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ORIGINAL ARTICLE

Experiences of People with Physical Disabilities in a Low-Income Neighborhood of Bogota, Colombia

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Individuals with disabilities living in developing countries often face numerous challenges which make particularly difficult for them to fulfill basic life needs. We present the case study of twelve people unable to walk in a low-income neighborhood of Bogota, Colombia. As health professionals and human rights advocates, we have provided care to these individuals over the past 15 years. Following a subjectivist epistemological approach to qualitative research, we found that these individuals experience four main types of limitations: socio-economic, structural/environmental, emotional, and functional, which restrict their autonomy and life satisfaction. Their limitations make life strenuous and usually produce feelings of sadness, uselessness, and hopelessness. Social support, primarily from family members, alleviates these limitations. By following this group over time, we witnessed a rapid impairment of their health and emotional status, as well as their family members' growing exhaustion. Several policy changes and practical measures to address this situation are proposed.

Keywords: Colombia; disability; families; caregivers; poverty; social support

Introduction: The Context of People with Disabilities in Colombia

People with disabilities have a physical or mental impairment that substantially limits one or more major life activities (ADA 2017). This limitation can be reduced, and in some cases nearly eliminated with individual, social, and broad environmental interventions. Impairment refers to the physiological disorder or condition, cosmetic disfigurement or anatomical loss affecting one or more of the body systems; and disability to the social construct (ADA 2019).

Life for individuals with disabilities can be challenging regardless of location. Critical disability theory and research have contributed to make it visible that even in highly developed nations, '[a]mong those who face recurring coercion, marginalization, and social exclusion are persons with disabilities' (Devlin & Pothier 2006: 1). Similarly, feminist perspectives have shed light on differences in the experiences of men and women with disabilities in developed nations (Gerschick 2000; Thomas 2006), and the dangers of 'exclusion through nominal inclusion' (Thomas 2006: 183). Yet, people with physical limitations—both men and women—are often more vulnerable in the developing world (WHO and The World Bank 2011). Most advanced economies provide stronger social and environmental support for different types of impairments (Geiser, Ziegler & Zurmühl 2011).

While there are significant variations across developing countries, a number of nations lack the means to afford basic life needs and the physical and social infrastructures needed to support people with disabilities are undeveloped or they fail to reach all segments of society (The World Bank 2018b). These challenges have been associated with situations of social marginalization and economic inequality in various studies around the world (WHO and The World Bank 2011; UN 2015).

Colombia is an upper middle-income country located in South America. According to the most recent national census, 6.3% of Colombians live with a significant disability of which 2.6% are part of the RLCPD (National Registry for Location and Characterization of People with Disabilities). Ninety-three percent of people with disabilities in the country live with their family (Minsalud 2016); 80% in low-income neighborhoods and 82% in urban areas (Minsalud 2018; Janeth & Iván 2005). The most commonly reported impairments are movement and walking limitations (34.1%), nervous system alterations (25.7%) and visual impairment (13%) (Minsalud 2018). Twenty eight percent of the population refer a general disease as the origin of their disability, 11% accidents, and 9.7% genetic disorders (Minsalud 2018).

In recent decades, Colombia has experienced a paradigm shift in the level of attention devoted to people living with disabilities. The country has moved from a position of neglect to recognition of the problem and lately has made strides toward greater inclusion of those with disabilities amongst the population (Cuadros 2005). Today, articles 13, 16, 25, 47 and 49 of the Colombian Constitution, and Laws No. 361 of 1997, 1145 of 2007, 1346 of 2009, 762 of 2002, and 1618 of 2013, among others, guarantee the rights of people with disabilities and promote social inclusion of the same individuals (Republic of Colombia 1991, 1997, 2002, 2007, 2009, 2013). The number of organizations advocating for the rights of people living with disabilities has increased, as well as the number of activities aimed at social inclusion of this population. For example, strategies to promote education and employment among individuals with disabilities have recently been introduced (Guzmán-Suárez 2013).

Unfortunately, proposed interventions have not reached the majority of the Colombian population with disabilities. Those from low-income communities face numerous barriers accessing their rights (Rios Cruz, Guarín & Caycedo 2014). Stigma, violence, migration, flaws in the country's social support system, socioeconomic factors, and cultural beliefs all coalesce to create an unfriendly environment for Colombians with disabilities. People with disabilities find barriers for their mobility and daily activities in streets (46%), public transportation (34%), platforms (29%) and parks (26%) (Minsalud 2018).

Stigma on people with disabilities remains a problem in Colombia. Social stigmatization is rooted on ignorance about disabilities and limited interaction between individuals with disabilities and the rest of Colombian society. Until now, having a family member with an impairment has been considered an embarrassment for many people; families in this situation would try to hide their relatives from society, because their disability was seen as a punishment from God (Cuadros 2005).

Violence has dramatic implications for Colombians living with disabilities. The effects of violence include: (a) an increased population with disabilities caused by intentional injury, and (b) the creation of a hostile environment that impedes service provision to those living with disabilities. Colombia has endured over fifty years of political and social violence, and even though the country is currently experiencing one of its most peaceful periods in the last decades, its population still suffers the consequences of its history. For instance, violence has led to decades of massive population migrations within the country. According to the UN Refugee Agency UNHCR (2016), Colombia has the highest number of internally displaced people (6.9 million), followed by Syria (6.6 million) and Iraq (4.4 million). Migration has led to the establishment of many neighborhoods on the outskirts of the country's largest cities. This has created unplanned and disorganized settlements with inappropriate construction mainly located on mountains (Zibechi 2008). These neighborhoods lack proper infrastructure to provide support for people with disabilities (Obando-Ante, Lasso-Benavides & Vernaza-Pinzón 2006).

The social systems in Colombia are far from ideal. While the health care system provides broad coverage, securing high-quality service can be difficult (Atehortúa et al. 2013; Gómez-Arias & Nieto 2014). Social security affiliation is legally required for all Colombian employees. Yet, since the majority of low-income population work in the informal economy, the penetration rate of social security is low. A subsidized parallel social security system (*regimen subsidiado*) is supposed to cover the entire Colombian population, but both service coverage and quality are severely flawed (Bejarano-Daza & Hernández-Losada 2017). These weaknesses in the country's social safety net create considerable hardship for people living with disabilities, and therefore, the prevalence of unattended basic needs is particularly high in this population.

The most disadvantaged people with disabilities are those from the low-income segment of society (Rios et al. 2014). Colombia is one of the most unequal countries in the world, according to the Gini index of income inequality (The World Bank 2015). While the country fares better in terms of its global rating on health equality indices (GBD 2015), inequality in the health sector is still significant and it is growing under the current system (Rios et al. 2014). This not only poses mayor challenges for people with disabilities for whom it is very difficult to find a well-paid job, but also to their families who care for them.

In this paper, we examine the situation of twelve people living with physical impairments in a low-income neighborhood of Bogota, known as *El Codito*. We have had the opportunity to visit residents of El Codito in their homes to attend their health needs and advocate for their rights for the past fifteen years. The purpose of this study is to understand the needs and daily experiences of this population. This paper also considers the feelings and perspectives of the families of those afflicted with disabilities.

Research Question

We explore the situation of people living with disabilities in El Codito by answering the following question: What are the experiences of people living with moderate to severe acquired physical impairments in El Codito? To answer this question, we have considered two themes:

> First, people living with disabilities in El Codito face not only physical limitations imposed by their impairment but also the limitations of external constraints presented by the adverse environment in which they live. How do these people perceive these limitations? How do they cope with them over time?

Second, life circumstances in El Codito force residents with disabilities to adapt to a unique way of living. How do they see their life? What would they like to change? How does this change over time?

Methods

Approach

We present in this article a subjectivist epistemological approach to qualitative research. It is particularly relevant, to this approach, the way individuals gear into their taken-for-granted life worlds including not only the individual's subjective perceptions of the world but how that individual understands experience within the intersubjective milieu of the shared social environment. According to the subjectivist epistemological position, there is no separation between the knower and the known because knowledge is constructed through a meaning-making process in the mind of the knower. It accepts that knowledge is subject to differing viewpoints and explanations, subject to the interpretations of different value standpoints and subject to revision as a result of changing conditions and circumstances. This approach follows the critical paradigm as stated by Daly (2007). People with disabilities in El Codito are a highly vulnerable population. Many of them are not able to leave their houses, and sometimes not even their rooms. It is sad to witness that after 15 years of regular interaction, providing health services and advocating for their rights, and 12 years conducting this research, we have not been able to improve their situation. Furthermore, the population of individuals with disabilities has increased over the time of this study, and their situation has deteriorated severely.

A potential contributing factor to our failure to observe an improvement in the living situation of these people is an incomplete knowledge about all aspects of participants' daily routine. In this study, we explored individual experiences of twelve people using a combination of different ethnographic methodologies, including weekly observations in the neighborhood and annual in-depth individual interviews at home, during a period of 5–10 years depending on each individual.

Four epistemological assumptions governed this research: (a) meaningful reality – people with physical disabilities are able to anticipate future events, assess their situation, and self-reflect; (b) social reality – they understand their own situation when comparing themselves to others; (c) symbolic reality – we can communicate with them because we share common meanings of the world; the fact that we are from the same country and have participated for years in the same environment helps the communication process; and (d) temporal emergent reality – reality of people with disabilities is influenced by their experiences from the past and their expectation for the future. These peoples' opinions and views of their situation have changed over time and will change in the future. Following Daly (2007), we present here their current experiences and perspectives, as well as some relevant changes during the time of this research.

During the meaning-making process, we checked with the participants if a real understanding of their reality was taking place and collected data from observations and interviews. We followed constructivist induction to obtain an explanatory model of the main elements that affect the lives of people with disabilities in El Codito.

This paper focuses on the experiences of people with disabilities, but it also explores the situation of their families. In the context of El Codito, the families are virtually the only source of support available to them. The long-term care of a person with disabilities, even among loving family members, implies a great physical and emotional burden on family members, which leads to feelings of sadness, entrapment, and despair, which must be recognized and addressed.

We consider the situation of low-income people with disabilities to be of public concern, and it is incumbent upon all of society to ensure effective recognition and enforcement of their rights. Our purpose is to create consciousness about what seems to be an almost invisible problem that is currently affecting the personal development of some of the most vulnerable members of our society. Our ultimate goal is to promote interventions that may advance concrete and tangible improvements in the daily living conditions of these people. A deep understanding of culture, feelings, needs, and expectations is necessary to design targeted and successful interventions.

Sample

El Codito neighborhood was chosen as the research site because of the researchers' familiarity with the area, the obvious socioeconomic shortcomings of its population, and the irregular availability of community services. El Codito is an 'invasion' neighborhood (*i.e.*, a slum partly built in a natural reserve zone, unfit for construction) located in the nor-eastern mountains of Bogotá (Olaya & Ramirez 2004). Unattended health needs are pervasive in the neighborhood, and health indicators are significantly lower than city-wide averages.

Twelve individuals participated in this study. Only cases of acquired physical impairments – mainly limiting or precluding the ability to walk – were included. All the participants acquired the impairment unexpectedly. We sought to understand patterns and shared meanings for people living in this situation. They were between 18 and 40 years old. **Table 1** shows the gender and condition of all participants, as well as dates of weekly observations and in-depth interviews.

All interviews were conducted at the participants' homes and accompanied by people of their choosing. Participation in the study was strictly voluntary and no health care or other service or benefit was linked or conditioned to participation in the study (medical care was offered and provided to all people with disabilities in the neighborhood, regardless of participation in the study). Informed consent included information on the study's purpose, data collection, and

Table 1: Participant's gender, condition, observations and interviews.

Participant	Condition	Weekly observations in the neighborhood	In-depth interviews at home
Male	Spinal cord injury	Since October 2006	Nov-2006, Dec-2007, Jan-2009, Jan-2010, Jan-2011, Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Female	Spinal cord injury	October 2006 to February 2013 (death)	Nov-2006, Dec-2007, Jan-2009, Jan-2010, Jan-2011, Jan-2012, Jan-2013.
Male	Multiple Sclerosis	November 2006 to April 2012 (death)	Nov-2006, Dec-2007, Jan-2009, Jan-2010, Jan-2011, Jan-2012.
Female	Spinal cord injury	Since January 2007	Dec-2007, Jan-2009, Jan-2010, Jan-2011, Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Male	Spinal cord injury	Since December 2009	Jan-2010, Jan-2011, Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Female	Rheumatoid arthritis	January 2010 to March 2017 (death)	Jan-2010, Jan-2011, Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Male	Sequels from cardiovascular accident	March 2010 to August 2015 (death)	Jan-2011, Jan-2012, Jan-2013, Feb-2014, Feb-2015.
Male	Spinal cord injury	Since May 2010	Jan-2011, Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Female	Spinal cord injury	Since June 2010	Jan-2011, Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Female	Rheumatoid arthritis	Since April 2011	Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Male	Spinal cord injury	Since September 2011	Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.
Female	Spinal cord injury	Since January 2012	Jan-2012, Jan-2013, Feb-2014, Feb-2015, Feb-2016, Feb-2017.

expected results. Average length of weekly or bi-weekly visits was 20 minutes. Average length of in-depth interviews was two hours. This research project was considered and approved by the ethics committee of the Universidad del Rosario School of Medicine in 2006.

Data Analysis

Information collected from the interviews was organized in an open coding system to identify the relevant categories. Given the time that this research lasted, new interviews and observations were added periodically, and therefore a constant review of the codes created was performed. Finally, we grouped the codes into three categories: limitations, social support networks, and feelings at baseline and overtime.

Data Quality

To enhance data quality, we: (a) transcribed immediately after collecting the information, (b) used the common understanding of six researchers, (c) exchanged information with people from different disciplines interested in qualitative work, (d) called the participants to check the researchers understanding, and (e) used an official translator unaware of the study purpose to avoid researcher bias during the translation process.

Reflexivity

As doctors we have had interaction with people with disabilities from a position of power. We do not wear lab coats. They have known us for years, and we have a friendly relationship; still they call us doctors — a term that in the Colombian ideology implies not only a profession, but also a person who occupies a position of power, has received some sort of advanced education, and is, in general terms, worthy of respect. We are still viewed as outsiders.

We feel disheartened by the discrimination and inequality we witnessed. We perform this research in hopes of finding solutions to these common complications facing individuals living with disabilities in El Codito, and probably also in other vulnerable neighborhoods. From our position of privilege, we feel it is our duty to advocate for and assist these marginalized members of Colombian society.

As fieldworkers, we must concurrently perform our work and guard our personal safety. There are many Colombian citizens with disabilities living in places dominated by gangs, guerrillas, and paramilitaries. We recognize the probability that the most violent neighborhoods surrounding Bogotá may limit the mobility and well-being of individuals with physical disabilities way beyond our observations. However, due to safety concerns we were unable to conduct interviews in those areas.

Findings/Results

We found three categories that summarize the experiences and perspectives of people living with acquired physical disabilities in El Codito. These categories are limitations, feelings, and social support networks.

Limitations are factors that constrain an individual from being able to perform activities that people without disabilities regularly do. The subcategories of limitations identified were: socio-economic, environmental, functional, disability-related, and emotional. People with disabilities in El Codito perceive clearly how socio-economic, structural, functional, and disability-related limitations affect their daily life. Participants did not specifically recognize emotional limitations, but we include them here because it was evident from the observations and the interviews that these limitations impose additional burdens.

> *Doctor, don't make me laugh, how can I do anything? I can't move my legs. I can't leave this room, let alone the house* (woman with spinal cord injury).

Feelings are the states of mind reported by people living with disabilities. They are the personal emotional perception of their lives. The subcategories of feelings that we found were: positive and negative.

> *I feel fine, most of the time I am fine. I am happy because my mother always helps me…. Only sometimes (cries) I feel sad. I feel hopeless and useless because I can't help my mother* (woman with spinal cord injury).

Finally, social support networks are the favorable circumstances that people with disabilities encounter in their lives to assist them in leading a life without barriers. The subcategories of these networks found were: family, neighbors, and community services. People living with disabilities recognize their family as the main support system in their lives.

> *I have my mother and my neighbors and then sister X [Franciscan Nun]. Thanks to them I am fine* (man with multiple sclerosis)

Tables 2, 3 and **4** summarize the classification of categories, subcategories, and codes, with a brief definition of each code.

Limitations: socioeconomic, environmental, functional, disability-related and emotional

The limitations presented above are interconnected with each other. From the beginning of their lives, these people have been exposed to the consequences of low socio-economic status. This has led them, to some extent, to other limitations encountered at present (See **Figure 1**). These people have settled in inappropriately built neighborhoods because they cannot afford a better place to live. El Codito is located on a mountainside. It has only one paved street, which is riddled with holes and lacks sidewalks. The neighborhood's rudimentary paths are muddy and slippery; houses are small, cracked and not well suited for wheelchair users. Although local transportation has improved, it is still far from ideal, and neighborhood gangs are a community safety concern.

The disabilities observed are, in part, a consequence of the neighborhood's environmental factors. For example, seven participants were stabbed or shot in the neighborhood. One of them fell from the roof as a young girl (she had to clean a tank every day to obtain water). The other four face limitations due to deficient medical care. All of the causes of the observed disabilities were preventable and associated with the characteristics of this low-income neighborhood. Additionally, the lack of rehabilitation services has greatly decreased their mobility.

> *They always tell me that I can get better with therapy. But… (smiles ironically) We ask for the services, we even sue for nothing…. I always win but I never get the services. The last time they promised me services in Engativá. It is so far away from here and how can I get there? Then X [a volunteer] got me the money for the taxi rides. It was hard for her because they are very expensive. You know, not everybody wants to come here and then getting me in the car and all that. I went three days to Engativá and they never saw me. The last day they told me that they did not have an agreement anymore with my insurer. It is always like that.*

> *I went to the doctor, but he gave me some pills that were killing me. I started feeling really bad when I was taking them. When I went back and told him that I had not taken my pills, he scolded me badly, it was awful. I never went back. The healer of the neighborhood was much better. She treated me nicely. She would do massages and treated me with respect. I started feeling better.* (woman paralyzed by rheumatoid arthritis)

Table 2: Summary of Limitation Subcategories and Codes.

Subcategory	Code	Definition
Socio-economic	Poverty	Low household income.
	Unemployment	No participation on income earning activities.
	Low education	No-complete elementary school.
Structural/ environmental	Geographic	Rough characteristics of the earth's surface.
	Urbanistic	Lack of neighborhood planning.
	Architectural	Limitations in the house design.
Functional	Monotony	Repetitive routine.
	Dependence	Reliant on others.
	Caregivers	Limited number of caregivers, usually elderly.
	Aids	Lack of basic aid devices.
Emotional	Self-blame	Self-blame for their disability.
	Low self-esteem	Very low self-esteem.
	Depression	Depressed mood, loss of interest, thoughts of death.
Disability related	Direct	Limitations imposed directly by disability.
	Indirect	Other health problems associated with disability.

Table 3: Summary of Resource Subcategories and Codes.

Subcategory	Code	Definition
Family	Support	Assistance, comfort and encouragement from family.
	Commitment	Family assumes responsibility for him/her.
	Company	Family provides companionship.
Neighbors	Support	Receives assistance from neighbors.
	Company	Neighbors provide companionship.
Services	Health	Receives health services from community.
	Food	Receives food from community.

Table 4: Summary of Feeling Subcategories and Codes.

Subcategory	Code	Definition
Positive	Able	Capable of performing activities.
	Needed	Wanted by other people.
	Grateful	Appreciation to other people.
Negative	Sad	Unhappy.
	Useless	Not valuable.
	Frustrated	Disappointed, defeated, discouraged.
	Insecure	Unconfident.
	Burden	S/he is an impediment for other people.
	Hopeless	Current situation is irreversible and irreparable.

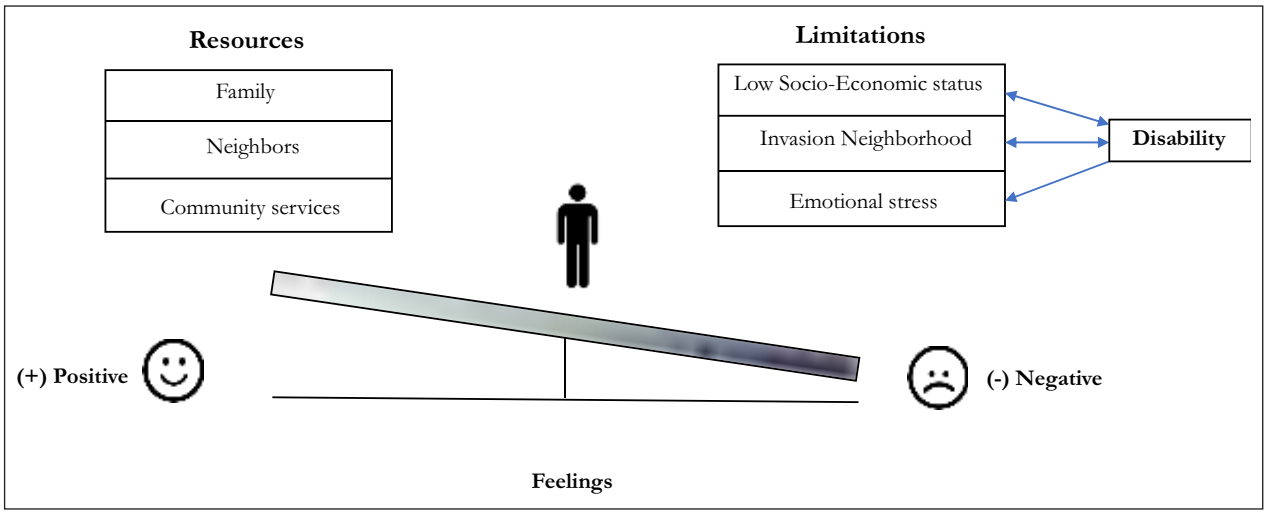

Figure 1: Explicative model of the lives of people living with an acquired physical disability (such as spinal cord injuries, rheumatoid arthritis and multiple sclerosis), in El Codito (a low-income neighborhood in Bogotá).

The acquired physical disabilities of the individuals in this case study worsen their economic status and limit the opportunity to leave El Codito. As a consequence of the disability, these individuals have not had access to education or employment. In these circumstances, it is extremely difficult to improve their standard of living.

Feelings

Disability, low socioeconomic status, and the structural characteristics of the neighborhood create functional limitations for each person in this case study. These individuals cannot leave their houses by themselves and feel trapped in a monotonous routine. They cannot afford aides or caregivers that would allow them to live independently, so they become dependent on family members. They worry about burdening family members who may get tired of supporting them. Functional limitations also impede access to peer support.

All the above contribute to the emotional limitations which likely exacerbate the other factors. The following transcriptions from interviews describe how individuals with disabilities perceive their limitations.

> *There are a lot of stronger difficulties but the biggest is to get out of these four walls: that is fully impossible, no? But this is a big difficulty for me. To bathe is also a huge complication because my mother, alone, has to wash me on my bed, and she is much older than me and she has to do twice as many things. And sleeping, Doctor, I can only sleep lying on my stomach, and this is tiresome; I can't sleep otherwise because the back-ache is terrible, then I get used to it, but I get very, very tired, anyway* (woman with spinal cord injury).

> *Well, I feel bad, the fact that I can't get out of the house, that I can't be useful for the family, that my brother has to sustain me, and also feeling every day even worse than the day before. Well, I don't know if you can understand what I mean, but it is damned difficult to live in this way, to get accustomed to depend on others, to ask for favors in things that you formerly were able to do by yourself* (man with spinal cord injury).

Social support networks: family, neighbors, community services

The aforementioned limitations are countered by the support that these people receive from their families, neighbors, and community organizations. This support is what we call 'social support networks'. Families are, without any doubt, the greatest source of support for these people. A parent, sibling, or spouse is usually the person who assumes the caregiving functions. These caregivers help them with virtually all daily activities, from eating and cleaning to using the toilet. This generates a feeling of gratitude among the people with disabilities that makes them fight to try to give something in return to their wonderful families.

> *I feel good. What can I tell you? In spite of my condition, I am well, thanks to God I have a family that has helped me through this, if they were not there, I would be even worse than I am now, more frustrated and sick. Well, in general, I feel good, Doctor, I feel good* (woman with spinal cord injury).

Neighbors are also an important resource for these individuals. Unfortunately, this is a resource often hard to access. Without the ability to go around the neighborhood at will, they must wait for neighbors to visit and offer help, which restricts their social life. In general, they have one or two neighbors that frequently visit and provide assistance.

> *The neighbors help us. X [a neighbor] comes with my lunch when my brother can't. She gets it from the community kitchen and when they don't have service she shares with us the food from her house* (woman with spinal cord injury).

The last resource subcategory is community services. Occasionally, El Codito residents with acquired physical disabilities receive food and health services from governmental and nongovernmental organizations. Regrettably, these services are not consistently available. Many community organizations and politicians have committed to improving disability services for this community, but no sustained programs or infrastructure have been developed. People with disabilities in El Codito are not able to rely on the availability of community services, but they appreciate the sporadic assistance they receive.

The following transcriptions describe how people with disabilities in El Codito perceive their social support networks.

> *They say that women in the Servitá Quarter, of that health center in Usaquén, will help. They also say that I have to get out, out of my bed, talk with the people, but till now I have seen nothing…What can you ask, for example, from my mother? I can't ask for anything, she has no means, from the dispensary, also nothing because, I say, there are no possibilities. They say that I have to rehabilitate, but everything is so far away, they say that with a transportation route, that this and that, that they would do a lot of things, that the Mayor's Office will do thousand things for me, but you see nothing, and nothing will be seen in the future* (man with spinal cord injury).

Individuals with disabilities living in El Codito experience a mix of emotions. They have positive feelings when talking about the support they receive from families and neighbors or the occasional community assistance. On the other hand, they have negative feelings when they reflect on the limitations that they encounter in their daily routine. As illustrated in Figure 1, limitations outweigh the available social support networks for these people. Despite the impact of positive support, negative feelings tend to dominate the experiences of these individuals. These people face very difficult life circumstances and have adapted to their infrahuman conditions. The following transcription describes common feelings.

> *I feel resigned, she starts to cry again, I feel sort of bad because of my child, because I can't take him out, I can't help him in the things that he needs most. For the rest, well, routine. Sadness, I feel sad that I can't help very much at home, materially depending on my mother, and also, Doctor, my father left us six years ago, he left us with debts. We, alone, with a child, and the fact that I can't do things, I can't help my mother, with … things, with my son, ah, resignation, and for such a long time!*

> *It's hard; my sister is helping me and the teacher and also the doctors. At times I can study… but then… the wounds, the urinary infections. I have to stop. It is frustrating because then I get better and the people that was helping me are busy doing other things. Every time it is hard to start again* (woman with spinal cord injury).

During the first years of their disability, these people have hopes and dreams.

> *Doctor, they have told me that seawater could help me. A friend of my neighbor went to Cartagena (a coastal city from Colombia), and she was just like me. And then she went in the sea and she got better. She is not perfect, but she can walk again. I think that maybe if I go to the sea. What do you think doctor? Do you think the sea can help me as well? Do you think there is a way for me to go to the sea? I know I will get better there.*

> *I want to be a lawyer. I want to study. I have always wanted to be a lawyer and I think it is possible* (man with spinal cord injury).

On the other side, family members try to hide their exhaustion in front of them, but they complain and often cry with the research team. Their relatives' disabilities also limit their life.

> *I love her, and I know... But it is hard. If I don't work, how are we going to eat? How are we going to pay utilities? I wake up at three. I have to leave everything ready for her. If I forget anything she would be dirty or hungry or sick all day. How she can get things? She depends on me. I don't have friends. I don't have a life anymore. I can barely work and take care of her* (mother of woman with rheumatoid arthritis).

The analysis overtime shows growing feelings of hopelessness. As time passes, these individual's limitations increase due to the lack of rehabilitation. Eventually, their family develops more and more signs of exhaustion, which decreases support for their relatives with disabilities.

Every day I feel worse. Now I need dialysis. My kidneys don't work anymore, after so many infections they stopped working. Everything is even worse. I feel I am now a big load not only to my mother but also to my child. He needs to help me, and he is still so little. He cannot fulfill all the school requirements because he needs to help me. At this point I feel they would be better off without me. My mother is very old, and she keeps working because we need the money to pay for all this.

From time to time I feel I can't hold it any longer. I am so tired, I do not have a life and I can't afford all his needs. It is so hard to see him every day worse and worse. I would do whatever to help him but nothing I do seems to help. He is deteriorating, and I don't have energy to support him. As time passes everybody seems to forget us. (woman with spinal cord injury).

Discussion

Summary of Key Factors

People with disabilities in El Codito experience the direct impact of their impairment, plus four additional types of limitations: socio-economic, structural, emotional and functional. These limitations make their lives very difficult and produce feelings of sadness, uselessness, and hopelessness. They partly compensate their limitations with family support, and, to a lesser degree, with assistance from neighbors and community services. Help received from family members generates feelings of gratitude and a sense of belonging that fosters well-being. Despite this, they face substandard living conditions, particularly with regard to mandated disability services. The quality of life of family members is also affected, as they often devote themselves to the care of their relative with disabilities, at the expense of their own needs.

Over time, lack of treatment and rehabilitation services tend to increase limitations imposed by the disability. Neighbors slowly stop their help as they get used to the situation and family members get worn-out, which decrease the opportunities and support for people with disabilities. They lose hope as they notice the passage of time without any positive change in their situation, and negative feelings start to dominate their daily life.

The characteristics of the neighborhood, coupled with low socio-economic status, limit the ability of El Codito residents to successfully advocate on their own behalf. Members of this community living with a physical disability cannot afford private caregivers to compensate for inadequate community support. These circumstances adversely affect many aspects of daily life and force individuals with physical disabilities to adapt to a way of living that violates the Colombian Constitution and disability laws and compromises their basic human rights. This condition seems to be a paradox in a country with the level of institutional development and material resources of Colombia. As an upper-middle-income country (The World Bank 2018a), Colombia should be able to afford the social and physical infrastructure to support people with disabilities. Multiple factors likely contribute to the current situation, including corruption, deficient resource allocation, poor design and coordination among governmental services, lack of broader societal awareness of the problem, and other competing social priorities.

Household members of low-income people with physical disabilities are forced to seek new ways of economic support to help maintain not only their basic needs but also the special care required by an individual with a disability. This hardship not only generates feelings of frustration for the person with a disability, but also for their families.

Multiple efforts by Colombian lawmakers and well-meaning government officials to address the needs of this population have systematically failed over the past fifteen years. A series of broken promises and false hopes created by multiple government officials only reinforce the feelings of frustration and marginalization among them. In theory, the Colombian Constitution guarantees their rights to equality, education and a minimum standard of living. In practice, though, these people are unable to leave their rooms, let alone be able to go to court to enforce these rights through an *'accion the tutela'* proceeding. While court access is free-of-charge and litigants can appear without a lawyer, this theoretical access is meaningless in practice. When bare-minimum survival consumes 100% of the family's resources and energy, all other considerations (including not only medical care, education and employment, but also fighting for their own rights) become unaffordable luxuries.

The astonishing differences in the experiences of people with physical disabilities in El Codito and other parts of Bogota, provide strong refutation to the biological/medical model of disability (Atkins & Hayman 2017), and related theoretical models that focus on the individual: the moral model, the deficit model, the survival-of-the-fittest model, and the eugenics model (Reid-Cunningham & Fleming 2009). Considering the experiences of participants in this study, the individual physical impairment experienced by these people is clearly the lesser of two variables, *i.e.*, the lack of societal response to the situation of physical impairment carries most of the weight in explaining this study's findings.

Consistent with the social/cultural model of disability (Atkins & Hayman 2017) and critical disability theory (Devlin & Pothier 2006), the rapid health deterioration experienced by people with acquired physical disability in El Codito over the past twelve years, as well as their feelings of sadness, uselessness, and hopelessness, and their families' exhaustion, are all highly preventable outcomes resulting from the Colombian society's insufficient recognition and inadequate response to life situations experienced by some of its most vulnerable members. Indeed, in accordance with the social construct model of disability, the multiple negative consequences and feelings experienced by people with physical disabilities from El Codito, are largely explained by 'society's inability to address the needs of its members by removing environmental and social barriers to participation and institutional benefits.' (Reid-Cunningham & Fleming 2009:12).

Limitations

This research has a number of limitations. Among them are: (a) researchers come from a different socio-economic status and neighborhood and have not personally experienced a physical disability. This limits our possibility to understand the situation of individuals living with disabilities in El Codito. At the same time, this perspective permitted us to compare what we see and experience in our environment with the situation encountered by those in El Codito. (b) This article is based on the interviews and observations of a limited number of people. Although we do not have reasons to believe that these individuals differ dramatically from others in the neighborhood and other sectors of the city, it is important to recognize the limited sample size afforded by our case study approach. (c) It is focused on present experiences and did not explore circumstances in the past. Nonetheless, the study's long time span partly compensates for this limitation.

Conclusion and Implications

It is essential to develop an integrated program which provides health care and support services – such as transportation, personal care, peer support networks, assistive devices and housing assistance – for people with physical disabilities in El Codito, and other lowest-income populations in Bogota. In order to be successful, this program must overcome the social barriers found in this study. The goal must be to decrease the persistent limitations to mobility and autonomy amongst this population, and to increase the minimal resources available to El Codito residents living with physical disabilities.

To decrease the burden of existing limitations we recommend:

Socio-economic limitations: Improve access to employment and education.
Structural limitations: Build infrastructure (*e.g.* sidewalks and ramps), adapt the public transportation system to mobilize disabled users, and/or assist in relocating residents with physical disabilities to a different neighborhood.
Functional limitations: Provide necessary mobility aids, increase support networks and find occupations suited to their abilities. There are multiple forms of disabilities, and they do not imply the same employment limitations. Many jobs and occupations may be performed equally efficiently by a person with a certain impairment.
Emotional limitations: Provide required psychological support through support networks. This includes both professional and peer support, as well as broader awareness among society about the situation of people with disabilities, and the need to treat them as equals (not as inferior members of society). Even small deeds, such as a proper greeting in the morning, may help to improve the self-esteem of people living with disabilities.
Disability limitations: Provide therapies and tools, including catheters, wheelchairs, and rails, needed to function with an impairment.

To improve the social support networks available, we recommend:

Family: Increase assistance available to families to help them in their caregiver role. Usually, one or more family members change completely their life to care for the person living with disabilities. These people need support, including advice on self-care and commitment to their own future. Family therapy at home would likely be beneficial, as well as direct economic support.
Neighbors: Educate neighbors about disabilities through community advertising and group talks hosted by community leaders. Although neighbors' attitudes were not highlighted in this research, it is possible that the neighbors do not associate with the individuals living with a disability because of fear or misinformation about the nature of disabilities. Inadequate community infrastructure, which prevents individuals with disabilities from leaving their homes, also serves as an obstacle to disability awareness in El Codito.
Peers: Peer support among persons with disabilities has been found to be an important strategy for persons with disabilities in multiple settings (Schon 2010; Mead, Hilton & Curtis 2001). However, in low-income neighborhoods, such as El Codito, physical and financial limitations impede people with disabilities to meet each other and stay connected as peers.
Community services: It is vital to provide adequate health services to this population. The ongoing, unfulfilled commitments to improve disability services in this community are both unethical and illegal. Compartmentalization in the provision of social services and holes in the social safety net, are contributing factors that must be addressed.

Greater accountability of service providers is also needed. The subsidized social security insurance agencies reluctantly provide free-of-charge therapy (to which they are legally entitled) to participants in this study. Yet, these services are often offered at faraway locations and after lengthy waiting periods; since these people are unable to travel by themselves and cannot afford transportation and caretaking services, in reality they do not receive therapy, are unable to seek employment and must forego all educational opportunities.

The concrete circumstances of this study's participants (as compared with the situation of people with disabilities in other neighborhoods of Bogota), show a complex vicious circle that must be broken: lack of education leads to unemployment; unemployment is tied to lack of income beyond bare-minimum survival; lack of income means inability to afford mobility and care (including necessary therapy), which in turns not only weakens their health status, but also means that family members must devote themselves to providing necessary care, further eroding the family's ability to

raise income; and lack of mobility impedes access to care, education and gainful employment. In the long run, effective access to education, employment and health services, could break this vicious circle.

Greater political will from various sectors of Colombian society must be garnered to help this group of underserved individuals receive the care and support to which they are legally entitled. El Codito is one of many low-income neighborhoods surrounding Bogotá, where individuals living with disabilities are 'trapped' in their own houses. Since 80% of Colombians with disabilities live in low-income neighborhoods (Minsalud 2018), the implications of this study may be of broader societal significance.

Competing Interests

The authors have no competing interests to declare.

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