equalizing opportunities, reducing poverty, and including individuals with disability in society (WHO, 2010a). In the late 1970s, WHO developed the first generation of CBR with the attempt to extend rehabilitation and medical care to disabled poor in developing areas. In 1994, the WHO, United Nations Organization for Education, Scientific and Cultural Development (UNESCO), and International Labor Organization (ILO) collaboratively developed the current concept of CBR that extends far beyond simply meeting medical and functional needs of the disabled population (WHO, 2010b). CBR is defined as:

“A strategy within general community development for rehabilitation, equalization of opportunities and social inclusion for all children and adults with disabilities. Available in more than 90 countries worldwide (WHO, 2010b), CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services” (WHO, 2002).

In areas with low levels of resources the WHO (2011) recommends that CBR efforts focus on identification of people with disabilities, referring them to appropriate resources, and providing education to health workers and families in strategies to reduce secondary complications related to disability.

Although there is no standardization in studying the effectiveness of CBR, current literature indicates a promising outcome for CBR programs. In an analysis of 29 CBR programs

in Asia, Africa and Latin America, Velema, Ebenso, and Fuzikawa (2008) reported that independence and social integration improved in at least 50 percent of CBR clients, roughly half of disabled children were enabled to attend school, and improved self-esteem in clients. Evidence indicates that quality of life for disabled individuals and caregivers of disabled individuals can improve with basic rehabilitation intervention (Velema et al., 2008).

Historically, most disability-related research is conducted in high-income areas like the United States and Western Europe, although it is understood that the disability and poverty relationship differs greatly between developed and developing countries (WHO, 2011). Since few disability research studies have been conducted in developing countries, little is known about the lives of individuals with disability in low-income areas, including shantytowns of Lima, Peru.

Context

Peru is a rapidly developing country in South America with a population of 27.5 million people (Peru National Institute for Statistics and Information, 2007). The capital city of Lima is the most highly populated with approximately 8.5 million people (Peru National Institute for Statistics and Information, 2007). In 2010, the GNI per capita in Peru was US \$4,710 (World Bank, 2010). According to the World Bank (2011), 34.8% of Peruvians live in poverty, or live on less than US \$2 per day, and over 14.7% live in extreme poverty, or live on less than US \$1.25 per day. Peru has a high estimated rate of disability: approximately 31% of Peruvians live with a disability, which is much higher than the global prevalence rate of disability of 15.6% (WHO, 2011). Only 12% of the disabled population has received some rehabilitation services in Peru (Campoverde et al., 2003). Less than 25% of adults with disability in Peru are gainfully employed, and 51.4% of disabled children do not attend school (Campoverde et al., 2003). It is estimated that less than 1% of the buildings in Peru are handicap accessible (National Council for the Integration of People with Disabilities, 2000). Old buildings have not been updated to accommodate the mobility needs of individuals with disabilities; the doors are too narrow and there are no elevators or ramps in place of stairs. Even new buildings with ramps are often not accessible because the incline of the ramp is too steep. Rehabilitation services in Peru are limited and costly, resulting in poor access to rehabilitation for individuals living in poverty. According to the World Bank, in 2009, the average yearly health expenditure per capita in Peru was US \$201, and 75.7% of health care expenditures are out-of-pocket expenses.

Methods

The WHO recommends that the first step before the implementation of CBR is to conduct a situation analysis (WHO, 2010b). CBR programs must be based on information that is unique and specific to each community in order to meet the needs of that specific community. According to the WHO framework for CBR, a situation analysis includes identifying what is known about people with disabilities and their living conditions through data collection of “the environment, social, economic, cultural, and political situation at the national, regional and/or local level” (WHO, 2010b). Information gathering should also be conducted through in-depth personal interviews and review of current literature and government documentation.

This study is a situation analysis of available and desired resources for individuals with disabilities in shantytowns of Lima, Peru. It was conducted through rapid ethnographic assessment procedures, including participant observation, semi-structured interviews, and focus groups (Scrimshaw & Hurtado, 1987). The WHO recommends that rehabilitation efforts first conduct a situation analysis that includes identifying what is known about people with disabilities and their living conditions through data collection of “the environment, social, economic, cultural, and political situation at the national, regional and/or local level” (WHO, 2010b). The WHO also recommends (2010b) that information gathering should be conducted through in-depth personal interviews and review of current literature and government documentation.

In order to gather diverse information related to disability in these communities, fifteen in-depth qualitative interviews with members of households with disability were conducted and one focus group of caregivers and individuals with disability was conducted. The semi-structured qualitative interviews and focus group provided an opportunity to voice opinions openly in order to provide a deep understanding and rich description of living with a disability. Qualitative interviews elicited personal accounts of barriers and facilitators to individuals with disabilities in these communities. The focus group discussion concentrated on social integration and employment opportunities for disabled individuals. Observation of participants, their environments and home life provided additional insights that did not occur through interviewing. Photography (with consent) was utilized to capture the essence of life with disability in these communities.

The field work was conducted during August, 2011. During this time the first author was familiarized with the socio-cultural and physical environment of the shantytowns of Comas, Huaycan, and Villa el Salvador near Lima, Peru. Visits were made to orphanages, therapy clinics, and a government funded pediatric rehabilitation hospital. Informal discussions occurred with adults with disabilities, caregivers of adults and children with disabilities, community health workers, therapists, social workers, and humanitarian workers. Formal semi-structured interviews and the focus group were conducted with formal consent procedures approved by the Wright State University Institutional Review Board (Dayton, OH) and by the non-government organization (NGO) that the author partnered with in Lima, Peru.

Households with a member with a disability were identified and recruited by utilizing the database of recent recipients of charity wheelchairs from the NGO. Purposeful sampling was used to identify participants representing a variety of disability types and ages. Participant inclusion criteria included residents of Comas, Huaycan, and Villa el Salvador, Peru, age 18 years and older who were familiar with disability through personal experience, familial experience, or community-based knowledge.

One focus group was conducted in the shantytown of Villa el Salvador consisting of five individuals with disabilities and two caregivers. Participants of this focus group were identified during a local government sponsored disability advocacy group meeting. The nature of this meeting was to discuss employment opportunities for individuals with disabilities. Focus group members were identified through a disability employment advocacy group that works with local

government officials. The focus group members were not participants of the individual interviews. Community health workers, therapists, social workers, and humanitarian workers were also interviewed. They were identified through snowball sampling techniques. For instance, one therapist introduced the first author to a social worker who works with the disabled population within that community.

A translator and a community health worker or community social worker was present for each interview. The community health worker has a working relationship with each participant, and their presence helped the interviewer gain access to homes with disabled residents. Additionally, the community health worker helped the interviewer successfully navigate the shantytowns. All participants were asked for oral informed consent prior to the interview or focus group. Additional consent was asked for taking photographs. Individuals with disabilities and their caregivers were interviewed in their homes. Length of the qualitative interview varied from 20 to 75 minutes and consisted of open-ended questions on the following topics:

- 1) Perceptions of and attitudes concerning disability
- 2) Access and barriers to health and education resources, mobility aides, and employment opportunities for individuals with disabilities
- 3) Openness to rehabilitation services for individuals with disabilities
- 4) Perception of resources needed to improve quality of life for individuals with disabilities
- 5) Any other topic that the interviewees wished to share related to life with a disability

The qualitative interviews ended when the interviewee had no additional information to add about life with a disability. Following each interview, the focus group, and informal discussions with community health workers and professionals, field notes were written, providing additional information for qualitative data analysis. All interviews and the focus group were digitally audio-taped and transcribed. Qualitative data was analytically organized through a case study approach, followed by thematic coding (Guest & MacQueen, 2011). Thematic coding was based on themes that emerged from interview narratives and field notes, in addition to common themes related to disability: barriers to rehabilitation, employment, education, and social integration, as well as facilitators of health and social wellness, the availability and use of durable medical equipment (DME), and self-perceptions and attitudes of others towards individuals with disabilities. Names of individuals are fictitious in order to protect the privacy of the interviewees.

Results

Characteristics of Participants

Fifteen homes with a disabled member were visited; there were 17 disabled individuals identified in the 15 homes. Two homes had two disabled family members. Age ranges of the individuals with a disability were 6 to 73 years. Eight of the individuals with disability were minors under the age of 18. The caregivers (parent or other adult family members) were

interviewed when the disabled individual was a minor. The most common diagnosis of disability was cerebral palsy (n=7). Other diagnoses represented included stroke, polio, amputation, Parkinson's disease, deconditioning, encephalitis, and spina bifida. For 15 of 17 of the individuals with disability, family members were identified as the primary caregiver, including parents, children, siblings, and grandparent. Key characteristics of the interviewees with disability are outlined in Table 1.

Through the semi-structured interviews, focus group, and direct observation, several themes emerged about life with disabilities in shantytowns of Lima, Peru. The following discussion provides insight into these themes: poverty, inclusion, education, violence and abuse, family life, and rehabilitation.

(See Chart Below)

Table 1. Characteristics of key participants

Age (yrs)	0-10 [1]	11-20 [7]	21-30 [1]	31-40 [1]	41-50 [2]	51-60 [0]	61+ [5]		
Marital status	Single [11]	Married [3]	Widowed [3]						
Disability type	Cerebral Palsy [7]	Polio [2]	Amputation [2]	Stroke [2]	Encephalitis [2]	Chronic conditions* [1]	Parkinson's disease [1]	Spina bifida [1]	
Age of disability onset (yrs)	Congenital [9]	0-10 [3]	11-20 [0]	21-30 [0]	31-40 [0]	41-50 [0]	51-60 [1]	61+ [4]	
Primary caregiver	Single parent [5]	Married parent [1]	Spouse [1]	Sibling under age 18 [2]	Child under age 18 [1]	Child over age 18 [3]	Grandmother [2]	Non-family member [1]	Does not need caregiver [1]
Provider of household income	Parent [8]	Disabled individual [1]	Sibling under age 18 [1]	Sibling over age 18 [1]	Child under age 18 [1]	Child over age 18 [3]	No income [2]		

[x], x = number of participants with characteristic

* Chronic conditions include heart disease and kidney disease.

Poverty and Disability in Shantytowns of Lima

The connection between disability and poverty in shantytowns of Lima, Peru appears strong. Most of the homes visited in each community were one or two rooms, lacked indoor plumbing, had dirt floors, and gaps in the walls, the roof providing little protection from the outdoor elements. Although most homes had access to electricity used to power one or two lights and a television and/or radio, often the electricity was “borrowed” from power lines by the home owners pulling electricity with a wire into their homes. The houses, furnished with few pieces of furniture were cold, dark and damp. On the walls of a few homes were religious pictures and traditional artwork. Most families cooked over an open fire or propane stove without adequate ventilation.

Although the family structure of the fifteen households that were visited varied greatly, family members were the caregivers for all but one of the houses visited. Single-parent households represented almost 80% of the households with a child with a disability. In two of the houses, the mothers had abandoned their family after their child was identified as having a disability. In these instances, the fathers provided income for the household, and an extended family member assisted with caring for the child with a disability.

Gainful employment opportunities are limited in the shantytown; so many fathers leave the home for weeks at a time for farming and mining work in the highlands east of Lima. Despite employment, these families could not afford daily motorized transportation, and the distance was too far to travel on foot. Although two families did have two parents, those households functioned as a single-parent household due to the absence of working fathers. The burden on the caregiver is great; caregivers and disabled individuals both express feeling like prisoners in their own homes. In most cases, the caregiver stays home 24 hours each day, limiting opportunities for his or her to provide additional income for the family. This is a double disadvantage since the expenses for households with a disabled member are greater than households without disabled members due to special needs for medical supplies, medicines, tests and health care visits. When work is available, average weekly income is 100-150 soles (US\$37-55.50). Caregivers report that diapers for incontinent children and adults cost 2.50 soles each (equivalent of US\$0.90), often totaling 10 soles each day. After the expense of medications (typically costing 5 soles per dose) and diapers, there is little money left over for food, clothing, home maintenance, and other bills.

Caregivers are creative in finding additional means for income. In two households the primary caregiver of a child with a disability earned income completing tasks that they could do in the presence of their disabled child. One mother washed clothes in buckets at home earning a few soles each day. Another single mother collected recyclables from trash piles along the street while carrying her six-year-old son with cerebral palsy. The income she earned selling the recyclables did not meet the needs for her four children; her income was supplemented by money from the father of one of her children.

Parents have to make the difficult decision between providing safety and supervision for their disabled children or additional income for their families. In two households both the father and mother of a disabled child were absent from the home. In one household, siblings cared for

the disabled child, and in the other household the disabled child was left home alone. In the case of “Mariella”, a 15 year old girl with cerebral palsy, her younger sisters, aged 6, 9, and 12 took turns staying home from school to care for their sister. The sisters reported that their father was at work in the mountains outside of town, and he likely would not return until the next week. Their mother was away “travelling” and the girls were uncertain when she would return. For this family, the poverty cycle will continue as the children forfeit education in order to care for their sister while their parents are absent from the home.

In the case of “Juan”, a 14-year-old boy with cerebral palsy, the single mother daily leaves the disabled son home alone while she works at a local store. The home’s only door was padlocked from the outside, providing “Juan” no way to escape in case of fire. The neighbor reported that most days the mother leaves the boy sitting on a chair on his front porch, but today he was inside. No one would be able to enter the home to help him. His mother’s need to provide income for the household compromised the physical needs and a safe environment needed for a child to thrive.

In one single-parent household with six children, two of whom had disabilities, the mother chose not to work in order to provide care for her children. One of her able-bodied sons works in construction and provides a modest income for their family. She reports that at times her family “must go without food so [they] can pay the bills.” She reports difficulty paying the water bill of 7.50 soles/month (approximately US\$2.75/ month) and electric bill of 22 soles/month (approximately US\$8.15/month). Her 11-year-old child with a disability has never seen a physician or been formally diagnosed because they lack the funds to visit the doctor. When asked about the family’s financial situation, the single mother says, “This is life, my life. I am used to this now. Before I cried, but I do not cry anymore. This is my life.” Disability affects not only the individual with the disability, but also their caregivers and the economic livelihood of the household.

Social Inclusion and Disability: Why Are People with Disabilities Hidden in Shantytowns?

As the first author walked through the streets and pathways of Comas, Huaycan, and Villa el Salvador, she wondered why people with disabilities were not visible. Based on a review of literature, it can be expected that more than 15% of the population of poor areas has a disability, but in Huaycan and Comas the author did not see a single person with a disability outside of their home. One caregiver stated that his mother, who had advanced Parkinson’s disease, had not left her home in more than one year because it was too difficult to assist her up and down the steep path that led to their home.

Factors that affect social inclusion in developing areas include infrastructure, terrain, geography, safety and violence in the neighborhood, transportation, self-perception, and attitudinal barriers of others. The roads to the interviewees’ homes often were not navigable by automobile or motortaxi (a motorcycle with a bench on the back for riders). The only way to reach most of the homes visited was on foot. Twice, in order to safely make it to the house, the author used both hands and feet to climb the steep hillsides. Couple the steep hills, rocky terrain, winding pathways with weakness, balance difficulties, and poor safety awareness, and a person with a disability easily becomes a prisoner within his or her own home. In the case of 15-year-

old “Mariella”, who has cerebral palsy, she remains confined in her home nearly every day. The 3 foot wide pathway around her home to the main walkway lies along a 10-15 foot drop-off. Her sisters report that she can only leave her home when her father is available to carry her down the hillside. The wheelchair she received from the charity through which we recruited her for this study is unable to navigate the steep, narrow, and rocky pathway, and her father is rarely available, as he works in the mountains for weeks at a time. Without someone to help her navigate the hillside, Mariella is unable to attend school, church, community events, and socialize with non-family members. Her community has a government sponsored school for children with special needs, but Mariella has never attended school due to the fact that her younger sisters, who are her primary caregivers, are unable to physically assist her to school.

Although each household visited had received a charity wheelchair within the previous two years, seven of the fifteen houses reported that they never use the wheelchair because it is unable to negotiate the terrain. Only one participant reported that he was able to use the chair independently, all other participants reported that they need a helper to navigate the wheelchair outside the home. The style of wheelchair that each interviewee received does not fold, and therefore has limited portability. Even if the family could afford to hire a taxi or motortaxi, the chair would not fit in the taxi or motortaxi, thus limiting the mobility of the individual with a disability once they have reached their destination.

Children and Disability: Why Not School?

Although each community did have a school for children with special needs, seven of the eight children in this study do not attend school. In each case, the caregiver identified transporting the child to school as the main barrier to education. Educational barriers expressed by the caregivers included: the school was too far away, the terrain was too difficult to navigate, and transportation by taxi or motortaxi was too expensive. Additional barriers to education reported by three caregivers were that the special education school was “a bureaucracy,” and the admission and enrollment processes were laborious and unfair. One community health worker reported that the school did not have appropriate equipment to meet the needs of children with disabilities. She stated, “The school does not have proper equipment. The children must sit in regular chairs and they tie them to the chair so they do not fall out of the chair.” One community health worker said she did not trust the special education school because of the lack of proper equipment and the teachers’ inadequate understanding of disabilities. If community health workers cannot recommend that caregivers pursue education for disabled youth, who will advocate for the education of the disabled child? If no one, the child remains uneducated, thus limiting the economic and income potential for the future.

Violence, Crime, and Disability

Shantytowns can be dangerous places, with densely populated areas and people in desperate situations. On several occasions, community members advised caution as we travelled about their communities: “Do not carry anything valuable” and “be aware of your surroundings” were common statements heard. The individual with a disability could be an easy target for crime outside of the home. An individual with a mobility-related disability may have limited ability to physically move out of harm’s way if threatened. The individual with a cognitive-

related disability may have limited ability to make sound judgments in stressful situations. The individual with a communication-related disability may not have the ability to call for assistance when found in a dangerous situation. For this reason and the factors discussed earlier, the individual with a disability often remains isolated at home. But, is a shantytown home safe for individuals with disabilities? At least two interviewees were victims of rape in their own homes. The following narratives give insight into their experiences of violence while living with a disability.

Elena's Story

"Elena" is a vibrant 21-year-old female with cerebral palsy. She is friendly, curious, and social. Her speech is limited, but she communicates in simple sentences when given adequate time. Elena lives with her mother, her 11-year-old brother who also has cerebral palsy, and four healthy siblings. According to her mother, the father is an alcoholic and she does not allow him to visit. She states, "When he comes around, I throw things at him to keep him out of my house." Their home is three small rooms, one of which does not have a roof. The floors are made of dirt. There is no sanitation system or running water.

According to a community health worker, Elena was raped at the age of 16. The rape occurred when her single mother was out of the home working to provide an income for the family. Elena was discovered to be expecting a child when she was seven months pregnant. Once she was identified as pregnant, she was sent to live in a government institution for disabled youth. Elena's son lives in an orphanage for children of disabled and/or mentally ill women. Most of these children were conceived through an act of rape. Once Elena's mother could prove that she was able to provide 24 hour care, her daughter returned home.

Rebecca's Story

"Rebecca" is a 34-year-old female with spastic cerebral palsy who lives with her mother. Rebecca cannot walk, sit up, or roll over on her own. She has spent most of her life lying in bed. Until she started going to therapy in the past year, she had been unable to speak and unable to feed herself. Rebecca's mother works outside the home, and Rebecca is left home alone all day. She has two children under the age of 10, who are both the result of rape. Rebecca's mother cares for her and her children.

In both of these cases, young women with disabilities were raped within their own homes when they were without the supervision of a caregiver. Their mothers made the difficult choice of seeking income over providing 24-hour care for their disabled children. Unfortunately, individuals with disabilities can be victims of violence both inside and outside of their own homes. Women with disabilities are an easy target for sexual violence because they are without a voice to be heard. Their silence can be physical, manifested in the inability to speak, but it also is figurative, as the disabled individual is not respected in the community. According to community health workers, their stories are similar to those of many other women with disabilities in these communities.

Family and Disability

Caregivers' Perception of Disabled Children

When a family is living within a mentality of merely surviving until the next day, a disabled family member is often overlooked and undervalued. Little time is spent investing in the disabled individual and working towards developing their motor, communication and cognitive skills. In several homes, individuals with communication difficulties, especially family members with cerebral palsy, were not viewed by their caregivers as having the ability to think. Caregivers have little education, often only three or four years of formal schooling. Health care providers have not educated the caregivers in techniques to maximize the potential of the disabled individual. Many caregivers knew little, if anything, about the diagnosis of the disabled individual. As a physical therapist, the author saw the potential in the individuals with disabilities; despite their difficulty communicating vocally, it was evident that many understood and desired to socially interact with others. Their eyes were bright, making contact with us. They smiled when they were spoken to, hugged, or touched. The clinical impression is that if given the opportunity to develop their communication skills, many of the non-verbal disabled individuals would be able to communicate with others either through spoken word or assistive technology.¹ The lack of opportunity for individuals with disabilities often begins in the home.

Rebecca's Story(cont.)

For 34 years, Rebecca had little opportunity to interact with other people. Living with severe cerebral palsy, she spent nearly every day bed-ridden, surrounded by newspapers to sop up her waste as her mother went to work. She was unable to speak and did not attempt to communicate or interact with her surroundings. She was unable to feed herself. Several months before my visit, a rehabilitation organization learned of Rebecca's situation and she began attending a rehabilitation clinic once each week. Her mother told the rehabilitation specialists that her daughter did not have the potential to improve, but she was willing to allow the rehabilitation specialists to pick up Rebecca and bring her to their clinic weekly. By the end of the first session, Rebecca verbalized one single word to the rehabilitation specialists: "pee-pee." The rehabilitation specialists assisted her onto the toilet, and she used the restroom. The rehabilitation specialists saw potential in her, and continued to bring her to the clinic weekly. Four months after starting rehabilitation, Rebecca was able to speak in complete sentences: "I want music" and "I don't like that," and she was able to feed herself. It is evident that she has the ability to learn and be more independent; however, this potential was not seen by her caregiver until Rebecca demonstrated her latent abilities.

What happened at the rehabilitation clinic that encouraged Rebecca to speak and be heard for the first time? Someone was willing to give her the opportunity to speak and the extra time required to do so. What would Rebecca be like today if her potential was realized when she was young? What if she had received rehabilitation services starting at a young age? How many children with disabilities are not given the opportunity to develop their skills?

Family Support and Disability

The family unit in Peru is strong and the family is the default caregiver for individuals with disabilities in low-income Peruvian families. Hired caregivers cost 1500 soles/month (approximately US \$555/month), making it a luxury accessible only to the wealthy. “Louisa” is a bed-ridden elderly woman with chronic health issues. Her husband of over 50 years quit his job in order to care for his wife when her health began to deteriorate 10 years ago. Working as a baker, his monthly income was 500 soles (approximately US \$185) and they were able to live a decent life off his salary until his wife became disabled. He said, “I would like to hire help so that I can work as a baker, but it is not possible to pay their wages [1500 Nuevo soles/month]. I miss baking.” Fortunately, Louisa has a spouse who is able to provide care for her, and her adult children provide income for the family. Not all disabled individuals in shantytowns are as fortunate.

Pedro’s Story

“Pedro” is a 73-year-old man who worked as a distributor of potatoes to local markets until the year before my visit. His job required him to carry sacks of potatoes, each weighing 50 pounds or more. According to community members he was one of the strongest and most respected men in the community. However, one day while he was at work, he developed weakness of the left side of his body and fell. Since that day, he has been unable to work, and for several months following the incident he was unable to walk. His mobility has improved, and now he is able to walk with the assistance of a walker.

Soon after suffering the stroke, Pedro’s wife passed away. The stroke that Pedro suffered did not only cause him to lose his job and his income, soon after suffering the stroke he lost his house. Without the ability to work, he was unable to provide income he needed to pay for his wife’s funeral and pay the lease to his house. Without any children or living family, Pedro quickly found himself homeless. He now resides in the back room of a soup kitchen in a shantytown. Volunteers from a local church have provided him with clothes, meals, and physical assistance with bathing and dressing him. According to the community health worker, Pedro has applied to live in a government institution for the elderly without family. However, because he has health issues and requires a caregiver to assist with showering, dressing and meal preparation, he was denied residence. She stated that elderly homes are only for healthy elderly people in Peru. Instead, Pedro stays in the small, dark, dusty room behind the community soup kitchen, wishing people would visit him. He is tearful and lonely.

It is not known how many disabled individuals in Peru are without family and caregivers. Similarly, there are no statistics to indicate how many others with a disability have been forced into homelessness. The family unit can be an asset, when they have the ability to provide adequate care for disabled family members. But, when the family unit is broken or an disabled individual has no family, they will be without adequate care and support. In the shantytown, support is almost exclusively given by families. Neighbors and social programs provide little, if any, assistance to families with members with disabilities.

Rehabilitation, Disability, and Poverty: Why Not Rehabilitation?

Rehabilitation (vocational, mental, physical, and occupational) is a means by which mobility, self-care, communication, and recreation are maximized. Of the fifteen shantytown homes visited, only one household's disabled members were currently receiving rehabilitation services. In this household, there were two individuals with disabilities, the rehabilitation services they received were free of charge, and transportation was provided. In the other homes, lack of money and lack of transportation were identified as the main barriers to rehabilitation. Two other interviewees, one man with a history of stroke and one man with an above-knee amputation, did not know that rehabilitation services could benefit their condition. They reported that health care providers never recommended rehabilitation to them. Eight of the 15 interviewees had received rehabilitation services previously in outpatient clinics, and all of those clinics were several miles from the home of the individual with a disability. All of them cited lack of money for transportation as the reason that they discontinued rehabilitation services.

No rehabilitation for individuals with disabilities leads to decreased levels of independence with mobility, self-care and communication, thus contributing to the social exclusion of individuals with disabilities in shantytowns. Social inclusion affects the quality of life of the individual with a disability. Education, friendships, recreation, and employment opportunities are key areas of life that are limited by social exclusion.

Martin's Story

"Martin" worked in construction as a concrete and plaster expert. He was well-known in the community as one of the best workers in construction. He made a good living, supported his large family, and was "content". One day at work he stepped on a nail, but due to diabetic neuropathy, he did not feel the sharp object in the foot. By the time Martin realized that the nail was in his foot, it had become infected. The infection was severe and antibiotics and wound care did not improve the infection. Eventually, his leg was amputated above-the-knee in order to get rid of the infection.

When I met Martin in his home, he was sitting at the kitchen table and he reported being sad. He said he was sad because he could no longer work at his job, which he loved very much. He said it is impossible to do heavy labor jobs from a wheelchair or while using crutches. When I asked about prosthesis, he reported that he could not afford prosthesis. Without a prosthesis, he would not be able to walk. Without being able to walk, he would not be able to work. He said his family was now poor because he could not work.

For Martin, the barrier to rehabilitation and prosthesis was money. Without money to pay for these services, his independence would not significantly improve. In the shantytowns of Lima, Peru, rehabilitation services are not utilized because there is no money available for such services, despite the fact that all of the interviewees reported that rehabilitation would improve their conditions.

Discussion

Where Do We Go From Here?

Although the United Nations' Millennium Development Goals do not specifically address disability, one of the goals is to reduce poverty by one half by 2015. We propose that social inclusion of individuals with disabilities is an integral component of achieving this goal. The former president of World Bank, John Wolfensohn, stated, "If development is about bringing excluded people into society... then unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half" (Mji, Maclachlan, Melling-Williams, & Gcaza, 2009). This situation analysis was a preliminary attempt to identify the available resources and needs of individuals with disabilities in the shantytowns near Lima, Peru. We present the following recommendations for local policy makers and community based rehabilitation organizations.

Educating Families About the Potential of Children with Disabilities

The lack of opportunity for the child with a disability often begins within the home. Parents, grandparents, siblings, and other caregivers often do not see the potential of the child with a disability. Caregivers do not see the benefit of sending their child with a disability to school. Community based rehabilitation programs can play a key role in providing education to caregivers to maximize the potential of the disabled child. Education topics can include the following: (1) maximizing communication, mobility and self-care of the disabled child; (2) education for the child with disability, (3) nutrition for the individual with a disability, and (4) psychological, physical and sexual health of the individual with a disability. Support groups for individuals with disabilities and their caregivers could develop partnerships between community members and advocacy groups for the inclusion of disabled individuals into the community. As potential is recognized in individuals with a disability, respect and social inclusion will improve.

Location Matters in Community Based Rehabilitation

Key components to social inclusion for the disabled individual within their community are access to education, rehabilitation and employment. For residents of shantytowns near Lima, Peru, the main barriers to education and rehabilitation are lack of money and lack of transportation. Schools and rehabilitation clinics are typically too far away to walk to, and the household has no money to hire taxi or motor taxi transportation. Thus, it is important to advocate for transportation of disabled children to the public schools. Community based rehabilitation programs should be located in accessible areas by individuals with disabilities. It may not be feasible to utilize one building to serve as a rehabilitation clinic for the entire shantytown. A mobile community based rehabilitation program may be better utilized by individuals with a disability and their caregivers. One may consider renting a room in a community building, like a place of worship or soup kitchen, one day per week, so that individuals with disabilities within a few blocks can more easily access the rehabilitation program. Another day of the week, the clinic could be set up in a different part of the community. Each location can target interventions to meet the specific needs of the individuals with disabilities that attend the rehabilitation program.

Volunteers as Assets to Community-Based Rehabilitation

Non-disabled community members expressed an interest in assisting and working with disabled individuals in their community, but they were unaware of opportunities to do so. Community based rehabilitation can utilize volunteers to supplement rehabilitation and health professionals. Educating volunteers on identifying the needs and assets of the disabled person and basic rehabilitation techniques, like range of motion exercises and self-care techniques, will promote partnerships between the community and the disabled community members. Identification of volunteers can occur at religious organizations, local colleges, and other community organizations. Community based rehabilitation programs should consider partnering with local universities to provide service learning experiences for therapy students. These students would benefit from the hands-on experience while the community based rehabilitation program would benefit from increased labor for minimal cost.

Employment for Individuals with Disabilities

Adults who acquire a disability report difficulty returning to work in the shantytowns. Most employment opportunities in shantytowns are manual labor jobs, and a new disability that affects mobility makes it difficult to return to work. Vocational rehabilitation is a strategy within community based rehabilitation that assists and trains individuals with disability to find meaningful work to provide income for their households. It will be important to partner with businesses in the community and advocate for the employment opportunities for individuals with disabilities. By encouraging business owners to hire individuals with a disability, it would allow individuals with a disability to be seen for their abilities rather than their challenges. In turn, respect and social inclusion of the individual with a disability would probably improve.

Happiness in Life with a Disability in a Shantytown

Although most interviewees with disabilities expressed feelings of helplessness, frustration, and worry, surprisingly, two interviewees expressed that they were content with life. One interviewee who has been unable to walk since contracting polio that affected both of his legs at the age of one said, "My life is good. I cannot complain." The two individuals who said they were happy had these factors in common: (1) positive family support and (2) social integration within their community. Both expressed that they ventured outside the home on a nearly daily basis, had many friends, and had plans for their futures. Despite the economic challenges and physical barriers in the community, it is possible to be happy and have a healthy outlook on living with a disability in a shantytown.

Limitations

This study speaks only from the perspective of individuals with mobility-related disabilities and their caregivers. The needs of those with cognitive, mental health, or sensory related disabilities may differ greatly than those with mobility challenges.

Future Considerations for Research

This study is only a preliminary attempt to understand the barriers to rehabilitation and social integration of individuals with disability in the shantytowns of Lima, Peru. Additional questions arose during interviewing and in the analysis process. Specifically, the issues of sexual health, sexual and domestic violence, rape of disabled females, employment opportunities, the capacity of special education schools, and the differences of life with disability for males and females in shantytowns, needs further investigation.

Conclusion

This study indicates that physical limitations are not the sole reason for social exclusion of disabled individuals in the shantytowns of Lima, Peru. Concern for personal safety limits the individual with a disability's inclusion in society. Limited knowledge and the low perceptions of others, especially caregivers, limit the potential of individuals with a disability. Environmental barriers, including steep and rocky terrain and inaccessible community buildings are indicated as barriers to education and rehabilitation for individuals with a disability. Access to rehabilitation clinics is limited due to a limited number of rehabilitation clinics and no finances for rehabilitation visits and transportation to appointments. It is expected that as accessibility of buildings, education, rehabilitation, and employment opportunities improve, advancements in health, quality of life, social inclusion and the livelihood of these communities will be noted.

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Endnotes

¹Assistive technology includes communication boards and adapted computer software utilized by individuals with disability to increase the possibility to better participate in society and live independently (Eide & Oderud, 2009). The UN Convention on the Rights of Persons with Disabilities (UN, 2006) calls for states to provide disabled individuals with mobility aids, devices, and assistive technology in order for disabled individuals to have equal opportunities and improved independence. However, in low-income countries, it is estimated that only 1-2% of individuals with disability receive such services (Eide & Oderud, 2009).