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Stories from the Margins: Refugees with Disabilities Rebuilding Lives

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Cover Page Footnote

This study was completed as a qualitative research requirement for a doctoral degree at Syracuse University. I would like to thank Dr. Marjorie DeVault for her constructively critical insights and feedback. I extend my appreciation to the participants, interpreters, case workers, and other contacts in the field that made this study possible.

Stories from the Margins: Refugees with Disabilities Rebuilding Lives

“I am independent. I’m not being beaten. I’m not getting hurt. You know I feel so much better, so much lighter. I have worries, but not like that. And now I am with my mother like we were before I got married. I’m happy I’m with my mother and my daughter. I want to work hard to take care of my mother the way she worked hard and took care of me. Now that I am here, I have the opportunity to do that. I feel like I am free, I’m not a slave anymore. I can fly free.” --Monu

Every day around the world, people are displaced from their country of birth, are labeled as “refugees,” and are relocated to refugee camps run by the Office of the United Nations Refugee Agency (UNHCR). The most fortunate refugees live in camps for a decade or less before relocating to a country offering refuge. Others may live in camps for 20 years or more before resettlement. Some never leave the camps. Many reports from the United Nations (UN) and the World Health Organization (WHO) acknowledge that refugees with disabilities are at a higher risk of human rights abuses (UNHCR 2010; WHO 2005). However, the identities of this displaced and vulnerable population are often obscured by clinical checklists, protocols, and emergency refugee toolkits.

In this paper I outline the relevant literature as it relates to refugees with disabilities. I then describe the theoretical frameworks that inform my perspectives while engaging in such work. Then, I highlight the qualitative and ethnographic methods used in gathering and analyzing data. Following the methods is the results section that is composed mainly of participant responses categorized by significant themes that arose from the data. I conclude the paper with a discussion of the numerous identities enacted by participants, the implications for people who experience multiple intersectional oppressions and their ability to lead self-determined lives.

LITERATURE REVIEW

The UNHCR (2012) puts the number of forcibly displaced people at 45.2 million. The WHO (2011) estimates the number of refugees with disabilities between 2.3 and 3.3 million, with one-third of those being children. Many refugees acquire visible disabilities (e.g., acquired amputation through violence) or invisible disabilities (e.g., anxiety disorders) at a higher rate than the population at large (Bradley and Tawfiq 2006; Loutan, Bollini, De Haan, and Gariazzo 1999; Silove 2000; Dekel, Solomon and Bleich 2004). These numbers are thought to be low estimates as many refugees do not report disabilities acquired through persecution, trauma, or abuse during displacement (Bradley and Tawfiq 2006; Loutan et al. 1999; Silove 2000; Dekel, Solomon, and Bleich 2004).

This vulnerable population exists on the margins of society, and experiences life at perilous intersections of multiple oppressions (Reilly 2008).

The Women's Refugee Commission (2013:1) reports that refugees with disabilities are "among the most hidden and neglected of all displaced people." Not only are these people excluded from society, but are also stigmatized and often hidden away by their families (Ahern and Rosenthal 2005, 2006, 2007). Many refugees with disabilities who experience this invisibility are at an increased risk of abuse, violence, exploitation, and exclusion from humanitarian services (UNHCR 2011; Kett and Ommren 2009; Women's Commission for Refugee Women and Children 2008). These harsh realities perpetuate human rights abuses, maintain refugee invisibility, and limit refugees' ability to live self-determined lives.

Throughout this paper, self-determination is defined as individuals "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer 1996:22). The concept of human rights is a Western export through which much work related to disability in the global South is based. In theory, human rights are granted universally on the basis of being human (Bickenbach 2009). However, collective human rights are only universal from a Western perspective (Zizek 2006; de Sousa Santos 2008; Meekosha 2011). International instruments like the United Nation Convention on the Rights of the Child (UNCRC 1989) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD 2006) define human rights as universal (Bickenbach 2009).

Many countries do not have the resources to implement such policies, which makes ratification largely symbolic. This leaves implementation to non-governmental organizations (NGOs) that have their own interpretations and agendas in relation to human rights (Connell 2011). This leads also to inappropriate application of Western-based human rights in the global South.

Supporting human rights becomes even more complex when people are forced to flee their countries of origin. According to a United Nations Department of Economic and Social Affairs (UNDESA) (2009) report on international migration, more than 200 million people emigrated to more developed regions of the world in 2009. This immigration accounted for 12.5% of the foreign-born population in the United States (Migration Policy Institute 2009; United States Census Bureau 2010). Of this population, it is reported that between 7% and 10% have identified disabilities (Women's Commission for Refugee Women and Children 2008). The term "identified disabilities," as it is referenced here, means that the individual self-identifies as having a disability, either visible (e.g., the use of a mobility device) or invisible (e.g., post-traumatic stress disorder).

To better understand the lives behind these statistics, this study was framed by the following question: What stories do refugees with disabilities tell about their lives from childhood through the resettlement process? This question serves to fill gap in the current literature on refugees with disabilities. This paper attempts to re-identify this population of refugees as people with compelling and meaningful stories to tell. “Refugee.” “Displaced.” “Marginalized.” “Unemployed.” “Victimized.” “Poor.” These are words that frequent the literature on displaced people with disabilities. Words like “teacher,” “father,” “advocate,” “student,” and “mentor” are seen less frequently. Previous publications on refugees with disabilities are invaluable as they publicize the realities experienced by far too many displaced people around the world, however, there is a need to amplify personal narratives from refugees with disabilities in literature (Ahmad 2000). This study attempts to animate the lives that exist behind the current statistics, footnotes, and clinical summaries of refugee literature. Though many stories gathered from these life history interviews were sad, violent, and upsetting, many, if not more of the stories were compelling counter narratives to what typically comes to mind when one thinks of “refugees.”

THEORETICAL FRAMEWORK

To better understand the life histories of refugees with disabilities, multiple theoretical perspectives were utilized including: critical cultural theory, critical race theory (CRT), critical disability studies (CDS), and disability studies (DS). These theories and disciplines provide lenses through which to interpret and navigate the nuanced intersections of the multiple and shifting identities of refugees with disabilities. Due to the complex experiences of each participant, multiple theoretical perspectives were required.

The need for more self-narratives from refugees with disabilities is situated in the work of Hall (1990) and Ewart (2010) and their work on cultural theory and diaspora. Though cultural diaspora can be viewed through multiple perspectives (e.g., religion, ethnicity, nation), the work of Hall (1990) describes displaced identity as a never-ending contextual performance that creates fluid identities that are unique and “constantly producing and reproducing themselves anew...” (p. 235). Ewart (2010:147) similarly frames cultural diaspora, but adds disability as something that complicates displaced identities as they intersect with “race, gender, class, trauma, and performance.”

This notion of fluid and intersectional identities is also present in CRT and the work of Crenshaw (1991). Crenshaw’s (1991) work on intersectionality is imperative when analyzing the narratives of people who experience multiple and simultaneous oppressions because it counters essentialist notions that marginalization is uniform and experienced equally by members of multiply

oppressed groups. Aside from CRT, both DS and CDS served to further examine these oppressions.

Both DS and CDS were important lenses through which to understand the stories of refugees with disabilities. Each discipline, however, each informs this paper in different ways. A disability studies perspective takes into account many “ways of knowing about the world” (Ferguson and Nusbaum 2012:74), and actively includes perspectives from people with disabilities within the prominent discourse (Ferguson, Ferguson, and Taylor 1992). A DS framework is critical of existing oppressions that individuals with disabilities face in current and historical service delivery systems (Heshusius 2004; Ware 2005). However, disability as it pertains to participants’ life histories, was not constructed independently of other oppressions discussed in the interviews. The work of Chris Bell (2011) outlines the cultural barriers like homophobia and heterosexism that maintain hegemonic, white, heteronormative power dynamics, which were present in the life histories of the participants. Both Bell (2006) and Davis (2006) argue that DS is largely concerned with white bodies and too often ignores bodies of color.

In response to the historical omissions within DS, CDS evolved out of the tensions inherent in much DS scholarship. Critical disability studies scholars Meekosha and Soldatic (2011) argue that disability is inherently entangled and intertwined with larger social structures and serve to oppress and marginalize people with disabilities in global South contexts. Critical disability studies identifies Western exports like colonialism, global capitalism, and neoliberal education as main causes of competition for scarce resources that then in turn create poor living and working conditions that produce disabilities and perpetuate systems of oppression (Connell 2011).

In countries in the global North, disability is beginning to be viewed as a cultural identity and a way to celebrate human diversity. In the global South, disability often intersects with extreme poverty and marginalization (Berger 2004; Barker and Murray 2010), and Northern notions of human rights are all too often forcefully (and unsuccessfully) applied to Southern contexts (Bickenbach 2009). This misapplication of human rights and disability is significantly underrepresented in DS literature (Meekosha 2011; Meekosha and Soldatic 2011). The exclusion of lived experience of people with disabilities in a majority of DS literature in the global South is why a CDS perspective was vital to the interpretation of the participants’ lived experiences in this paper.

Through the analysis of stories from disabled refugees of color, it is hoped that the white dominant discourse in DS is disrupted in ways that can allow space for narratives from marginalized minorities. In these life histories, disability was inherently linked to and inseparable from multiple intersections of oppression stemming from identities participants either voluntarily took on (e.g., teacher, mother, advocate), or identities participants were forced to perform (e.g., disabled,

homeless, refugee). With the Northeastern region of the United States being one of the major entry points for refugees in America, the population of refugees with disabilities needs more opportunities to amplify their stories, and to disrupt the multiple oppressions that exist at the perilous intersections of their various identities. It should be cautioned that there is not one “essentialized” refugee experience. However, the absence of first-hand refugee resettlement stories suggests there is greater need for their representation in the literature. All participants in this study expressed their desire to improve the supports and living conditions for refugees with disabilities by sharing their life histories.

METHODS

This study focuses on the life histories of refugees with disabilities who live in an urban city in the Northeastern United States. The research was conducted over four months with informal meetings and life history interviews occurring between September and December of 2013. With over 800 refugees settling in the Northeastern United States annually, this growing trend of international resettlement has implications (e.g., refugee access to resources) for the region as a whole (Holtz and Muticelli-Heath 2012). The region has received a large number of refugees. Consequently, this region has a significant population of refugees with disabilities.

Research Design

The stories told in the life history interviews took place across multiple locations over many years, and fit into a global ethnographic design (Gille and O’Riain 2002). A global ethnographic framework examines “the world from the standpoint of participants located at the intersection of the most remote forces, connections, and imaginations” (Burawoy 2001:148). The aim of this study was to explore the personal experiences of refugees with disabilities, and examine their linkages to larger systems and structures to better understand which environmental factors may have influenced their life experiences (Burawoy 2000). This study focused primarily on the narratives of refugees with disabilities that pertained to the multiple oppressions participants experienced, and how they disrupted those oppressions while rebuilding their lives. Grounded theory techniques were used to guide the analysis of data (Corbin and Strauss 2008).

Sampling

Six participants, three male and three female, ranged in age from 26 to 52. They were recruited by snowball sampling (Patton 2001). Participant contacts

were gained through a sign language interpreter volunteer and a case manager who works with a local refugee service agency. With the exception of one participant who required five life history interviews due to the need for a spoken language interpreter, all other participants partook in three interviews.

All participants were born outside of the United States, and self-identify as having a disability. Two participants, Muse and Eden, are from Eritrea, married, and have a visual impairment. Yared, a man from Ethiopia, has a visual impairment. Bilonjwa and Kiza, a man and woman from the DRC, both have a physical impairment. Monu is a woman from Bhutan, but comes from a Nepali family, and identifies as Deaf. While Monu does not self-identify as having a disability in her personal life, she had to identify as disabled to the UNHCR in order to go through the resettlement process. Participants may have chosen not to disclose other invisible disabilities (e.g., post-traumatic stress disorder) that may have been acquired as a result of being displaced (Bradley and Tawfiq 2006; Loutan et al. 1999; Silove 2000; Dekel, Solomon, and Bleich 2004).

Three participants, Muse, Eden, and Yared, wanted their real names and some personal information to be changed in the publication of the study. However, all participants emphasized their desire to tell their stories to a wider public audience in the hopes that the support systems for refugees, namely refugees with disabilities, will improve. See Table 1 for more participant information.

All participants were able to speak English to varying degrees. Some participants had been in the United States longer than others, and had more command of the English language. Other participants learned English in school while growing up in their native country, and were very fluent in English. In the Institutional Review Board (IRB) document, it was outlined that “all participants be fluent and proficient in English, or signed English equivalent, and in the researcher’s judgment, be able to independently consent to and understand participation in the study.” All participants met these criteria.

During interviews with Monu, a nationally certified American Sign Language (ASL) interpreter volunteered to interpret the sessions. Kiza expressed that she felt more comfortable telling her story in Swahili rather than English. When I requested a Swahili interpreter from a local refugee agency, Kiza did not feel comfortable telling her story to “someone that was not [her] friend.” Kiza asked that Bilonjwa, a friend and co-participant in the study, interpret for her instead.

Although all participants were English speakers, some were more fluent than others. All participants were able to tell their stories clearly with appropriate supports (e.g., signed or spoken language interpreters, my use of clarifying questions). Despite these communication challenges, I chose to include data from all participants because I felt they all had valuable stories to tell. If their responses

were omitted, I would have been further policing and oppressing diverse ways of knowing, and silencing stories that have been historically missing from disability studies literature (Bell 2006; Davis 2006).

Table 1. Participant Characteristics

Name:	Muse*	Eden*	Yared*	Kiza	Bilonjwa	Monu
Country of Birth:	Eritrea	Eritrea	Ethiopia	DRC	DRC	Bhutan
Self-Identified Disability Label:	Vision impairment	Vision impairment	Vision impairment	Physical impairment	Physical impairment	Deaf
Years living in a refugee camp:	15 days	Never lived in a camp	9 years	15 years	10 years	19 years
Education:	Master's degree	Bachelor's degree	Associate degree	High school	General Education Development (GED)	Associate degree in progress
**Job Title in Country of Origin/U.S.:	Teacher/Freelance interpreter	Teacher/English as a Second Language (ESL) student	Trainer/College student	Seamstress/Advocate for women refugees	Student and vendor/student	Disability Program Assistant/Deaf refugee community advocate, Deaf interpreter
Year resettled in the U.S.:	2010	2013	2009	2011	2007	2011

*Some names and personal information have been changed to preserve participant anonymity

**Participants were asked how they wanted to be identified in their job title in their country of origin and in the United States

Data Collection

Prior to the start of interviews, I met with each participant individually to go over the basic information of the study, and explained issues related to consent to participation in the project. All participants partook in at least three 45-60 minute semi-structured life history interviews, with the first interview covering the participant's childhood, the second interview recounting the participant's transition into adulthood, and the third interview explaining the participant's

resettlement experiences in the United States. The interviews were structured this way because I wanted not to impose topics but to let the participants shape their own stories, and working chronologically through their lives seemed the best way to allow them to direct the topics. Most informal meetings with participants took place in the “refugee neighborhood” in an urban city in the Northeastern United States. These informal meetings were arranged in the refugee neighborhood because that is where the participants lived, and the locations were easily accessible. Most life history interviews took place in the homes of participants.

Interviews were audio recorded, and field notes were simultaneously documented. I conducted the interviews with the support of interpreters as outlined above. Audio recordings were transcribed by an outside transcribing service. I checked all transcriptions for inaccuracies and edited them to reflect each participant’s story.

Data Analysis

At the start of analysis, open coding was used to categorize important data (Creswell 2013). Actors in life history interviews, locations, and systems emerged naturally from the transcriptions. Broad codes (e.g., displacement, education, family, government) were utilized to allow for flexibility in data analysis. Following the open coding process, prominent categories had emerged in the data. The code of “Displacement” became the focus of further analysis. Though displacement seems like a fairly obvious category to emerge from life history interviews of refugees, what was curious about the displacement data were the different types of displacement oppression participants experienced.

Each participant sustained multiple oppressions, but all participants experienced multiple factors that limited or facilitated their ability to self-determine their lives. These oppressions were reported before, during, and after displacement. At some point all participants were not in control of their lives for extended periods of time. These limitations are tied to power structures that maintain systems of oppression and intersect with their diasporic, disabled, and refugee identities. These marginalizations and the ways in which participants disrupted them will be discussed throughout this paper. Participant excerpts represent refugees as people rather than numbers and figures. They exemplify how displacement and larger oppressive systems and structures shaped how participants continually rebuilt their lives.

The labels of diasporic, disabled, and refugee both limited and facilitated participants’ abilities to rebuild their lives. How each participant reformed and rebuilt their lives depended on the resources available to them at any given time. The results are broken down into two major categories: 1) multiple oppressions, and 2) disrupting oppressions. Each participant expressed their desire to tell their

stories with the hopes of improving the quality of lives for refugees with disabilities around the world. Their stories are outlined below.

LIMITATIONS

As in most life history research, only the stories of available participants are included in this study. Consequently, findings cannot be generalized to other populations. However, the findings remain important, and the methods of inquiry could be applied to other marginalized and underrepresented groups. For example, learning about multiple identities of a multiply oppressed individual could be useful when working with queer or transgender populations in countries in the global South.

During interviews that required Swahili spoken language interpretation, a certified Swahili-English interpreter was unavailable. Interpretation was done by another participant who was himself a refugee and an emerging English learner. Given his positionality, this could be a potential source of bias. A bilingual Swahili and English speaker was not available to verify the interpreted Swahili interview transcripts. Interviews were transcribed by a certified transcription service. Though all transcripts were checked for accuracy, there is a possibility some meaning and inference was lost during the transcription process.

RESULTS

In traditional qualitative methods, short excerpts are traditionally used to highlight findings. However, in a life history approach, participants' words are given primacy (Bogdan and Biklen 2006). Such an approach to research requires a retrospective telling of one's life, either written or oral, that is elicited by someone other than the subject (Watson and Watson-Franke 1985). In the discussion that follows, it is primarily the words of the participants that build the analysis.

Multiple Oppressions

Displacement from their country of origin is a common life experience for refugees. However, it is not often that one hears firsthand accounts of genocide and violent forced emigration brought on by military forces. In the following excerpt, Monu recalls one of her earliest memories as a young girl living in Bhutan being forcibly displaced by the Bhutanese military.

MONU: They went into the houses and they pulled all the clothes out. They put them in a pile and they set them on fire. They had guns pointed,

and there were many people who were hiding. The military would go into a house, look for them, and pull them out... You know, they were trying to hide at night because the soldiers would come. They would look in the houses, and they would take you out and they would beat you. They would shoot their weapons in the air. My family hid too. We tried to hide, and then we were found. They pushed us into the line, then we had to go. Many people were handcuffed. I was five. I remember that, I absolutely remember that.

In this excerpt, Monu describes the beginning of her diasporic displaced identity referenced by Hall (1990).

In the following example, Muse describes a similarly violent displacement. Though he was not forced out by the military, Muse fled from the Eritrean government, and had to illegally cross the border to Ethiopia to escape persecution for his alleged ties as a spy with the United States government. He was accused of espionage by co-workers at an Eritrean organization for the blind that developed inclusive community programs with United States government funds. His work on the project was cut short when he asked that receipts be provided to the United States government for evidence of monies spent on the project.

MUSE: It is common practice that someone, a donor, asks for financial reports. "So why are you refusing?" I say [to] them. "Oh, Muse is siding now with the U.S. government, he's working in a subtle way, a secret way, with the U.S. government. He's trying to put pressure on us..."

BRENT: They wanted you out?

MUSE: Yeah. They were looking for an excuse... I was known in the public now, my project was written with the U.S. government, so it was in the newspapers and everything. The [organization for the blind] has done these workshops, [they] were carried out, and I was speaking on this topic.

BRENT: So you were kind of well known for this project?

MUSE: Yeah, for the project. The U.S. Government staff [was] very much close to me. They were asking me to [start] another project for the Deaf. I gained a lot of recognition... I was very much famous, and [members of the organization] were not happy... They said, "No, this guy is working for the interest of the U.S. government, he's working for their interests, and we need to arrest him."

The mismatch between perspectives of development work and the sometimes violent implications for local participants like Muse represents the challenge created when Northern concepts of disability rights are applied to countries in the

global South (Bickenbach 2009). His alignment with American development standards is one factor that led to nationalist suspicion of Muse and his work, and eventually led him to leave his family and flee Eritrea. He risked his life to reach Ethiopia, and eventually the United States. He described his forced relocation to a refugee camp in the excerpt below.

MUSE: “Our plan is to go to Addis Ababa...We have our tickets, and we will go tomorrow in the morning.” “No, that’s not the way,” he (Ethiopian hotel owner) said. He advised us to give back the bus tickets, and not go to Addis Ababa...“There is a station where all the refugees settle, [at] the security center near here...They will give you a permit to go to Addis Ababa...” So, we registered there as refugees. The only other problem was then they said we have to go to the camp. We tried to oppose it, we said that we had to go out [immediately] to Addis Ababa. They said, “No, [the] Ethiopian government only accepts Eritrean refugees in the camp.” [So] we went to the camp...We went there. We were expecting it. It was difficult for us to live. There [was] no one who could help us, there [was] nothing there. They simply threw us there...No support...So there was not any cooking, there was not anything for us to do. There were no bathrooms, not anything...There [were] no smooth roads in the camp, we couldn’t move [around] easily. It was very difficult for us. Then we asked the Ethiopian authorities to give us a pass immediately as urban refugees...They said, “No, you have to stay at least [a] minimum [of] three months. Ninety days.”

Systems and routines for processing refugees were clearly in place on a basic level in Ethiopia, but basic supports were not provided to Muse to accommodate his visual impairment. This inaccessible camp environment relates to the structural oppressions DS scholars Heshusius (2004) and Ware (2005) seek to dismantle. Had the camp been more accommodating to his needs, Muse would not have had to flee the camp illegally in search of basic living supports while he awaited relocation. Bilonjwa similarly discussed the experience receiving inappropriate accommodations and supports when his family relocated to a refugee camp in Tanzania.

BILONJWA: A camp where [there] are refugee people, yeah [it] is kind of like...people are in prison. People don’t have [anything] to do...so they just wait [for] help from other people. It is in horrible condition this place, where people live if you are [a] refugee...It’s [a] very, very difficult place to live, especially [for] the people who [have a] disability like us...When I came to the refugee camp, I didn’t have any[one] who [could] help me,

like getting out, or [finding] work.

The horrible camp conditions did not just happen to Bilonjwa and his family one day. His displacement is a result of his disability intersecting with inequities maintained by the colonial history of the DRC and global capitalism. In the case of DRC (and other post-colonial countries), global capitalism has created economic circumstances where people are desperate for employment and survival (Connell 2011). This eventually which leads to violent circumstances where people like Bilonjwa have to flee (Meekosha 2011).

The camp conditions that constricted Bilonjwa's independence were not limited to living or working conditions, but extended to his school experiences in the camp as well.

BILONJWA: It wasn't very easy to go to school because I [am] a person with a disability. I can't walk, I can't move anywhere by myself. I am supposed to be with somebody who can help me. And when you [are] in a camp, you don't have nothing... You can't have clothes, even food, so you need to get food from somebody who can support you, [someone] who can help you.

Bilonjwa did not have access to a wheelchair, and relied on his brother taking him to and from school on a bicycle. When his brother moved away, Bilonjwa was left without any way of getting to school. Legally binding international treaties like the UNCRC (United 1989) and the UNCRPD (2006) are supposed to protect children and people with disabilities and guarantee access to education. However, in Bilonjwa's case, simply acknowledging education as a human right in international instruments did little when his disability intersected with displacement.

Inappropriate access to education was something that was also experienced by Monu in her camp in Nepal.

MONU: When I first moved to Nepal, I went to school with hearing [people]. I started out with other hearing kids and we were sitting outside, we were not in a shelter of any kind. There was no roof or anything... And all these Deaf people we would talk to each other and say, "I don't like going to school, I don't understand what's going on." And we would tell stories about how the teachers were beating the kids, we were afraid. If you were Deaf we would get beaten because you didn't know what was going on. You couldn't keep up with the lessons... All the Deaf would gather and we would say, "What happened today in class? Did you get spanked?" And we would tell stories to each other and we would talk

about what we would do. “Maybe we’d leave the school, what do you think? And maybe we can get other skills. Maybe we can do embroidering. Maybe we can do laundry...We can’t sit here with hearing people all day. We don’t know what’s going on, we’re completely left out and we don’t want to be beaten.”

Monu’s access to education differs from Bilonjwa’s because though she was provided access to education alongside her non-disabled peers, she was not provided an interpreter. Consequently, Monu was unable to follow along with the class and was physically abused as a result of not being able to provide correct responses. According to the UNCRC (1989), abuse of a child is a violation of basic human rights, but Monu was denied these rights. She was denied access to legal recourse because of her status of a displaced woman with a disability.

This inability to access appropriate education in refugee camps was similarly evident in Kiza’s story. However, her ability to attend school was not limited by resources in a refugee camp. Her family restricted her educational opportunities.

KIZA: It was the time when other children started to go to school. [Everybody went] to school except me. [My] uncle’s children and his sister [went] to school...[I] went to [my] uncle and asked him, “Why do you [take] only [these] children to school and not me? You don’t do anything for me...I can start [school] like the other children... Why don’t you take me to school?...[My uncle] said, “Okay wait, I will take you to school.” The first year came...the second year came, with no information about going to school. [I] went back to my uncle and asked [again], and he said, “No you have to wait, you have to do it step by step.” In [my] mind, [I] took all this stuff and realized I understand, “I know you guys hate me. [You] don’t like me, and when you don’t like me, you don’t want to help me get an education.”

The familial shunning Kiza experienced is a result of her nondisabled family members receiving preferential access to scarce resources. This competition for resources is a byproduct of the unilateral export of Northern concepts like capitalism and neoliberal education to the global South (Connell 2011; Meekosha 2011).

Familial oppression was something Monu also experienced, but in the form of physical and emotional violence from her in-laws.

MONU: He beat me, it was relentless. I put up with it time after time after time. And then I moved here to America and he still beat me. The beatings

were regular. I have a bump on my nose. It was probably cracked. He hit me with the chair. He hit me in the nose. He hit me in the head with the vacuum cleaner. Every week, two times a week, sometimes every three days, I mean it was just regular...I was crying because the family was also oppressive to me, and they all ganged up on me. Five of them against me...you know about the food stamps. They didn't want to give me any money for the food stamps. I said, "I needed the money for me and my daughter..." They would take the money from me, they controlled the money.

The abuse Monu experienced continued when her daughter was born.

MONU: I was pregnant while I lived with [my ex-husband's] family. I had a hard time giving birth. It was outside. It wasn't in the hospital...I looked at my husband, "I'm in such pain I need to go to the hospital!" And he said, "No, I'm sleeping, don't wake me up..." He didn't want to do anything, so he disagreed with me to go to the hospital, so I put up with it. I was crying...it was maybe four or five in the morning, the pain was so amazingly intense and I hit him...I whacked him hard. He woke up, "What are you doing?" I said, "I can't take it anymore, we have to do something. I'm in so much pain we have to take care of this..." What am I going to do? I can't do anything. I have no power. So obviously I had to put up with the labor. The pain was so intense. There were bamboo walls in the house. The pain was so intense I grabbed a piece of bamboo and broke it...I just snapped the bamboo...The neighbors in the hut next door heard the breaking of the bamboo and they came out, "What's going on?"...They said, "Take her, take her to the doctor! What are you doing?"...The neighbor grabbed a cloth and helped me. They tried to carry me in a big cloth to the doctor. The head was starting to emerge, to come. And so while we were on the way to the doctor, the baby was born outside.

In this instance, Monu was not allowed to make choices for her or her unborn child. This put both of their lives at risk, and is an example of how multiple marginalizations increase the chances of abuse and exploitation (Bradley and Tawfiq, 2006; Loutan et al. 1999). Yared was similarly denied the right to choose how and when he would receive medical treatment that he experienced as a result of the living conditions in a Kenyan refugee camp.

BRENT: What were your thoughts about receiving this treatment?

YARED: Yeah I never knew. It was a new thing all together for me. And to be honest, I did not know that it could damage my memory. I can't remember them telling me to be honest, so I don't know. I can't say anything because I don't think they told me, and I can't remember. I think this went on for one month or two months...

BRENT: Did the treatment help?

YARED: Yes, I think it helped, but its two-edged knife. Again, you know it's actually...the treatment, I don't know if it worked for me. You know Brent, to be honest, the treatment can help, but if you lose your memory again, you get depressed you know? I mean...it disturbs you.

Yared's memory was negatively affected after undergoing treatment he does not remember consenting to. Yared's forced medical treatment is a modern example of the medical violence people with disabilities have been subjected to for years (e.g., forced sterilization, lobotomies, etc.)(Meekosha and Shuttleworth 2009). Rather than looking to the depressing conditions of the camp, the "problem" was located in Yared, and now his memory has been negatively impacted. After describing his experiences with refugee medical treatment, Yared elaborated on his thoughts about displacement and being forced from his family at a young age.

YARED: I had to go to another refugee camp...However, the term refugee also frustrates you. For me it wasn't really good. I am away from my parents, and I don't know what's happening to them. I don't have any contact, any communication. So that's where I started feeling low...Because now you are a refugee, you aren't an Ethiopian, you aren't a Kenyan. I mean it has a very, very negative impact...We were just in an enclosure, I mean we couldn't go out without permission you know? You don't have power over yourself there.

The traumatic and rootless diasporic existence Yared described experiencing from a young age and was similarly lamented by Bilonjwa when asked about the possibility of ever returning to the DRC.

BILONJWA: My family, we stay together and [know] we can't go back. We have so [many] problems over there. [It] was happening when we were there, and it's going to be difficult for us to go back over there...For people like me, [we] would suffer if we [were] there.

Like Bilonjwa, Yared realizes his inability to return to his former life, and echoes Hall (1990) and Ewart (2010) as he reflects on his preparation to leave his camp for resettlement in the United States.

BRENT: So what was that like? Leaving the camp.

YARED: Of course excitement. You are always insecure you know. You don't know what will befall you. You don't know what will happen to you. To be honest, I never lived in the camp, I mean mentally... I couldn't think of my future. I knew my future as far as tomorrow, just like waking up and carrying out my routine things. You can't plan for months and years because my future [was] in someone else's hands, which really frustrates you. It's not easy. It's difficult to explain to someone who has never lived that kind of life... if you can't think [about] your future, if your future is not in your hands, then you can't plan, "After three years I will do this and that." It's really frustrating... I mean it's really difficult to explain. You're always down. You feel deflated. You never think you're a human, you're just a... you live a vegetative life you know? You can't aspire for a future. But we survived, and it was not easy... [Survival] depends on someone's kindness as I've told you. For years I couldn't run my own life. That's the dark side... it's painful.

Disrupting Oppressions

Though each participant experienced multiple and intersecting forms of oppression for extended periods of time, each participant also disrupted those oppressions by engaging in a variety of activities that included education, employment, and advocacy. Due to a variety of factors (e.g., age, family resources, gender, label of disability), some participants had more opportunity to disrupt these systems of oppression than others. The following excerpts highlight how each participant disrupted the multiple systems of oppression they experienced.

Prior to being displaced from her home in Eritrea, Eden attended a teacher training college in Ethiopia and then taught in an Eritrean middle school for 20 years.

EDEN: And then I changed universities, Addis Ababa University to college.

BRENT: You went to a different college?

EDEN: Yeah a different college, diploma, uh TTC, Teacher Training College.

BRENT: And that's in Addis Ababa?

EDEN: Yeah, I joined TTC [from] '85-'86. Then I continued [for] two years.

BRENT: And you were teaching English?

EDEN: No, history. I changed it to history. Up to now, I was there for twenty years from 1992 up to 2012.

BRENT: Wow.

EDEN: I was at [my] school because it is nearer to my home and I loved it.

BRENT: So you were there for twenty years. Wow. So you taught history for twenty years.

EDEN: Yeah.

Eden's success in higher education and the teaching profession counters the oppressive representations of disability that are all too common, especially in the global South (Erevelles 2014).

After years of familial oppression, Kiza eventually accessed education when she enrolled in a secondary boarding school in the DRC. While there she learned job skills, joined a supportive community of peers with and without disabilities, and was gainfully employed.

KIZA: There were people there with disabilities, people without disability, and [we] used to work together... it made [me] feel [very] happy.

BRENT: Okay. So it sounds like there was some community there. You found people that had similar experiences to you.

KIZA: Yes. I was happy also because Sister Maggie was helping [me] to go to school...It was kind of like [bringing] people together and giving them stuff to help them work, like if you [didn't] have support. If you don't have anything to start your business with, they can give you something, "Okay you have to start with this..." They tell you, "Okay make this, and after that we [will] take [it] to the market." After selling [it] they take a little money and bring [it] to you. And that money [helped] with things...a lot of stuff...everything that you want.

Through access to education and employment, Kiza was able to live a more self-determined life, as outlined by Wehmeyer (1996), and have life choices comparable to her peers without disabilities.

Like Kiza, Yared was also employed. He worked as a supervisor of trainers in a refugee camp to help teach life skills to refugees who have vision impairments.

YARED: First I was employed as a trainer teaching daily living skills. Teaching them how to cook. They're blind and mostly elderly actually. [There] were very few children...[mostly] old people. And we also

[taught] them Braille. I was also a supervisor. I was also working as a Braille transcriber, and [doing] different activities...

Not only was Yared a supervisor in the refugee camp, he also became a leader within his community advocating for the rights of refugees.

YARED: I was a community leader for two years. After that, I was a community elder you know? So, whatever we [did] I was taking part in. I was participating in all the community activities, like advocating for the refugees, and representing the refugees in the elder's committee...I was elected as a vice-chairman of the community...we have representatives. Each community has a representative that communicates with UNHCR...As a vice-chairman, what we normally do is deal with the UNHCR and NGOs. We advocate for the rights of the refugees.

It is these stories of leadership that are missing from literature on refugees with disabilities.

Following resettlement in the United States, stories about seeking education and employment were prominent in the life histories of the participants. When asked about his post-resettlement goals, Bilonjwa said, "Before I used to take the bus, but right now the school is not that far away from me, I can use my wheelchair for getting there. Now I'm taking GED classes."

Similarly, Monu enrolled in a local community college ASL program. As she became more fluent in ASL, she began advocating for other Deaf refugees to enroll in a sign language-based language school that she founded.

MONU: So I got into the sign language program at [the community college], non-credit, non-matriculated. I would go, and in exchange for sitting in the class I helped the teacher with other students, because I could help them sign and other students who were learning to sign, hearing students. Well, you know my whole thing was I was planning to get Deaf refugees together to teach them. So I started to get them together. I went to their homes, knocked on their doors, and brought them to the [refugee language] school with me.

Like Monu, Muse also chose to teach refugees and get involved in his community with his ultimate goal becoming a certified teacher in the United States.

MUSE: I need[ed] to work. Then they told me, "Muse, [you have this] African qualification, but it may not be evaluated as the same by the

employers as the U.S. certification...” [The organization] thought, “Okay this guy is very much intelligent, so even though he has no U.S. certificate, he can at least interface and help us.” I tried to work a little bit to help with a [local refugee organization]. Then I took training, medical interpreter training, and I started to work at the hospital. Then gradually I tried to apply myself to an [organization for the blind]. They started to work with me. They tried to find me some tutoring. Yeah so that’s what I am doing now. I do tutoring, some apprenticeship. But in the meantime, I am trying to make some income to get the official teaching certificate from the [state].

Education was also the path Yared chose as he became a Braille instructor and took classes to become a vocational rehabilitation counselor.

YARED: I went for an interview to see if I could start English classes, but after they interviewed me, they found out that I don’t need English class...

BRENT: And then you started classes at [community college]?

YARED: Yes before that I got a job teaching Braille. But I said, “No, I want to focus on my education, my schooling.” So, I started straight in my school...

BRENT: Okay, so you had a job, and then you wanted to focus on school. You said you’re doing public management?

YARED: Human services.

BRENT: Human services, yeah. And how much longer do you have for that?

YARED: Actually I [have] six courses.

BRENT: Six more courses?

YARED: Yes, six more including the internship.

BRENT: And when you’re done, what do you hope to do?

YARED: Well... I really don’t know. You have to look for a job, and I just wanted to be a vocational rehabilitation counselor. So maybe if I go up to my master’s level I can be maybe employed by [a local agency for the blind]. Yes, I have a clue that I can work there. But I don’t think with my first degree in human services I can work there because the qualification required to work there is a master’s degree.

Like Yared’s goals above, all participants discussed larger goals they had for their future. When asked about her goals, Eden said the following:

EDEN: Oh I must do something.

BRENT: Like what? What would you like to do?

EDEN: I want to get training, I don't know, maybe business.

BRENT: So you're thinking about going back to school?

EDEN: Yeah to get training, and a bachelor degree or master's degree. I don't know. Not simply for training. I want to train in something because I know I must do something, I must work. But for a year I don't want to do anything...I don't have any plans. I know I must do something, but now I can't identify it.

While Eden wanted to think about her next steps, Bilonjwa had a very clear idea of his career path.

BILONJWA: For work, when I was in my country, I did some accounting...So now I'm focusing [on] learning language...So maybe in [the] future, I can try to do something like technology, learning how to fix some things like computers, or networks, or things like that.

Aside from working in technology, Bilonjwa wished to engage in advocacy that could benefit the larger international refugee population.

BILONJWA: There [are] a lot of people with disabilities, and I can tell you don't stop here...I have a lot of friends who are handicapped people. [Some] get treated good, and some [get treated] badly, like Kiza. So for me, in my family, I can say thank you, thank you for my family because I didn't get [treated] wrong in my family. Other people, they have awful things in their family so... don't stop right here. Try to reach other people to [give] more [to] them.

This desire to advocate for refugees with disabilities was something that was important to Kiza too.

KIZA: I want these things to help other persons, to educate other people. Maybe [I] can work at a place where it is fine to be a person with [a] handicap. Maybe this can help other people...I'm working hard with everyone. And now [I] have this project with [my case manager]. Maybe one day it's going to be work, and I can find [a] way to help other people. And you know in [my] mind, [I] want to be the person who can work with other people, working with people with problems like ours. And [I] want to find information about people like me. I am feeling like I want to do that job.

Like Kiza, serving the local and international refugee community was something that was important to Monu as well.

MONU: I do plan to work with Deaf people. And I would love to go back to the camps. I love refugees too. I know that I want to do more work with [the local] refugee community, [the] Deaf refugee community...I have a vision that I think sometimes, not necessarily a full plan, but I think maybe in 2015 I think I am going back to Nepal...But I think we can help them, and we can meet with Deaf people and talk to them. Maybe meet with the families. And we talk about what's in their options when they come to America so they don't feel alone.

Aside from her large vision for the future, Monu felt it was important to reflect on her life following the trauma of displacement. After surviving ethnic cleansing as a child, living for 19 years in a refugee camp, giving birth to her daughter without a medical facility, and surviving domestic violence, Monu has this to say about her life as a refugee post-resettlement:

MONU: And now, I am with my daughter and my mother and I am happy. I am independent. I'm not being beaten. I'm not getting hurt. You know I feel so much better, so much lighter. I have worries, but not like that. And now I am with my mother like we were before I got married. I'm happy I'm with my mother and my daughter. I want to work hard to take care of my mother the way she worked hard and took care of me. Now that I am [in the United States], I have the opportunity to do that. I feel like I am free, I'm not a slave anymore. I can fly free.

DISCUSSION

This study was an opportunity for refugees with disabilities to construct their life stories in a venue that would otherwise be inaccessible to them. These interviews did not “give voice” to participants, but rather served as a way for me to facilitate a space for participants to tell their stories. About “giving voice,” Ashby (2011:14) says, “Perhaps instead of attempting to “give voice” we need to “facilitate voice and agency,” further leveling the researcher/researched hierarchy.” This facilitation of voice was at the forefront of the study. The purpose of this study was to facilitate a forum for refugees with disabilities to share their unique life experiences, and to fill the gap in refugee literature with personal narratives of displacement.

Since this study focused on the life histories of refugees with disabilities, perspectives of disability studies and intersectional identities informed the

analysis of data. Throughout the study, it was imperative to view the participants as capable people, with rich and diverse histories and identities to share. By analyzing these data through this intersectional disability studies lens, it was possible to understand the multiple oppressions reported by the participants. Using this lens, life histories of refugees with disabilities have the potential to become a medium through which to better understand the complex identities and lived experiences of “disabled” “refugee” populations, and expand on the critique of white disability studies offered by Bell (2011).

All participants shared many experiences throughout the course of their lives where impairment was not adequately accommodated. Whether accommodations were not provided in schools, within families, in the workplace, or otherwise, this lack of appropriate access across settings limited participants’ abilities to live self-determined, dignified lives. What would participants’ lives be today if they had had equal access to education as their peers without disability labels? What types of employment opportunities would each participant have today if their disability had been located in social arrangement rather than seen as a personal trait? What if the participants had not become refugees?

Regardless of the limitations placed on participants at various points in their lives, all rebuilt their lives (e.g., Monu and Muse becoming local advocates for refugees, Bilonjwa and Yared enrolling in school). As each participant experienced oppressions, they adjusted their life and identity to fit the situation. At various points in time, different identities were more salient than others. For example, when Monu was married in the Nepali refugee camp, she was a survivor of domestic violence. When she relocated to the United States, she removed herself from that violence and became the head of her household. While certain identities (e.g., disability identity) may have been more important in their home country, identities were fluid post-resettlement. This was especially evident in Kiza’s story. When she was denied an education due to her disability, she languished as an outcast in her family home. Upon resettlement, Kiza self-identifies as a “seamstress” and “advocate for women refugees.”

During the interviews, it was common to have many refugees from the same country coming in and out of participants’ houses. It was clear that a new, cultural diasporic identity had developed for each participant that at times included their national identity. At other times, a diasporic disability identity was present when people with similar disability labels congregated at the homes of participants. During the project, it was not uncommon for participants to invite me to disability-related gatherings, refugee-related community events, or advocacy meetings about increasing community access for refugees with disabilities.

CONCLUSION

The participants in this study told powerful stories about how they are actively rebuilding their lives. They created new identities related to culture, disability, displacement, or their new activities in the community. These fluid identities were based on past experiences that shaped and influenced each participant's life. The construction and performance of each new identity came to represent a new way of being, understanding, and interacting in the world. There was an active building and performance of identity that relates to Hall's (1990) and Ewart's (2010) work on cultural diaspora where disability and refugee status may or may not be at the forefront. These life histories are about identity formation, the reestablishment of community, and shared human experiences. Each participant's story is a powerful example of how people respond to oppression when given the opportunity to self-determine their lives.

All participants told stories about resiliency, adaptability, and resourcefulness. These words are not typically used to describe people with disabilities, let alone refugees with disabilities. Through this lens, this diasporic, disabled, refugee population can be seen as a powerful model as to how to rebuild displaced lives. Refugees with disabilities need to be given appropriate accommodations and a chance to control more aspects of their lives. Their complex multiple identities and intersectional oppressions must also be taken into account when providing such supports. It is through these personal narratives that there is hope to change how supports for refugees with and without disabilities are conceived, delivered, and improved upon. Aside from improving supports for refugees, these stories offer insights as to how human rights in the global South can be better understood and applied in diverse transnational contexts. If refugees with disabilities were given a chance to share their thoughts on resettlement in a public way, then perhaps the struggles these participants experienced would not continue to be the reality for millions of other people with similar labels around the world.

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