

FACE-TO-FACE WITH DISABILITY AND POVERTY IN CENTRAL AMERICA: LEARNING FROM AMPUTEES ABOUT SOCIAL SUPPORT AND RESILIENCE

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Working as a program evaluator of a human services program in Central America, the author was confronted with her conceptions of disability, resilience, and social support. She presents three stories of amputees, each with a unique story of survival. As the stories unfold in this reflective discourse, lessons of acceptance and even forgiveness emerge as central themes.

Background

When I heard that there was a short-term contract opportunity to complete a program evaluation of a human services agency in Central America¹, I could see that it was a wonderful opportunity to return to and work in the region. The job would require work in some difficult and impoverished conditions; we would be making home visits to interview clients in urban and rural settings. On the face, "difficult conditions" did not intimidate me because I had worked as a Peace Corps Volunteer in Belize and as a community health technical trainer for Peace Corps in Guatemala, one of the poorest countries in the region. I thought that I understood the conditions of the people of Central America, though I now realize that in the past I had only scratched the surface of the multiple realities of people living in poverty.

A Basic Description of the Individuals That I Interviewed

With the aid of a translator, another social worker and I completed semi-structured interviews. We conducted ten interviews in three days with three women and seven men. Their amputations occurred due to a variety of factors, including diabetes, traffic accidents, and landmines. With the exception of one interview with a diabetic patient, which took place in a hospital, all the other interviews were completed in the subjects' homes. Three individual stories are presented as composites for the purpose of protecting confidentiality and honoring human subject standards.

Learning by Hearing About Life and Disability in "Difficult Conditions"

I realized that even though I had lived in Central America for several years where extreme poverty was a daily reality, my understanding of the human condition of disability in this environment was actually naïve and uninformed. In fact, these interviews raised my level of consciousness in such a way that I was forced to contemplate my superficial understanding of disability in a developing nation. And, in each interview there was a story or a unique lesson about survival, social support, and resilience. Each interview was a powerful experience. The following three composites are presented to "tell" the story of limb loss in a developing country.

Lessons From Carmen

Carmen was a married young woman in her early twenties. We arrived to interview Carmen at her modest apartment and began the interview in Spanish. She quickly responded in an almost accentless English and suggested that we could conduct the interview in either language. For me, this was intriguing because she clearly had a strong command of the English language. We proceeded in English, and she told the story of how she lost both of her legs in a train accident.

As a young woman, Carmen, like many other young people of her village, made the northward migration to the United States looking for work. In the past, she had been successful crossing the border and finding

work. She would periodically return to her country to visit her family and bring back money. Because she was young and strong, she viewed crossing the border as a challenge that she, her husband, a group of friends made periodically. The following excerpt from the interview is how Carmen described the last time she attempted to cross the border when the accident and amputation occurred.

"We were in Mexico and the Federales (Mexican police) were chasing us. They always used to chase us and we would laugh because they could never catch us—they were too fat. We were running towards a moving (freight) train and I had to jump quick. I thought I had my grip, but I slipped. My legs fell under the train and it happened. At first I couldn't believe it, but I could see that my body was in one place and my legs in another. I was bleeding real bad and the Federales stood over me talking about what to do with me. I laid on the ground for over an hour—I think they left me to die. But, my husband and my friends stayed with me and argued with the police for help. I knew that I would bleed to death if I didn't get help and I could feel my heart beating—pulsing. Because of my will to live, I told my heart to slow down. Finally, I was taken to a hospital. The Mexican hospitals are pretty good. I stayed there for a few months and then they deported me back here. The care here [in her country] is pretty bad compared to Mexico."

As I listened to Carmen describe the trauma of losing both of her legs in a train accident, I was struck by how she laughed about the "fat" Federales whom she essentially described as incompetent and completely

uncaring. She made this description as a matter of fact, touching on the age-old tension between the Mexicans and the lesser developed nations to the south in Central America. She talked about how she ultimately survived the accident because her husband and friends stayed with her and because of the outstanding care she received in the Mexican hospital. She also talked about how she would have died in a hospital in her own country because the equivalent level of care is just not available.

I thought I understood resilience, but Carmen was truly an inspiring character. Not only did she slow her heartbeat and manage to survive the initial trauma, but she succeeded with rehabilitation and learned to walk again on prostheses—no small feat for a double amputee, especially in an underdeveloped country. She talked about how the prosthesis fit and her desire to get "new legs" because the equipment had worn out and was in need of replacement. Carmen shared that she currently had difficulty walking because of blisters on her stumps, but she continued working every day, teaching English to young people.

As a social worker, I found it difficult to hear about Carmen's need for new prosthesis without much hope of that need being met. She was lucky to have prostheses at all—there were many people waiting for such services in her country. As a privileged citizen of the United States, I felt a sense of guilt that I had never before felt. I was able to walk out of Carmen's home and continue on my way, eventually boarding a plane and flying back to a country where our citizenry is guaranteed basic disability services, such as prosthesis care.

Because it was not relevant to the program evaluation, I did not ask Carmen about regrets. I did not ask her if she "had known she would lose her legs—would she have taken the risk of jumping on the train headed north?" I feel pretty certain that Carmen would have said "yes." I believe this because with the exception of her leg loss, Carmen was a strong young woman. She had hopes and dreams like any young person and the northward migration was a reality for her and her family who were

subsistence farming and living in poverty. Working in the United States and sending money home is a way of life for many young adults of her country and the dangers of crossing the border are a necessary reality.

Sadly, in the aftermath of the accident, Carmen shared that her family had essentially washed their hands of her. Originally, it was planned that Carmen and her husband would take over her family's small farm once they saved enough money from earnings in the United States. However, with the loss of her legs, her brother had taken over that role and subsequently ostracized Carmen from the family. Carmen shared this with a sense of irony because her brother had the more invisible disability of alcoholism, making him an unreliable farmer. Looking forward, as a resilient person does, Carmen found a great deal of support and the important sense of family in her relationship with her husband, and she took on the professional work of teaching English. This new role as teacher was ultimately a more appropriate occupation given her amputations.



Lessons from Maria

Maria was a single woman in her forties. I will never forget the trek to Maria's home as it was the most rural setting of all ten interviews. We climbed a steep hill to reach her modest, one-room, cinderblock home that she shared with her two young sons. The home sat beneath a forest and one could not easily find it except by following a narrow trail.

When we arrived, Maria was resting and she wiped the sleep from her eyes. She was clearly happy to see friendly faces and had been expecting our arrival. I could see immediately that our visit was special to her because with the exception of her family, who lived close by, she was socially isolated and visitors were rare.

Maria's amputation accident was a tragic story of a young woman caught up in war as a member of the resistance forces. Recounting the history of how she was recruited by the militia, she talked about how her family was fleeing their dangerous home area and traveling across the countryside for safety. In their travels, the family had stopped for rest and received food and water from "the guerillas." When she was a young teen, Maria became entranced by the rhetoric of the militia leaders who she described as "charismatic." She became excited and decided to join the movement even though her parents pleaded with her to continue with them on their journey to a refugee camp. She resisted her parents' pleas and took up arms with the guerilla movement. At the age of fifteen, Maria stepped on a landmine and lost her entire left leg and two fingers.

Upon rehabilitation, Maria talked about how the militia leaders held her up as a symbol of heroism, valor, and strength. At first, she felt the support of that militia community and her comrades came to her comfort. Of course, with time, she was forgotten because she was no longer of value to the group as a fighter. Eventually, Maria left the opposition movement and reunited with her family. In the post-war years, Maria worked in a factory, or *maquiladora*, but her health was fragile. She complained of constant stomach pain that prevented her from working. The doctors told her that she had stress ulcers, and Maria described to us some of the physical symptoms of Post-traumatic Stress Disorder from which she suffered.

As we interviewed Maria, we learned how her family was caring for her needs of food and medicine. Her young, school-age sons were clearly a source of joy. In addition, we were introduced to three different pets that kept her company during the many hours that she spent alone on that Central American hillside while her family worked and her sons attended school. During the interview, Maria had two small dogs that sat at her feet the entire time. The dogs were friendly and did not respond to us as threats—however, it was obvious to me that Maria's companions could be fierce protectors in the face of danger.

The most interesting feature of the relationship between Maria and her dogs was that they mimicked Maria's movements. For instance, when Maria looked in a particular direction, the dogs looked in the same direction. When Maria stood up, one of the dogs stood up on hind legs while leaning the front paws on her leg. While I've heard that dogs and owners begin to look like each other, this was the first example that I had ever witnessed with such obvious *behavioral* patterning. Of course, Maria and the dogs spent so many uninterrupted hours together with few outsiders, they undoubtedly saw Maria as a part of their den—sharing sleeping quarters and what little food the family had. Clearly this was an important relationship for Maria that served some of her social support needs in otherwise isolated conditions.

Finally, just as I did not ask Carmen about any second thoughts or regrets, I did not ask Maria if she had any regrets about joining the resistance forces. However, the way that Maria talked about the guerilla leaders in hindsight with such disappointment in her voice, I can't help but think that an older and wiser Maria would have refused to join the militia.

Today, I think of Maria, as a symbol of youth who take up arms for a fight that they firmly believe in, often under charismatic leadership. They find themselves actors in a war that is always fueled by energy and the principles of freedom and liberty. During the interview, Maria focused more on the immediate and her survival in the face of her ongoing health problems. Now as Maria sits on that hillside and no longer identifies as a soldier, she has countless hours to contemplate how her personal freedom has been changed forever.

Lessons From Miguel

Miguel was a married man in his early thirties. When we arrived to interview Miguel at his home, we were greeted by a group of curious children who were playing in the yard. Four of the children were Miguel's and the other two were a niece and nephew that were living in the care of Miguel and his wife. It was immediately obvious that this was a cheerful, close-knit home.

Miguel's amputation was not as severe as the previous two cases. In fact, Miguel's disability was comparatively minor because he had only lost a hand in a factory accident. However, after the accident the supervisors at the factory ostracized Miguel because they no longer regarded him as a viable worker. In the face of the adversity of losing his hand and his livelihood, Miguel had to look to alternative employment, and that story revealed some new insights for me.

As we interviewed Miguel, his wife stayed close by his side; they were clearly a team. In the home environment, we could see that there were several micro-enterprises operating there. The two businesses that the couple talked about were car tire repair and t-shirt screen printing. Miguel had always been good at repairing tires, and after the accident he received a small grant to assist him with developing a small business. Miguel used this seed money to buy additional tools, and he hung a sign for his business. He was quite skilled at this craft and had become known in the community for this skill.

With that business underway and profitable, Miguel and his wife began to explore other opportunities. During the interview, Miguel excitedly showed us a t-shirt that he had printed with the image of the Christian cross. He talked about how he had learned to make the basic screen and then print onto t-shirts. He had received one large order from a local church for the t-shirt and he and his wife were excited about future possibilities.

While Miguel showed us the screen print and the t-shirts they had made, he often referred to the process saying, "I did" instead of "we did." However, in conversation he admitted that his wife had been instrumental in teaching him how to craft the screen for printing. At that moment, I began to understand that Miguel's wife was also quietly his business partner. She clearly did not need to be acknowledged officially. When it came to the t-shirts, she let him do the talking about that aspect of their micro-enterprise—even though it had become clear that the concept was conceived and initiated by her.

In an environment where *machismo* is a dominant aspect of Latino culture, the

relationship between Miguel and his wife was interesting. I knew that often men will do the talking for the family in Latino culture; however, the dynamics in this interview were different. Miguel's wife talked during the interview, but she also deferred to her husband when he spoke about the t-shirt business. It seemed to me that in her wisdom, she understood that Miguel needed to reclaim and demonstrate his sense of himself as the breadwinner as he transitioned into a new workplace—their home, which had previously been her domain. On the surface, I could have just viewed this dynamic as simple *machismo*, and there may have been aspects of this dynamic. However, Miguel's wife was an important source of support while he built a new identity as father and husband, and she did not appear to need acknowledgement during our interview.

Final Reflections

Although I've shared three stories with you, there are countless other stories of disability, resilience, and social support throughout the world. As I finished my interviews with amputees, I reflected on my new and deeper understanding of resilience, identity, and sheer survival. Carmen, Maria, and Miguel all found sources of social support and new identities after their amputations.

While I knew that social support was one of the most important variables to adjustment to limb loss and disability in general (Ferguson, Richie, & Gomez, 2004; Rybarczyk, Edwards, & Behel, 2004; Williams, Edhe, Smith, Czerniecki, Hoffman, & Robinson, 2004), I now have a deeper understanding. I also could see how all three of these amputees would have benefited from knowing each other as an opportunity for mutual aid. Unfortunately, there was no such support group existent in the country. This was a missed opportunity—an intervention that I strongly encouraged the human services agency to consider implementing. I know that Carmen and Maria, in particular, would have benefited from being able to talk with each other about adjusting to prosthesis, phantom pain, and the other physical and emotional realities of adjustment to amputation.

Also about social support, I was reminded not to underestimate sources of emotional support. Maria's pets were clearly as much her companions as well as her guarantee of security in an isolated location. Other interviewees, not presented here, also had important relationships with dogs and cats—often petting the animals during the interview and even introducing the animals as important members of their family. While this may not seem unusual for an American reader who identifies with a pet-friendly culture, this was particularly unusual in a Central American country where dogs and cats are often viewed as additional mouths to feed in an environment where malnutrition is rampant. As a result, cats and dogs are treated more like “animals” than pets in the region. However, these companions were clearly important pets and they looked well-fed, especially compared to the dogs and cats that we saw in the streets.

Another important lesson was the idea of identity and disability. For those of us who have not experienced “disability,” it is easy to underestimate how we define ourselves as “able” bodied. Of course, it is natural to take it for granted that we have all of our limbs. However, that could change rapidly for anyone—especially with the rise of amputation associated with Diabetes in the United States (Zimmet, Alberti, & Shaw, 2001). Since I have a history of diabetes in the family, I could not help but put myself in their shoes and wonder how I would cope. Would I be able to learn to use a prosthesis effectively? Would I have a sufficient social support system? Would I be able to overcome the depression that must occur post-amputation? How would I personally reconstruct my “identity” as a “disabled” person? Certainly I would be resilient because I have the benefit of living in an industrial nation with the benefit of health insurance and quality care. At least I *think* I would be resilient. Of course, I make the assumption based on the belief that I would be afforded quality care—however, in the U.S., I am not absolutely guaranteed health insurance. As such, quality care is not a guarantee.

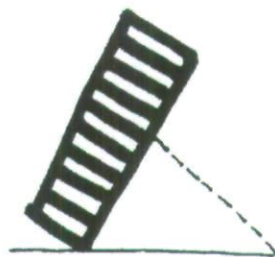
It was not lost on me that the amputation rate of military men and women serving in the

Global War on Terror is very high (Gawande, 2004; Noe, 2006). I wonder about their adjustment to amputation, especially with the accompanying Post-traumatic Stress Disorder (Friedman, 2005, 2006). Of course, they would have some of the best medical care afforded to amputees, but the human element of adjustment "disability" is relatively universal and inevitably difficult. Will they have the social support of their friends and family as they transition back from a war zone? Will general society be supportive of their experience and special needs given the fact that this war is highly unpopular? Or will they return, just as the Vietnam Veterans did, to an unfriendly community that treats them as suspect and damaged? What about their resilience as they must find new employment? I do not know the answers to these questions. Only time will tell.

As a social worker, I am accustomed to people sharing their personal lives, sometimes the most intimate of details. This was the first time that I felt some shame, almost like a voyeur, as I grappled with my own feelings of shock related to the descriptions of trauma during and after the interviews. Hearing the stories of the actual limb loss, especially the train accident and landmine explosion, was the first time I have actually experienced secondary trauma as a social worker. I now know that I had totally underestimated the idea of secondary trauma, even though I have specialized training in critical incident stress management with military personnel. My role as a specialized and impartial military social worker—an observer—shifted to a role which made me emotionally vulnerable. That role was less "detached" and the most human of all—I put myself in the shoes of another and came just about as close as one can to understanding limb loss and amputation without actually physically experiencing it.

My final thought about the amputees that I interviewed is ultimately the most important lesson. Survival of an extreme trauma in a developing nation, where health care is poor and infection rampant, makes them, by definition, resilient people. Also, as all of the survivors of amputation talked about their experiences, they were thankful to be alive

and when they had been further wronged in some way, such as being ostracized, I often sensed that they had arrived at some place of acceptance and even forgiveness. And I am reminded that Desmond Tutu wrote, "To forgive . . . is the best form of self-interest . . . forgiveness gives people resilience, enabling them to survive and emerge still human despite all the efforts to dehumanise them" (Tutu, p. 35, 1999).



Footnotes

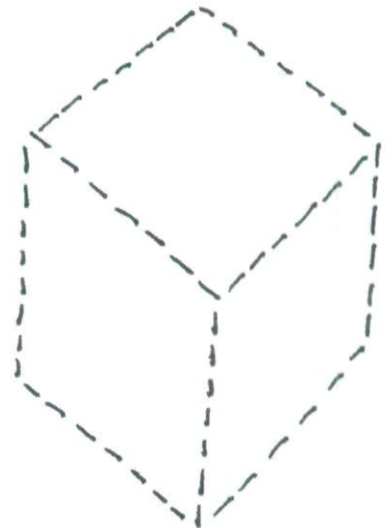
1. I have chosen to identify the region of Central America rather than the actual country in an effort to insure confidentiality of the agency and the individuals that I interviewed.

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