

Disability-inclusive healthcare in humanitarian camps: Pushing the boundaries of disability studies and global health

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A significant proportion of forced migrants live in humanitarian camps located in remote regions of the global South. Disabled persons have been historically neglected within camp programs across all service sectors, especially healthcare. This paper describes an exploratory research study on healthcare access for forced migrants with disabilities in the context of humanitarian camps. Based on the methodological framework of rapid ethnography, the research involved guided tours, community mapping exercises, ethnographic observations, and semi-structured interviews in a refugee camp in southern Africa. Additional key informants from other sites were interviewed remotely using a convenience sampling strategy. Several important insights emerged from the research including: misperceptions about the health-related needs of disabled persons, their specialized health needs falling outside the ‘social minimum’ of humanitarian healthcare, and concerns about distributional ethics in relation to disability-inclusive healthcare. The research also highlighted barriers and strategies for addressing disability-specific health needs given significant resource constraints in humanitarian camps. These findings are discussed in light of practical and theoretical challenges in the fields of disability studies and global health.

Keywords: refugee camps, global health, humanitarian health, disability, rehabilitation

Introduction

Approximately 35% of the world’s forced migrants live in humanitarian camps. These camps are predominantly located in remote areas in the global South, particularly in sub-Saharan Africa and Asia (UNHCR, 2012a). Historically, disabled persons living in these camps have been neglected within humanitarian programs (Kett & van Ommeren, 2009). Notable recent efforts have been made in the humanitarian field to redress this historical oversight (Mirza, 2014). As a result, disability inclusion is receiving increased attention in certain humanitarian sectors such as education (Pinnock & Hodgkin, 2010) and physical planning (see for example Sphere, 2011). However the healthcare sector continues to lag in this area.

Access to appropriate healthcare is an important human right enshrined in the Convention on the Rights of Persons with Disabilities (Stein et al., 2009). Yet this topic is frequently sidestepped in disability studies, a field dominated by western scholars. Working from the vantage point of industrialized welfare states, these scholars tend to be wary of medicalization of disabled persons. Consequently, focusing on healthcare is viewed as

deflecting attention from ‘real’ issues of social and political rights (Grech, 2009; Meekosha, 2011). Yet for disabled persons living in resource-constrained regions of the global South, unmet health needs not only diminish their quality of life but also threaten their basic survival. Within this context, disabled persons’ access to healthcare is a vital concern (Tomlinson et al., 2009).

The growing field of global health holds promise for improving healthcare access for disabled persons living in resourced-constrained settings. However, like the topic of healthcare is marginalized in disability studies, so is disability absent from global health discussions (Mitra, 2013). The lack of interdisciplinary dialogue and debate creates enormous gaps in knowledge development and service provision.

Resulting gaps particularly affect marginalized groups such as forced migrants with disabilities. Disabled persons are frequently sidelined during health sector planning in camps and encounter significant barriers to accessing basic health services, with availability of specialized health and rehabilitation services altogether lacking (Shivji, 2010). Much of the health-related research in humanitarian camps has largely ignored disability issues, focusing instead on issues such as infectious and communicable diseases (e.g. Roca et al. 2011), reproductive health (e.g. Howard et al., 2011), nutrition interventions (e.g. Khatib et al. 2010), and specific mental health conditions (e.g. Mollica et al., 1993). Consequently, health services in humanitarian camps have traditionally focused on preventive and curative responses to acute conditions. Additionally, population-based primary care and preventive interventions have seldom considered the needs of disabled persons.

The inattention to disability issues is a significant oversight given recent reports of the changing health and demographic profile of forcibly displaced populations. Healthcare concerns of displaced populations, particularly those in protracted situations, are becoming more complex (see also Pisani and Grech’s article in this special issue). While acute infectious diseases have always been an area of concern, chronic non-infectious conditions and long-term impairments are slowly on the rise as a result of longer life-expectancies among displaced populations and because significant numbers of displaced persons now originate from middle-income countries (Spiegel et al., 2010).

In summary, examining healthcare access for forced migrants with disabilities represents a scholarly pursuit that is both timely and important for pushing the boundaries of disability studies and global health. To this end, this paper presents an exploratory research study investigating the organization of healthcare in humanitarian camps and the state of healthcare access for camp inhabitants with disabilities.

Methods

Research Design

A qualitative, rapid ethnography research design was used. Rapid ethnography entails adaptation of traditional ethnographic methods for resource-constrained settings where the need for knowledge is immense but time and resources are limited (Afonja, 1992; Slim &

Mitchell, 1992). This research approach has been previously used with forcibly displaced persons (Weiss et al., 2000).

Specifically, this study incorporated two methodological stages. The first stage involved five days of site-specific field research comprising key informant interviews and ethnographic observations in a refugee camp in southern Africa. The camp was home to over 10,000 refugees, mostly from the Democratic Republic of Congo, Rwanda, Burundi, and Somalia. The size of the camp, both in terms of geographical area and population, made it an ideal setting to gain a quick yet comprehensive overview of 'typical' health-related services and needs. In the second stage of research, key informant interviews were conducted over a three-month period with humanitarian professionals who had served in diverse humanitarian contexts.

Sampling

Key informants at the field site were recruited through snowball sampling (Patton, 2002). A key point of contact in the camp introduced the researcher to potential candidates. These individuals then suggested other key informants for the research. This snowball strategy evolved into a participatory enterprise as many of the initial key informants were affiliated with the camp's association of disabled persons. These individuals helped the researcher reach out to others who could shed further light on the research topic.

Additional key informants from other sites were recruited remotely by email using a convenience sampling strategy (Patton, 2002). A pre-scripted email was posted to relevant listservs and sent to the researcher's contacts in the humanitarian field. Interested individuals were requested to contact the researcher to schedule interviews.

The sample size was originally set at 15 key informants, a number deemed appropriate to achieve data saturation (Patton, 2002) while presenting a feasible target given the limited scope of this study. However, recruitment was halted at 12 key informants, as by this point data saturation was believed to have been achieved, with no new insights expected to be gained from additional interviews.

Of the 12 key informants, half were female and two had personal experience with disability and forced migration. Informants' ages ranged from 25 to 64 years, although the majority were under 40. Their experience with humanitarian work ranged from 10 months to 10 years and their areas of expertise included social welfare, health, education, disability services, and disability advocacy within the context of displacement. At the time of research, three of the key informants were working for UN agencies, two were working for local NGOs, one worked for a Ministry of Health, and four were working for international NGOs.

All key informants, with one exception, had experience working with conflict-displaced populations; one informant had worked with populations displaced by both conflict and natural disaster. Between them, the respondents had worked in various geographical settings including: Kenya, Malawi, Sudan, Uganda, the Democratic Republic of Congo, Yemen, Thailand-Burma, Palestine, Haiti, Sri Lanka, India, Pakistan, and the Philippines.

In sum, key informants included individuals with and without disabilities who represented a variety of displacement settings.

Data Collection

During the initial stage of field research, multiple data collection procedures were used. The researcher conducted community mapping exercises and guided tours (Chambers, 1994) in order to develop an understanding of the general conditions and layout of the camp, the locations of key facilities and service centers. In addition, non-participant observations were carried out in key settings that were open for public visitation such as meetings of the camp's association of disabled persons, the waiting area of the camp health clinic, and the food distribution center.

The researcher also engaged in informal conversations and home visits with camp residents with disabilities. These informal exchanges offered a window into people's lived experiences (Patton, 2002) and helped corroborate key informant reports (Adler and Adler, 1998). Information gleaned from informal conversations and observations substantiated interview data gathered from key informants, as described below.

Finally, semi-structured interviews were conducted with key informants. Interviews lasted 30 to 60 minutes each and inquired about the health-related needs of disabled persons living in humanitarian camps, typical organization of healthcare in camps, accessibility of mainstream health services, and availability of specialized health services for camp inhabitants with disabilities. Interviews were conducted in English, audio-recorded and transcribed verbatim by the researcher.

In the second stage of the research, additional semi-structured interviews were conducted with key informants working in other sites. These interviews were similar in content to the ones described above, the only exception being they were conducted by phone. One informant chose to contribute responses in writing owing to problems with phone connectivity.

Lastly, extensive desk research and literature searches were conducted to supplement data from field research and key informants. All study procedures were approved by the research ethics board at the researcher's patron university. Measures were taken to protect participants' privacy and confidentiality. Voluntariness of participation was emphasized and informed consent was obtained prior to data collection.

Data analysis

Using step-by-step data coding procedures (Miles & Huberman, 1994), the researcher first read all transcripts and observation field notes while simultaneously documenting emerging insights and ideas. Next, transcripts and notes were re-examined line by line and codes were generated to categorize emerging themes. This process yielded an initial list of codes, which was refined and narrowed to a smaller list of key themes during a second review of the data.

This was followed by more interpretative analysis where conceptual links were formulated to yield patterns and relationships between key themes. At this stage, the analysis yields were discussed with the researcher's disability activist colleagues, other experienced researchers (both disabled and non-disabled) in the fields of disability and forced migration, and experts in humanitarian health and human rights. These discussions helped refine thematic patterns. To enhance credibility, the analysis procedure was subjected to an external audit involving a peer reviewer (Lincoln & Guba, 1985). This audit revealed a high rate of agreement between the researcher and the peer reviewer in application of thematic codes. ATLAS.ti version 6 software (Muhr, 2004) was used to facilitate data analysis.

Results

Key findings that emerged from the research are summarized under three broad themes: (1) unmet health needs of forced migrants with disabilities, (2) barriers to development of adequate health services, and (3) strategies for development of disability-inclusive humanitarian healthcare programs. These themes are supported by verbatim quotes from key informants where appropriate.

Unmet health needs of forced migrants with disabilities

Key informants reported that humanitarian health actors frequently misunderstood disabled persons' health needs as falling squarely outside the realm of mainstream health services. One key informant, who worked for a disability-focused international NGO described the situation thus:

With mainstream health actors...feeling that disability is kind of a specialized issue so they don't know to respond, they don't know what to do...one barrier would certainly be the existing mandate and mode of functioning of different health organizations where for them disability services are not necessarily part of health services...[there is need for] more awareness that persons with disabilities do have health needs, some of which are the same as everybody else and some of which are more specialized.

The above view was echoed by disabled persons who the researcher interacted with during fieldwork. These individuals reported that health professionals at the camp clinic tended to assume that disabled persons only visited the clinic for services related to their disability. Ironically when these individuals presented at the clinic with disability-specific needs, these needs were also not well understood by health professionals.

Among the disability-specific needs identified by key informants, one of the biggest priorities included access to orthotic and prosthetic equipment and technical aids, in particular mobility aids like wheelchairs. A key informant, who was employed with an international NGO and had worked in two humanitarian camps, explained:

Dire shortage...[of] generally any medical equipment be it a wheelchair, be it crutches, be it any form of prosthesis or support you may need, even glasses at

times...I've seen quite a few people actually... who umm would be walking on the floor on their knees ...they don't have a wheelchair so they're walking like that... there is definitely demand for wheelchairs.

For many disabled persons, unmet needs for mobility aids such as wheelchairs, constituted a double setback by further hindering their access to mainstream healthcare. At one site, there were reports of people with mobility impairments foregoing medication refills due to long distances between their homes and the health clinic. Access to other social services in the camp was also similarly hindered. In the words of one key informant:

If a person has lost a wheelchair, they're not going to be able to access the World Food [Program] distribution. So if we can replace their wheelchair, we can give them the independence that they need in order to be able to access other health, camp services.

Another unmet need was access to specialized medical care in the form of advanced orthopedic or neurological surgeries, pharmacological treatment for chronic physical and mental health conditions such as epilepsy, and rehabilitation services such as physical and occupational therapy. During field research, several parents of disabled children came forward to report that they had made formal requests for one or more of these services, to no avail. Key informants reported that such needs were perceived by humanitarian actors as being complex, long-term, and non-life threatening. Therefore these needs were most difficult to address in the displacement context where healthcare infrastructure is limited to short-term emergency aid and basic primary care. One key informant, a humanitarian professional, provided the following examples:

For example in cases of people who have psychiatric conditions or people who have some sort of mental illness and would require follow up with that and would require a particular medicine for that ... simply there is shortage of those particular medicines or it's situations which are too complex, are long-term...it's just difficult to put someone on treatment and guarantee the treatment will be available a long time. At times people require surgery for a particular condition or as a follow-up to something that has already been done back home and so on. And when it comes to non-emergency primary healthcare you have to be very lucky. If you don't have the means, it's very difficult.

In general, rehabilitation services were reported to be limited and fairly non-existent in most humanitarian camps. Notable exceptions included Kakuma refugee camp in Kenya and refugee camps in the Palestinian Occupied Territories. In Kakuma, the International Rescue Committee, which provides essential healthcare, also operates a center for basic rehabilitation services within the camp (Karanja, 2009). Similarly, the United Nations Relief and Works Agency for Palestine Refugees (UNRWA) includes physical rehabilitation among the main elements of its primary health provision within refugee camps (UNRWA, 2010). The dearth of similar services in other settings appeared to have caused widespread frustration among both service providers and disabled camp inhabitants. One key informant, who was a social worker employed by an international NGO and worked closely with children and families in the camp, described the following experience:

...I meet with the parents [of disabled children] on a regular basis... to find out what's going on. And every time, every time, despite how many times I tell them...I'm not a doctor, I can't do anything for them medically, they're like 'I need medical help, can you do this, can you do that for us'...And I'm like 'Well what do you want me to do... it's not the UK, it's not the United States, it's not Europe. There are no kind of rehab[ilitation]...So it's very frustrating.

The next section addresses some reasons for the high level of unmet needs uncovered by the study.

1) *Barriers to development of adequate health services for forced migrants with disabilities*

Theoretical literature on humanitarian relief and welfare uses the language of 'social minimum' to describe the basic bundle of resources needed for a person to live a decent life (Leaning, Spiegel & Crisp, 2010). Combined data from field and desk research revealed that the 'basic bundle' of health services available in humanitarian camps, the social minimum so to speak, comprised such services as first aid, outpatient medical consultation, maternal and child health services, and services related to HIV/AIDS and other sexually transmitted diseases.

The exact configuration of services varied from context to context, with some camp clinics offering limited in-patient care, some offering clinics for specific diseases like tuberculosis or malaria, and others offering psychiatric consultations. However, a consistent trend across camps was exclusion of disability-specific health services from the 'basic bundle' of healthcare. This point is illustrated by the following quote from a disabled key informant, who lived in the camp:

There is a clinic for everybody which treats malaria, diarrhea and [things] like that. But a clinic which concerns things like some kind of disability, we don't have...and when we go there...they used to say that 'Ah we don't have this service for disabled so you can remain at home because we cannot assist you...We don't have enough materials to assist disabled [persons].

In some camps, elaborate referral mechanisms had been developed for disabled camp inhabitants to request disability-specific care such surgical procedures and rehabilitation therapies. Referral protocols typically involved seeking approval and funding from multiple service entities and administrative authorities. In one camp, the process included: getting a referral from the camp clinic to visit a specialist at the nearest district hospital, lobbying with the United Nations High Commissioner for Refugees (UNHCR) to get permission for the same, applying for transportation and financial assistance from the designated social service agency, and finally securing permission from the camp administrator to leave the camp premises. An NGO-based social worker described the process thus:

You'll have to go and see a specialist in [capital city] and that in turn is very difficult

to do... it's a lot of hassle...to set up... you would have to go and see the UNHCR, you would try and lobby for you to try and get into that clinic. It's a very, very kind of, stuck in the mud kind of ... nothing flows very much with healthcare...you have to get permission from the camp administrator...it's a long way for someone here and the political situation kind of doesn't help either.

Lack of transportation and forced encampment policies imposed by host governments further contributed to the challenges of accessing specialized care outside camp premises, as illustrated by the following quotes, the first by a humanitarian professional and the second by a disabled camp inhabitant:

[Camp residents] don't have the right to live outside the refugee camp. It's a government policy... So for people who need physiotherapy every day or for kids who need daily assistance from [rehabilitation clinic in the city] or attend services there, the parents are not able to live outside the camp and they're not allowed to afford transport. We can provide the transport only once per week or twice per week for the families. So it's a great challenge for them to access regularly.

There is an ambulance...it is free for everybody. But the problem is this, if the ambulance takes you in the morning, you are on yourself to take you back from there. You have ... to pay your money for ticket. Well we don't have ticket... Or we have to sell some quantity of food in order to get some transport from [clinic] to [camp].

Navigating through the layers of bureaucratic complexity was thus a daunting and time consuming endeavour. Key informants reported cases where individuals in need of specialized care had discontinued their pursuit of services or had missed their appointments by the time requisite permits were obtained. Those successful in securing timely permits had to comply with UNHCR's policy of seeking care at the nearest healthcare facility before availing of advanced alternatives elsewhere. As described by an UN employee:

Here in the [camp] clinic we don't really have any services for refugees which are specialized or anything like that. It's quite basic. But we have an excellent system for transferring cases. So for example if they cannot be treated in the clinic in the camp, we can transfer to the district hospital and if not we can transfer to the main hospital in [capital city]. And then again if they still cannot be treated we refer them to private hospitals within [country] and UNHCR pays for 100% of all that including food and transport and all necessary treatments.

The emphasis on local healthcare options created additional barriers given the limited availability of specialized medical and surgical care. In the words of one disabled camp inhabitant:

Normally disabled [camp residents] ...tries to seek and get a treatment but it's not easy because UNHCR sometimes they send out to hospital... But if this hospital, if it fails to treat the disabled... you are transferred to [district hospital], sometimes the doctors say no according to the kind of disability you have, they may transfer to [other cities] so after that the doctors sometimes they transfer out of [country] to be operated or to

get the treatment out of [country]. But when [camp residents] presented the papers, the documents to UNHCR, they have never responded [to] that... So that's a big, very big problem we have.

From information gleaned through multiple informants, it emerged that advanced medical and surgical care represented needs that were so far outside the 'basic bundle' that they triggered difficult and uncomfortable decisions about competing needs and distributional trade-offs. One key informant who managed multi-sectorial responsibilities in a refugee camp offered the following explanation:

When it comes to health services... they have list of people who need operations, for example, medical intervention. That list is for priority...somebody who has something with walking or needs an operation to modify their feet or something like this, they will not consider it a priority than somebody who has...cancer or something, you know emergency, she will die or heart problem... she will die if she will not get it or kidney problem...there is a prioritization for health problems...[disabled persons] have to wait. Because...they will not die if they will not do those operations...It's [a] financial problem.

As a counterpoint to the above comment, other informants reported situations where persons with severe disabilities had also died from unmet medical and surgical needs, their needs having been side-lined as 'non-emergency' issues. This was also the unfortunate outcome in a few cases where needs were more basic such as special food rations for disabled persons with swallowing difficulties.

Thus, even in the absence of competing demands for life-saving treatments, any request for specialized services had to be weighed against the overall needs of the camp population. For instance, at the field research site, the entire camp population was facing shortage of essential supplies such as soap and cooking fuel owing to overall funding constraints. Similar situations were reported in other humanitarian camps as well. A social service provider working with the UN provided the following example:

I have a budget...allotted to the camp. How much can come out of it, how many cases can I cover in this camp...which has more than 30,000 person[s]...[including] many persons with disabilities...?...we can cover two to four of the medications in a year and umm perhaps I can provide three or four wheelchairs...that's all ... Because we have priorities...[whether] we fund ... professional services for people with disabilities or... cover the basic issues for all....

The above comments and examples highlight an important point - in humanitarian camps, often characterized by limited resources and vast needs, any service request that pushes the boundaries of the 'basic bundle' beckons deliberations over distributional ethics. In the camp where fieldwork was conducted, the non-disabled inhabitants also experienced healthcare-related grievances including dire shortage of basic drugs and lengthy waiting times at the camp clinic. This clinic was equipped to serve 10,000 people but was instead serving 40,000 locals from the surrounding villages in addition to the refugee residents of the camp. Similarly the lone medical clinic in another camp was catering to a much larger population

than it had been originally designed to serve.

For disabled persons, this portends a perpetual ‘us versus them’ situation, with many of their health-related needs configured outside the ‘basic bundle’ of healthcare and therefore constantly measured and pitted against the basic needs of other camp inhabitants.

Key informants indicated that given the resource-constrained landscape of humanitarian camps, making specialized care available to disabled persons depended on existing infrastructure in host countries. In the words of one humanitarian professional:

Issues in the camp pretty much reflect the general picture of the health situation [in this country] ...It is a field which has a dire shortage of human resources. I don't know if there are any public universities with faculty of medicine [in this country] ... As far as I know there is one private university that has faculty of medicine. A lot of the people who go through nursing train in the UK and never come back. So it's just a huge brain drain when it comes to health.

Lack of locally trained specialists and rehabilitation professionals was identified by key informants as a major hindrance in making specialized services available to forced migrants with disabilities. Dearth of locally trained professionals appeared to be pervasive across several host countries including Malawi, Uganda, Yemen, and the Thai-Burma border.

In one setting, informants reported the existence of only one center (established and supported by a western-based charity) in the entire country that had the capacity to provide rehabilitation therapy. The center was reportedly overwhelmed with serving the host population thereby limiting its ability to address the needs of forced migrants with disabilities living in a nearby humanitarian camp. A humanitarian agency representative working in the camp explained:

There is one organization in [capital] ...And I think they have one speech therapist, one physiotherapist, and two or three other qualified specialists. We're talking about less than five catering to...quite a large population and this is by far the most specialized service in the country. So the need is great and there is just no one really, people to provide the services... so it's very difficult to book an appointment with them for therapy regularly.

In other humanitarian settings as well, development of advanced and specialized health services was seen as mainly an NGO-driven effort, and therefore unsustainable given the broader context of healthcare scarcity in the host country. According to a key informant who was employed by an international NGO:

I think it's quite clear that each country has its own capacity to deliver to a certain level. So when you look at sustainability and you are there as an NGO and you can provide services and try to provide better [services] but the hope is always that at some point that will have to be handed over ... to the local system, to the local government and local health ministry and so on.

Taken together, barriers identified by key informants signified the need for a more long-term and locally-sustainable model for providing inclusive mainstream healthcare as well as specialized healthcare for disabled persons living in humanitarian camps.

2) *Strategies for development of disability-inclusive humanitarian healthcare programs*

This research revealed several strategies that had been either implemented or considered by humanitarian NGOs to make specialized health services more available to disabled persons living in camps. Some NGOs had tried to bring in western-trained, expatriate professionals. While this strategy had worked in some instances, in others, it had been challenging to find adequate housing and other facilities close enough to the humanitarian camp to host these individuals. Finding western-trained professionals with enough developing-country experience was another barrier. The following are illustrative quotes from key informants both of who had worked with disabled persons in different camp settings:

It is hard to attract medical personnel to stay close to a refugee camp so as to provide health services on a constant basis as there is normally lack of facilities like housing, among others.

We bring in people that stay for, umm you know longer periods of time, for some capacity building. We haven't had a huge difficulty finding people. We've had more difficulty finding people that have had a...developing country experience before that.

Some key informants proposed a 'train the trainer' approach, where arrangements could be made to have trained professionals visit camps intermittently to train and supervise lay community members. The following are quotes from a key informant who worked with a disability-focused international NGO:

I'm a big advocate of 'Train the Trainer'. So if you had somebody who could come in umm or a whole team go into camps...that could go from camp to camp and train the people in the camp - that would be wonderful.

We had a [Dutch] volunteer...a prosthetic tech[nician] that can do umm physical therapy. She did a chart that shows exercises...to strengthen the limb that had the prosthetic...with pictures, just a few words, something that can be put up on the wall, and that was a big boost coz then that can be put in workshops and they were distributed inside other places around ... the camps.

This research also unearthed community-based rehabilitation programs ongoing in many humanitarian camps. The community-based rehabilitation (CBR) model first emerged in the mid-1970s in response to staggering disparities in access to rehabilitation services in developing countries (Chermak, 1990). Drawing upon the principles of primary healthcare, the CBR model emphasizes local capacity-building to counter shortage of trained rehabilitation professionals in resource-constrained settings (Hartley et al., 2009).

Among the CBR programs found to be operating in various humanitarian camps, some were well-established while others were in nascent stages. A common feature across programs was the training of ‘disability community workers’ to carry out home visits for counselling and basic physical and occupational therapy (Women’s Refugee Commission, 2008; Karanja, 2009).

In some camps, CBR programs were initiated and managed by humanitarian NGOs while in others, programs had developed more spontaneously through collective grassroots efforts. In one camp, a rudimentary CBR program had emerged to fill in the need for rehabilitative services for disabled children in the absence of qualified specialists. A humanitarian professional whose agency supported the program described it thus:

So knowing that there is very much a shortage of experts...we said ok if we cannot help the children, what at least can we do for the parents? So we set up a, a kind of a respite care program where basically the parents of these 20 children can leave their children for a few half days per week...they can go and attend their other activities. And we trained 20 volunteers umm over a three-month period on how to care for these children...basic physiotherapy, nutrition and diets and also writing and painting and teaching them to eat on their own and such things.

The above program was especially notable because it had been developed collaboratively between UNHCR, an international NGO, and the camp’s Disabled Persons’ Committee, the latter being an enterprise led and initiated entirely by disabled residents of the camp. The researcher interviewed representatives from the committee who spoke at length about their respite care program. Parents utilizing the program frequently extolled its virtues during interactions with the researcher.

An additional outcome of the program was greater community awareness about disability issues. The disabled leaders of the program, the non-disabled volunteers, and parents of disabled children using the program had forged strong bonds demonstrated, among other ways, in a solidarity march on International Day of Persons with Disabilities. As stated by an NGO-employed social worker in the camp:

Disability group is acquiring visibility in [camp] due to the respite care program, due to, now the process of, the practice of celebrating international disability day, somehow the issue is coming out.

Examples such as the above particularly stood out in light of repeated assertions that more needed to be done to raise disability awareness in humanitarian camps. Key informants

disagreed with regard to effective strategies to generate greater disability awareness among humanitarian actors and donors. Some believed that stronger disability consciousness was needed at the highest levels of the humanitarian chain. Others advocated for more lateral diffusion of disability awareness, suggesting that disability was too much of a cross-cutting issue to be under the mandate of a single specialist agency. The following quotes from two informants, both employed by international NGOs, illustrate the varying perspectives:

Something like that needs some kind of seismic change...and it needs to come from high up...everything in, in the humanitarian sector really is coordinated by the UN so you can't do anything without the UN giving the say-so, really...So I would say it really needs to come from the United Nations.

Disability is a bit of a challenging domain in the sense that it's not a domain that stands on its own. A lot of organizations when you look at them and at the way that they function...[they] focus on specific sectors. Disability is challenging because it's not one sector...disability cuts through all sectors so it does make it a little bit more challenging umm to sort of look at it from a mandate from an organization perspective.

One key informant also cited the example of HIV/AIDS and sexual and gender-based violence (SGBV), both hot button topics in humanitarian healthcare. In recent times, these topics have garnered significant attention within humanitarian policy-making and also within field operations and activities (UNHCR, 2005; Rothkegel et al., 2008). Fieldwork conducted during this research indicated that SGBV and HIV/AIDS were prominent areas of concern drawing considerable resources in the field site. Prominence of these issues was described as the result of aggressive and sustained advocacy, the likes of which would need to be replicated to encourage similar uptake of disability-related issues. In the words of a key informant employed by an international NGO:

*These [SGBV and HIV/AIDS] are very sexy kind of issues within humanitarian kind of worlds. Disability I don't feel is a sexy kind of like an issue...if you say 'hey now', there's a huge global day of HIV/AIDS and everyone knows about it...in theory, 10% of the people in the world aren't afflicted by HIV/AIDS and 10% of the world... haven't been raped...10% of the people in this world **are** affected by disabilities... HIV/AIDS is a hot topic here because people are there pushing...there are meetings with you know in the government that say HIV/AIDS, HIV/AIDS, HIV/AIDS. Why is there not somebody in a meeting saying disabilities, disabilities, disabilities?*

Few key informants acknowledged that in recent times, there has been some political traction around disability issues within the humanitarian field. These developments were generally lauded and key informants acknowledged that disability inclusion was being increasingly promoted within certain humanitarian sectors such as education (for example Pinnock & Hodgkin, 2010). However the health sector was perceived as lagging in this regard. Additionally, disability-friendly rhetoric was deemed too slow in trickling down to create ground-level change. The following are quotes from two key informants, both of who had extensive experience working for international NGOs in multiple humanitarian settings:

I must say that I'm seeing a change in other domains outside of the health sector...where slowly, slowly you do see large humanitarian actors that are present in a lot of the emergencies umm where through sensitization by different disability specialized organizations they tend to take into account accessibility features a little bit more and more.

Internationally there is growing understanding and awareness about disabilities and about what it takes in an emergency context to make sure that services are, you know, accessible. But by the time the discourse filters down to the ground level, to the camp, it takes a very long time. So you can have an international policy and a wonderful convention and policy papers and protocols and all that but then ultimately it's the behaviour on the ground and the people who are living in the sites which makes the difference.

Ultimately, key informants believed that development of disability-inclusive humanitarian health programs was nigh impossible without significant financial support from donors, which, in turn, required political will to rally around disability issues and sensitize donors about the same. According to one humanitarian professional:

[We need] funding for sure, sensitizing donors as to the need...that's definitely a challenge...UNHCR acknowledge they're not doing enough. But obviously their funding is not self-fund-raised, it comes from donors, so finding donors who are willing to worry about it [disability] ...So there needs to be will and there needs to be means to do that as well.

Discussion

Findings from this study paint a dire picture of unmet health-related needs among disabled persons living in humanitarian camps. Lack of adequate and accessible healthcare, in turn, negatively affects disabled persons' participation in other social services and activities offered in camps. Similar findings have been echoed by others studies about disabled persons living in resource-constrained regions of the global South (Grech, 2008). However the situation of forced migrants with disabilities is further complicated by their status as stateless non-citizens confined to humanitarian camps and largely dependent on the largesse of NGOs and international donors (see Pisani and Grech, 2015 in this special issue). This situation raises several practical and theoretical quandaries as discussed below.

The first quandary pertains to distributional ethics. Humanitarian camps are characterized by extensive needs and limited resources. This study revealed that within such a context, healthcare infrastructure tends to be limited to a 'basic bundle' of short-term emergency aid and basic primary care. Health needs of disabled persons are perceived as falling outside the 'basic bundle' of health services generally available in humanitarian camps. Consequently, efforts to address these needs are hindered by funding shortages and bureaucratic complexities. Furthermore, specialized healthcare needs (such as advanced surgeries, medications, and rehabilitation therapies) fall far enough outside the 'basic bundle' to raise

concerns about allocating scarce resources toward specific health needs of a few people at the risk of jeopardizing the health of the overall population in a camp.

Recent literature in the humanitarian field, in particular the work of Leaning et al. (2010; 2011) has tackled the issue of ‘exceptional’ healthcare needs of forced migrants within the framework of public health equity. In their insightful paper on this topic, the authors observe that the ageing of forcibly displaced populations might well create a situation where more and more people request ‘exceptional’ healthcare thereby warranting a strategic shift from making exceptions on a case-by-case basis to raising the ‘social minimum’ or ‘basic bundle’ of care for all persons. While funding constraints might impede such a development, such constraints are not entirely insurmountable. As pointed out by Speigel and Crisp (2010), UNHCR’s HIV/AIDS programs serve as case in point. The success of these programs demonstrates that political will and resource commitment can result in innovative strategies to integrate previously ‘exceptional’ conditions into regular healthcare delivery for forced migrant populations.

The success story of HIV/AIDS could be attributed to global forces driving the mobilization and allocation of resources and the prioritization of social and health issues in the developing world. The issue of HIV/AIDS is included among the United Nation’s Millennium Development Goals while disability is not (United Nations, 2005; Groce and Trani, 2009). Therefore, there is a dire need for large-scale advocacy to make disability a ‘sexy’ issue at the highest echelons of the humanitarian and global health armamentarium. However better investment in humanitarian healthcare cannot by itself tackle the *quandary of parity between citizens and non-citizens*. This study revealed that inadequate healthcare infrastructure in humanitarian camps often mirrors the broader situation in the host country. Other reports indicate that health and related services in some humanitarian camps, albeit limited, are far better than those available in surrounding host communities (Jacobsen, 2002). Given this scenario, expanding the ‘basic bundle’ of health services in humanitarian camps might exacerbate inequities between host communities and forced migrants, between citizens and non-citizens, and thereby encounter disapproval from host governments.

Countries hosting humanitarian refugees are frequently themselves impoverished (UNHCR, 2012a). Host governments lack the capacity to develop service systems for their citizens on par with western-funded, NGO implemented services in humanitarian camps. They are even less likely to open already strained service systems to refugee non-citizens. To work around this impasse, NGOs and their donors have sought to channel humanitarian assistance toward local development and state-building in host countries in a bid to appease host communities (Jacobsen, 2002).

However this marriage between humanitarian assistance and state-building is not without its pitfalls. Some critics argue that this merger represents the emergence of a form of liberal international governance, a system where wealthy donor states seek to exert their influence on refugee-hosting states with NGOs acting as conduits. Thus, good intentions notwithstanding, humanitarian aid becomes a ‘technology’ of donor governments. Often the underlying objective of donor governments is to seek returns on their investment by promoting neoliberal agendas which include free market policies, privatization, and cutbacks

in public spending (Duffer as cited in Curtis, 2001). Ironically such machinations are likely to further weaken the very services sectors they were intended to fortify.

The reliance on donor states and NGOs also raises *quandaries regarding the most effective approaches to expand the 'basic bundle' of care* for forced migrants with disabilities. Past experiences, with food aid in particular, have demonstrated that ill-planned humanitarian aid can create unsustainable parallel structures that prevent local development and perpetuate dependency (Cunningham, 2012). Similar mistakes may be repeated in the context of humanitarian healthcare. This study revealed that many humanitarian camps and host communities are besieged by the lack of trained medical specialists and rehabilitation professionals. This situation is likely exacerbated by 'care drain' or the migration of health workers from developing countries to wealthier countries. Ironically, countries with the greatest outflows are also those with most unmet needs (Hamilton & Yau, 2004). Given this scenario, bringing in western-trained health professionals might be the only pragmatic way to meet immediate needs for specialized health and rehabilitation care in humanitarian camps. However this approach is likely to provide only intermittent reprieve and is unsustainable unless combined with efforts to develop local infrastructure in remote camps and host communities.

The CBR strategy can be an effective complement in this regard and merits further discussion, not least because of the controversies surrounding it. For example, the CBR approach has been criticized for focusing too much on health and rehabilitation while failing to address social and community change (Lang, 1999). Ironically the same CBR approach has been criticized by some observers as failing to meet health and rehabilitation needs of disabled persons (Evans et al., 2001; Deepak et al. 2011). In addition, CBR programs have also been critiqued as convenient and cost-saving alternatives to fill service gaps created by mass privatization and public sector cuts in pursuit of neoliberal agendas. Indeed there is a real danger that CBR programs may be used as an excuse for state actors to devolve responsibilities onto local communities (Miles, 2004, 2007).

However, in resource-constrained situations such as humanitarian camps where few alternatives are available, CBR programs might offer a pragmatic stop-gap measure to address unmet needs. Additionally, the example presented in this study illustrates how CBR programs, when done right and nurtured through grassroots momentum, can serve as nuclei for generating disability awareness within humanitarian camps.

Such programs can complement the work of NGO –based expatriate professionals and extend the reach of their professional expertise through 'train the trainer' mechanisms described in this study. Moreover, such programs and organizations like the Disabled Persons' Committee mentioned in this study can play an important role in holding NGOs and UNHCR accountable for ongoing unmet needs. Recent UNHCR initiatives, such as the 'Ageing, Gender, and Diversity' initiative and the 'Community-based approach' to humanitarian aid and protection, offer opportunities to formalize the role of indigenous disabled persons' organizations (UNHCR, 2008; 2012b, see Integra Foundation & UNHCR work in this special issue). These initiatives call for UNHCR and contractor NGOs to partner with grassroots community networks to identify community priorities, develop appropriate interventions, and evaluate effectiveness of programs. Such initiatives can help ensure that beneficiaries of

humanitarian aid are not reduced to a 'means of production' for NGOs as they focus on their own 'sexy' projects or seek to serve donor interests and ideals (Dunn, 2012). Partnering with local disability advocates is also critical for ensuring that western-centric disability models and heuristics are not uncritically applied to situations of humanitarian crises where different worldviews and priorities might prevail.

On a related note, this analysis would be incomplete without discussing the *theoretical quandary of rehabilitation and its contentious place in disability studies discourse* where honest discussion of this topic tends to be stymied by self-censorship or disclaimers (Swartz and MacLachlan, 2009). In this study, the researcher expected to gather evidence related to inaccessibility of primary health services. However the frequent and strident articulation for rehabilitation care, mostly from disabled persons, was an unexpected finding.

Access to rehabilitative services and adaptive equipment, has long been recognized by the United Nations as an important right for persons with disabilities and as inextricably linked to their societal integration and community participation (Chermak, 1990). Additionally, the watershed Alma Ata International Conference on Primary Health Care, jointly organized by WHO and UNICEF, pronounced these services as integral components of primary healthcare for persons with disabilities and essential for realizing the Health for All global strategy (WHO, 1978; 1981a; 1981b).

Yet the topic of rehabilitation care remains controversial and provocative in disability studies, a field dominated by scholars and activists in the industrialized western world. The lives and concerns of disabled persons in the developing world rarely make their way into scholarly debates in disability studies (Meekosha, 2008; Miles, 2011). Southern scholars are increasingly calling out western disability discourse for glossing over the harsh realities of disabled people's lives in impoverished regions of the world (Meekosha, 2011). In the case of specialized health and rehabilitation care, concerns about over medicalization, that seem justified in a context where everyone has access to basic healthcare and where medical specialists abound, are entirely misplaced in contexts where trained healthcare professionals are abysmally rare. For instance, rehabilitation services provided by trained professionals are reported to be accessible only in one third of low-income countries at the local level (WHO, 2001; 2010).

When western disability scholars and activists discuss the needs of people with disabilities in the developing world, conversations around health and rehabilitation care are entirely dismissed or subordinated to conversations about rights and legislation. This constitutes a serious injustice to the vast majority of disabled persons living in conditions of scarce resources and widespread poverty. As some scholars (see Grech, 2009) have pointed out, rights and legislation run the risk of being utopian in situations of extreme deprivation and poverty. Furthermore, empty legislation is far easier for political leaders to endorse rather than diverting resources to meet the basic medical needs of their populace.

The research study described in this paper revealed that, in the context of humanitarian camps, rights/legislation and health/rehabilitation are not irreconcilable dichotomies. Indeed, many forced migrants with disabilities who this researcher encountered during field work articulated their need for rehabilitation and care using the framework and language of disability rights. Some western disability activists and scholars might interpret this stance as a

form of internalized oppression, an interpretation that would be both cavalier and patronizing. Western scholars and activists are quick to hail interventions that focus on rights and advocacy as progressive and those that focus on health and rehabilitation as inherently regressive (Karr and Meyers, 2013). Instead of advancing blanket critiques of such interventions, a more useful approach might be to partner with and support local disabled persons organizations in humanitarian settings. Mechanisms of support might include: assistance with funding campaigns, promoting disability awareness among western-based humanitarian NGOs and donors, and sensitizing western-trained health professionals to recognize and respond to needs of disabled persons ethically and responsibly.

Limitations

This study involved qualitative data collected from one field site and a small sample of key informants. Therefore the findings presented here reflect the views and observations of these participants filtered through the researcher's subjective lens. Several strategies were implemented to enhance rigor and triangulate the data. These strategies included use of multiple data collection procedures, recruiting a diverse sample of key informants, and cross-checking emerging thematic insights with disability activists, experts, and academic colleagues external to the research. Another limitation is that findings mostly pertain to experiences of people with physical and developmental disabilities. Future research on this topic would benefit from a greater focus on mental health and related disabilities.

Conclusions

Forced migrants with disabilities who live in humanitarian camps face significant barriers to accessing basic as well as specialized health services. The same could be said for disabled persons living in any situation characterized by widespread poverty and resource limitations. However investigating this issue within the microcosm of humanitarian camps brings into relief unsettling undercurrents, that are always there but seldom acknowledged. One example is the conflict between distributional ethics and the right to healthcare for all, which poses practical challenges to the mission and endeavour of global health. Another example is the foregrounding of rehabilitation care as a relevant need of disabled persons whose lives are conditioned by the imperative to survive and function in the midst of harsh material conditions. Foregrounding of this previously taboo topic challenges dominant thinking in disability studies. In pushing the boundaries of disability studies and global health, this paper makes an important contribution to both fields. Disability studies has a lot to offer to the field of global health. But in order to do so there is a need for honest debate within the field, and the articulation of what Grech (2011) labels a 'critical global disability studies', one he insists is interdisciplinary, contextually nuanced, and open to heterogeneous ideas and experiences, including those that challenge some of its fundamental ideals.

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