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# Exploring the intersection of critical disability studies, humanities and global health through a case study of scarf injuries in Bangladesh

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Accepted 16 February 2022

Published Online First

2 May 2022

## ABSTRACT

This article puts critical disability studies and global health into conversation around the phenomenon of scarf injury in Bangladesh. Scarf injury occurs when a woman wearing a long, traditional scarf called an orna rides in a recently introduced autorickshaw with a design flaw that allows the orna to become entangled in the vehicle's driveshaft. Caught in the engine, the orna pulls the woman's neck into hyperextension, causing a debilitating high cervical spinal cord injury and quadriplegia. The circumstances of the scarf injury reveal the need for more critical cultural analysis than the fields of global health and rehabilitation typically offer. First, the fatal design flaw of the vehicle reflects different norms of gender and dress in China, where the vehicle is manufactured, versus Bangladesh, where the vehicle is purchased at a low price and assembled on-site—a situation that calls transnational capitalist modes of production and exchange into question. Second, the experiences of women with scarf injuries entail many challenges beyond the injury itself: the transition to life with disability following the rehabilitation period is made more difficult by negative perceptions of disability, lack of resources and accessible infrastructure, and cultural norms of gender and class in Bangladesh. Our cross-disciplinary conversation about women with scarf injuries, involving critical disability studies, global health and rehabilitation experts, exposes the shortcomings of each of these fields but also illustrates the urgent need for deeper and more purposeful collaborations. We, therefore, argue that the developing subfield of global health humanities should include purposeful integration of a humanities-based critical disability studies methodology.

## INTRODUCTION

In this essay, we reflect on the stories of young women in Bangladesh who sustained a particular type of spinal cord injury (SCI) known as a 'scarf injury'. Women in Bangladesh customarily wear long scarves called orna, which, when worn inside a recently introduced autorickshaw, can lead to serious injury. The autorickshaw is an efficient and cost-effective battery-powered vehicle, with parts manufactured in China and shipped to other countries for assembly. In

Bangladesh, it has become widely available in both urban and rural areas. Recently, the vehicle has become one of the most common forms of local transportation. However, the design of the vehicle is problematic because it leaves a gap behind the passenger seat, completely exposing the vehicle's driveshaft. Rugged roads and infrastructure are common in Bangladesh, and as the rickshaw navigates the terrain, passengers and their belongings are often jostled. While transport safety regulations exist, such policies are rarely enforced. If a woman's orna loosens during travel, it can become entangled in the exposed driveshaft, resulting in hyperextension of her neck. In this strangulating injury, the force of the entangled clothing can damage anterior soft tissue and dislocate the cervical vertebra. Women who experience the scarf injury frequently end up with a debilitating, high cervical SCI. Because the vehicle that causes scarf injury is often the lowest cost option available for transportation, scarf injuries mostly impact adolescent girls of low-income backgrounds. After the injury, these young women face a new reality: life with a significant disability, and a return to a community and a physical environment not equipped to accommodate them. For these reasons, our research approach sought to move beyond medical interventions, grappling instead with the meaning of the experience of disability as the women return to their home and communities.

## ORIGINAL FIELD RESEARCH METHODOLOGY

In summer 2018, Anna Tupetz and Michel Landry conducted a mixed-method study that explored the experiences of individuals and their families who sustained a scarf injury, received health and rehabilitation care, and were discharged back to their home and community. Landry is a global health and policy researcher with several years of service and educational collaboration with a local rehabilitation centre; Anna Tupetz is a physical therapist who was a global health graduate student at the time of the study. The research team visited a total of 12 families, spending between 2 hours and 4 hours with each of them to permit ample time to establish rapport and leave enough time for questions and concerns after the interviews.



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**To cite:** Tupetz A, Quirici M, Sultana M, et al. *Med Humanit* 2022;**48**:169–176.

Following data collection, Tupetz held consultation sessions with Bangladeshi health professionals and service users located at a rehabilitation facility, which added significant interpretive value around the meaning of disability for the individuals who sustained scarf injuries. At the time of writing this interdisciplinary reflection essay, another paper with the full scientific results of the original study is under review elsewhere.

### A CONVERSATION ON DISABILITY STUDIES, GLOBAL HEALTH AND NARRATIVE DATA: AN INTERNATIONAL, COLLABORATIVE APPROACH

Tupetz published a commentary describing scarf injuries and calling out public health approaches that, ‘aim(ing) for cost-effective interventions that have the highest impact on mortality reduction’, prioritise men’s survival as the population at higher risk for fatal injuries overall (Tupetz *et al.* 2021). These data-driven, cost-motivated approaches have the effect of deprioritising women’s health, and overlooking quality of life among disabled survivors of injury. Tupetz’s dissatisfaction with these outcomes prompted a conversation with humanities and critical disability studies scholars, leading to the cross-disciplinary methodology employed in this article. By incorporating the humanities, global health can approach disability holistically, exploring not merely the fact of injury and prospects of recovery, but the full human experience of life with disability, as well as the broader structural forces shaping those experiences. We, therefore, assert that the developing subfield of global health humanities, which this special issue explores, should include purposeful integration of a critical disability studies methodology, which we introduce here.

While global health research has tended to view disability primarily from a medical and rehabilitative perspective, critical disability studies enable a deeper analysis of *how cultures make embodied differences meaningful*. An academic field born in concert with burgeoning disability civil rights activism in the USA and UK in the 1980s, the foundational contribution of disability studies was ‘the social model of disability’, shifting the focus to inaccessible environments rather than individual impairments (Shakespeare and Watson 1997). Several decades of scholarship later, engaging disciplines across the social sciences and the humanities, critical disability studies today offers a range of complex political, relational and biocultural models of disability, and grapples with both the harms and the benefits of medicine (Clare 2017; Davis and Morris 2007; Kafer 2013). As a methodology—as opposed to a ‘subject’ of study—critical disability studies provide a flexible framework for scrutinising the social norms that govern and organise bodies, engaging intersectional analysis of race, gender, sexuality and class (Minich 2016). In our interdisciplinary discussions of scarf injuries in Bangladesh, the introduction of a critical disability studies methodology opened up questions not only about how accessible homes, roads, education and employment systems could improve these women’s lives but also about the intersecting economic and cultural circumstances that gave rise to the injuries in the first place (ie, histories of exploitation and colonisation in Bangladesh producing intergenerational poverty; the affordability of the autorickshaw due to cheap labour and manufacturing in China; norms of dress for women in Bangladesh vs in China; and so on).

This article reflects a cross-disciplinary conversation about scarf injuries, including the perspectives of Bangladeshi physiotherapists Mohsina Sultana and Kazi Imdadul Hoque, who initially discovered the pattern of scarf injuries; Tupetz and Landry introduced previously; and Tupetz’s colleagues at Duke University working in humanities-based critical disability studies.

Kearsley Stewart a medical anthropologist, and professor of the practice at the Duke Global Health Institute, who had advised Tupetz on the qualitative research methods of her study, introduced Tupetz to Marion Quirici, director of a cross-disciplinary faculty working group in disability studies. Discussing the Bangladeshi scarf injuries in this multidisciplinary venue illuminated the shortcomings of each of our fields. Physical therapists aiming to rehabilitate individuals are not equipped through their clinical training to confront larger societal obstacles, such as the lack of affordable and accessible housing and transportation in Bangladesh, which present the greatest barriers to re-integration. In addition, the European and American-centric origins of disability studies as a field pose a significant problem for global health researchers: although 80% of people with disability worldwide live in what is called the ‘developing’ world (United Nations, Department of Economic and Social Affairs Disability), scholarship is overwhelmingly concentrated in, and concerned with, the USA, the UK, Canada and Australia. Coming together as a cross-disciplinary team, we learnt something that, perhaps, all cross-disciplinary teams learn: that before we can find answers for complex problems, we must first learn to ask better questions. What is a ‘discipline’ if not a framework for crafting research questions (Comer 2015)? This paper will therefore explore, through consideration of scarf injuries in Bangladesh, the new *framework for questions* that a critical disability studies methodology offers global health researchers.

Integrating a critical disability studies approach raised questions in four categories: access, structural disparities, cultural norms and avenues of empowerment.

1. **Access.** Starting with a simple social-model perspective, the first question we posed was, *What are the social and structural barriers impacting quality of life for survivors of the scarf injury?* This inquiry begins with a consideration of survivors’ needs. Disability studies scholars and activists insist that there is nothing ‘special’ about disabled people’s needs because disabled people need the same things as all humans: safety, clean water, nutrition, housing, healthcare, transportation, information, education, recreation, occupation, community and acceptance. In environments built for the non-disabled, disabled people are denied access to these basic human rights. For people with SCI, a wheelchair can help facilitate access to almost anything *if the infrastructure is accessible*. What would a survivor’s life look like if she had a power wheelchair, an accessible home, and accessible transportation to an accessible school and community? These questions help us see how an inaccessible environment can be more disabling than the injury itself. These questions also enable us to view infrastructure and design as public health issues.
2. **Structural disparities.** Delving deeper into critical disability studies, especially Nirmala Erelles’s historical-material approach (Erelles 2011), we recognised that impairments themselves often have origins in social circumstances. Our next set of questions asks, *What political and economic circumstances created the conditions for the injuries in the first place?* This is an extension of the infrastructure question, but with attention to the history, laws and international relations that operate invisibly behind the life of the street. What affordable transportation options are available in the places where these injuries occur? Why is this specific type of rickshaw, often the most convenient option, also so dangerous? Why was the exposure of the engine shaft not considered a fatal design flaw? How does global capitalism reinforce the low cost of labour and manufacturing in China, and how does this perpetuate human rights disparities? What would

it take to maintain smooth surfaces on roads in rural Bangladesh as a safety precaution? These questions carry the conversation beyond individual choices and responsibilities, to broader forms of structural violence. These questions also facilitate a recognition that health disparities—including the incidence of disability—disproportionately impact people with the least amount of wealth and power. While the argument may arise that Bangladesh has extremely scarce resources and cannot be expected to meet Western standards of public safety and human rights, we should question the circumstances of that scarcity rather than accepting scarcity as *natural* or *the way things have to be*. Contextualising each woman's experiences within a long history of colonisation, extraction and exploitation forces acknowledgement that human uses and abuses of power created these conditions, and the international community can and should be held accountable.

3. **Cultural norms.** Critical disability studies scholarship also emphasises intersectionality, reminding us that we cannot analyse the experience of disability as separate from culturally specific experiences of race, class, gender and religion, all of which operate simultaneously (Clare 2017; Erevelles 2011; Piepzna-Samarasinha 2018). We next asked, *How do cultural norms of gender, class and religion shape a disabled woman's prospects?* What is the traditional role of the woman within the family or within society, and how does disability complicate that role? To what extent is disability represented and visible within Bangladeshi culture? Familiarity with disability diminishes its stigma and increases acceptance. But in inaccessible environments where people with disabilities are prevented from participating equally, disability remains outside the realm of the familiar. What are the beliefs about disability in Bangladeshi culture? Are the cultural narratives of injury and disability always tragic ones? What specifically are the beliefs and practices regarding women with disabilities? What prospects does a disabled woman have, and how are these prospects contingent on social class?
4. **Avenues of empowerment.** The principles of disability justice call for leadership of the most impacted, cross-movement organising, collective access and collective liberation (Berne 2015). These principles led us to raise questions about what hope there is for change, and the role women with scarf injuries might have to play. We asked, *Is there potential for the women to discover disability community, culture, and collective liberation?* Do survivors have opportunities to find and connect with each other? If not, what would it take to create these opportunities? If the survivors could connect, could they take part in building disability culture? Could they agitate for improved access? Could coalition-building be a way of accessing community and occupation, leading to broad changes that would improve the quality of life for all people with disability in Bangladesh?

Our process of articulating these questions brought discomfort. Quirici, as the critical disability studies scholar on the team, grappled with her status as an American, situated within a broad and diverse disability community preparing to mark the thirtieth anniversary of The Americans with Disabilities Act (ADA) (2021). While the ADA remains problematic in many ways, it nevertheless enables disabled people in the USA to enjoy many freedoms not available to the women in the study (Americans with Disabilities Act (ADA) 2021). Is it possible from this vantage point to imagine a future for these women that is not modelled on the civil rights struggles of disabled Americans? Through dialoguing with the global health researchers on the team, Quirici confronted the

limitations of disability studies scholarship situated in the USA, the UK and commonwealth nations. Do the accessibility ideals and emancipatory frameworks of the American disability rights movement (DRM) become forms of cultural hegemony within majority world<sup>1</sup> contexts? We use the term 'majority world' in keeping with the example of Bangladeshi photojournalist Shahidul Alam, to reject the Western-centric language of 'developing nations' which hides histories of oppression, extraction and continuing exploitation (Alam 2019). Landry, reflecting on his own career of global health rehabilitation practice in majority world nations, questioned whether the disability studies framework is an imposition, a form of white saviorism being mapped onto a culture with fewer resources and different norms of gender and religion. The question prompted the response that, in the first place, a country's relative poverty is not a neutral or natural circumstance to be taken for granted, but a direct consequence of histories of extraction and exploitation that need to be openly named and interrogated. The question also invited a review of what 'disability studies' has been and what it has the potential to be. Is it a Western, hegemonic discourse, or a framework for emancipation? We contended with what Chris Bell has termed 'white disability studies'—scholarship that prioritises white cultures and bodies, or erases the significance of racism by presenting ableism as the 'real' culprit (Bell 2006)—and made an explicit allegiance to disability studies scholarship that insists on intersectionality. Returning to the DRM from which the field of critical disability studies emerged, Quirici overviewed its indebtedness to the black power, women's liberation and gay rights movements, to argue that there is nothing inherently 'white' or 'American' about the concept of freedom; quite the opposite when one considers that the founders of this nation owned slaves, enacted genocide on indigenous populations, classified women as property and exploited the working class. Rejecting the idea that concepts of 'freedom' and 'progress' are somehow uniquely American, we then called into question the assumption that women living in relative disempowerment do not want to improve their circumstances because of their culture and traditions.

Ultimately, while we do not wish to argue that the freedoms envisioned by disability activists in the USA could be won elsewhere *in the same way*, without critical attention to differences of culture, religion, gender norms, politics and government, we *do* want to begin the work of identifying culturally specific pathways of liberation. Disability studies as a field is only recently coming to terms with its whiteness and the relative privilege that scholarship celebrating disability reflects (Bell 2006). Nirmala Erevelles argues that by getting swept up in the transgressive potential of disability as an identity, the field loses sight of the 'violence of social/economic conditions of capitalism' (Erevelles 2011). We take cues from Erevelles's historical-materialist approach, as well as Anna Mollow's contention that in different cultures we will find different sets of priorities (Mollow 2013). Tupetz, sharing her research in Bangladesh with the Disability and Access Initiative at Duke, showed a picture of her hand with a henna tattoo, being applied by one of the young women holding the applicator in her mouth. Mehndi, known as henna in Western cultures, is the art of temporary skin decorations using the dye derived from henna plants. In a tradition dating back centuries, henna is applied to the hands to pray for happiness and good luck (Jo and Yoo 2004) and worn for special events such as weddings (Black 2011). The picture of the young woman engaging the researcher in her cultural traditions, and the creativity and artistry of her method, was arresting. Quirici could only describe the image as one of resilience—resilience being a word she resisted in most contexts because too often, calls for resilience put the onus on disabled people to

withstand and ‘rise above’ cultures of inaccessibility. But confronted with this captivating, graceful image, Quirici felt that *this* resilience was something to aspire to. There was so much power in this moment of human connection: for the researcher, for the young woman, for her family, and for others who may find themselves in a similar situation.

### BRINGING HUMANITIES-FOCUSED METHODS AND CONTENT INTO GLOBAL HEALTH RESEARCH, PRACTICE AND POLICY

As we conversed across our disciplines, we increasingly recognised our framing question: *can our disciplines make progress toward decolonising global health and globalising disability studies at the same time?* Stewart asked: Is it possible to mobilise ‘the voice of the patient’ in a way that amplifies—rather than appropriates—the stories of disabled women in majority world nations? And finally, how does the emerging field of global health humanities help move these efforts forward?

Reflecting on the results of the original 2018 qualitative study, in which Tupetz had interviewed 12 survivors of scarf injury, our cross-disciplinary team first grappled with questions of methodology. We wondered, how do we elevate the results of qualitative research to the level of systems change? How do we keep these individual stories in the foreground, while also linking them directly to the social and economic structures that put these young women in harm’s way in the first place? Furthermore, how do we co-facilitate, rather than ‘give voice to,’ these individual narratives when the fields of global and public health engage more readily with quantitative population-level data than with qualitative, experiential data (Ashby 2011)? And finally, how does a global health writing group situated in a privileged institution in the USA, at a moment when the movement to decolonise global health is coming into focus, equitably collaborate with the rehabilitation practitioners for whom the conduct of externally sponsored research may itself be an extra burden and therefore an obstacle to improved care for their patients?

Mulling over these complex conundrums, we discovered our only way forward: intentionally foreground the humanities as the lingua franca of our collaborations, and specifically through narrative. Why advocate for the inclusion of narratives and narrative analysis in global health, and what new insights and actionable evidence would it offer global health? Narrative is underused in global health research and practice. When narrative analysis does appear in global health, it is most often found in global health policy literature (Ney 2012; Ngoasong 2009), or in a simplistic format such as invoking the ‘voice’ of an individual to illustrate population-level statistics. For example, one of the best-selling introductory global health textbooks introduces the global HIV/AIDS pandemic through the narrative of ‘Getachew, a 20-year-old Ethiopian with HIV’ (Skolnik 2019); yet we are given only the barest of demographic information before moving on to population-level metrics. Similarly, the story arc of a medical or global health approach to traumatic injury is typically hyper-focused on the individual injury itself while limiting its end point to either cure or rehabilitation (Dickson et al. 2019; Sharwood et al. 2020).

We argue that citing population-level metrics of a global health challenge is necessary but not sufficient. What is missing is a method for expanding the medical and global health story arc to connect the lived experience of an individual injury with the structural inequities that established the conditions for the injury. But how do ‘voices’ speak to ‘structure’? Through narrative. For this essay, we define narrative as a conversational recounting of a personally experienced story as told to a listener (Polkinghorne 1995). Going beyond the use of an individual

‘voice’ coupled with a few demographic data points to elicit and analyse an individual’s complete illness narrative, as they define and describe it, is essential for developing locally relevant, meaningful and sustainable community interventions, programmes and country-level policies. Voices and individual behaviours are embedded in social, cultural and political contexts; therefore, it is critical to first listen to how individuals narrate and make sense of their own illness experiences and then to conduct narrative analysis that goes beyond merely searching for generalisable themes to exploring specific narrative aspects of the story, such as narrative arc and key characters (Greenhalgh 2016) or metaphor (Kleinman 1989). This will lead to a more complex and nuanced understanding of that lived experience which can then better inform global health practice, programming and policy.

We then searched each of our own disciplines further for nascent (or central) humanities ideas, methods and theories, and discovered that the humanities provided a unifying approach for our interdisciplinary collaboration: *look first for the human story*. In fact, what drew us together as a writing group was the realisation that our individual disciplines were not sufficient to grasp the complex scope of these young women’s experiences. We quickly realised that we could not meaningfully work together towards ideas to inform practice and policy until we all, and in a nuanced fashion, understood the different implications of the scarf injury for each of these young women. Beginning with the person means we can trace connections between individual experience and the more difficult-to-see systems and structures, such as politics, economics and culture, that directly influence the experience. With a deeper understanding of these issues and contradictions—gained through qualitative interviewing, home visits and ethnographic observations—we can link the local to the global to see the structural processes that shape experience. Understanding the complex factors that placed these young women at risk, we seek not only strategies to prevent future scarf injuries, but also to identify potential methods of empowerment for the women who survive with scarf injury today.

Just as global perspectives are urgently needed in disability studies, disability studies perspectives are urgently needed in global health. Only through sustained and intentional collaboration can we address the shortcomings of both fields. By engaging in disability studies, global health can begin to entertain alternatives to the restrictive medical model of disability, which defines disability as a functional limitation residing in the body of the individual. Below, we share the stories of three of the women who participated in Tupetz’s qualitative study, and the specific responses these stories elicited from our cross-disciplinary team. To protect the women’s privacy, the names have been replaced with pseudonyms and all identifiable information has been removed.

#### Nazia’s story

Tupetz: *If you don’t go back to school and study, how do you think your life will look? What else are you going to do?*

Nazia: *I will die.*

Tupetz: *Why do you think you will die if you do not go to school?*

Nazia: *Everybody is suffering for me. If I’m not alive, then no one will have to suffer.*

Nazia’s story illuminates themes of inaccessibility and stigma. Her emotional response is understandable: having to bathe on a public street would be experienced as dehumanising by anyone, and even more so within a culture in which women traditionally cover their bodies. The local rehabilitation team contemplating Nazia’s distress

observe a clear relationship between her suicidal ideation and social factors, such as the ostracisation she faced in the healthcare system, and her belief that she is a burden to her family.

Nazia was denied care at the first hospital she reached on her injury—in fact, several hospitals refused to treat her due to her critical condition. A complexity of the scarf injury is that it produces lacerations on the anterior part of the neck, creating the appearance of a suicide attempt. Suicide attempts can carry a great stigma, and given the clinical presentation of a scarf injury that can be misconstrued, many health providers turned their backs. After Nazia was moved from the accident site to the ambulance she was left alone. She received no education on treatment options.

Nazia's ongoing trauma stems not only from the accident itself, but from navigating the healthcare system, and ultimately being discharged to a wheelchair-inaccessible environment, as is the case in most homes in this region, with a family unable to support her needs beyond the most custodial care. Nazia is feeling isolated, questioning her purpose in life, and experiencing suicidal ideation. Due to the inaccessibility of her family home, she has to be bathed out on the open street. She has distanced herself from her school friends, finding their visits an unbearable reminder of the fact that she is no longer a student herself.

Observing her story through a disability studies lens, we begin to think beyond her individual bodymind (Price 2020; Schalk 2018) and contemplate the forms of access and infrastructure that would improve her quality of life. The term 'bodymind' in disability studies signifies the interrelatedness of 'body' and 'mind': in Margaret Price's words, 'mental and physical processes not only affect each other but also give rise to each other' (Price 2020). For Sami Schalk, the term also signifies the psychological and embodied impact of stress responses to oppression based on race and gender (Schalk 2018). The belief that she could be too dependent to return to school is largely anchored in the inability to push her own wheelchair. A power wheelchair<sup>2</sup> could contribute greatly to her independence, but these devices alone would not be enough without a more reliable electricity infrastructure, smoother road conditions, accessible and affordable transportation to the school building, and accessibility within the school itself. These facts testify to one of our main claims: that *infrastructure is a public health concern*. Another infrastructural justice concern is internet access. Increasingly, the access to information and freedom of expression that internet access provides is considered a human right and a necessity for survival in the present age (United Nations 2016). Additionally, internet access could be an avenue of empowerment, connecting Nazia to a community and even enabling her to participate in online activism, if she should choose.

For Nazia, access to education would provide not only relief from her home life but also opportunities for friendship and social advancement. During the interview, Nazia revealed that she had told her family many times of her wish to return to school, but the denial of that wish intensified her depression and resulted in a souring of relationships with her school friends. Hoque notes that Nazia's potential for returning to school could have been financially onerous for the family because although it is free to attend public schools in Bangladesh, the additional transportation and accommodations requirements are costly. Education in Bangladesh is either mainstream education or special education for persons with intellectual disabilities, but neither of these approaches offer an inclusive environment for students with physical disabilities like Nazia's. A recently published evaluation of the Government of Bangladesh

Education programme by Unicef concluded that 'despite the substantial quantitative progress, important challenges remain in terms of establishing child-friendly inclusive schools, particularly for girls and children with disabilities' (Toscano *et al.* 2019). Sultana points out that while schools are required to provide ramps for students with disabilities to access the school, that is usually where the conversation about accessibility and inclusive school systems stops. However, she also recognises that in recent years, schools have become more aware of inclusive concepts.

On the macro-level of policy, the adoption of the United Nations Convention of the Rights of Persons with Disabilities (CRPD) by UN member states in December 2006 (United Nations 2006) should, in theory, go some distance towards addressing the barriers to education and other basic human rights Nazia faces. The CRPD, the first human rights charter of the twenty-first century, provides an inclusive platform for people with disabilities to be viewed as people with rights rather than the 'object' of decisions. Its basic platform is to establish equity in access to services and opportunities. Bangladesh is among the many nations that have fully ratified the CRPD, but Nazia's story shows that large-scale policy does not easily translate to implementation at a local level. Through consultation with peer support networks, Sultana asked how this human rights framework can have an impact on the individual level? How can Nazia be convinced that she has—or should have—the right to live in a wheelchair-accessible home, that it is her right to attend a school that is inclusive and adaptive to her needs? Bangladesh is a signatory and has fully ratified the CRPD, and has made people with disabilities equal under the law, yet the lived experiences of disabled Bangladeshi citizens fall far short of these ideals. What are the responsibilities of the international community in this case?

When contemplating accessible infrastructure in the majority world, it is important to be mindful that these approaches to design have been capitalised on elsewhere as a means of gentrification and displacement. In *Crip Times: Disability, Globalisation, and Resistance*, Robert McRuer shares the example of reconstruction efforts in Mexico City inspired by the accessibility ideals of the London Olympics. Concerns around health and safety justified the displacement of families, paving the way for gentrification and for-profit development. McRuer urges a 'distinction between access and neoliberal access' (McRuer 2018). Access should be defined and designed by the local community rather than imposed by industrialised nations. Global health specialists, when making accessibility recommendations, must remain vigilant as to whose interests are driving renovations.

### Anusheh and Fatima's story

Fatima: 'After her injury, everyone thought Anusheh would not survive. They [the healthcare facilities] neglected us.'

(Later in the interview): 'My future?' (Fatima laughs.) 'My future is that my daughter will build me a house with money from her job.'

Anusheh's story illuminates much about the culture of medical practice, as well as Bangladeshi culture as a whole. Her experiences of neglect based on medical professionals' beliefs that she could not survive her injury demonstrate that the primary concern is *survivability* rather than rehabilitation. Hoque remarks that the disregard for the potential of rehabilitation to improve quality of life explains why so many doctors, rooted in medical-model interpretations of disability as impairment, respond by performing surgery on the spine and sending patients home without information on how they can access rehabilitation services. For patients, the main concern is typically the ability to walk, and they often do not see the point of rehabilitation if their walking ability cannot be regained. Even in cases of tetraplegic

patients who have the capacity to develop significant independence through upper-body rehabilitation, it would require a shift in perception to contemplate *living*, beyond mere survival.

After Anusheh's injury, she was transferred to a local acute hospital. The hospital believed her chances of survival were negligible and neglected her. In the early days after her accident, Anusheh was kept on the floor rather than a bed. Later, medical professionals falsely led the family to believe Anusheh would regain walking ability after surgery. It would be two months before Anusheh and her family were educated on what an SCI is and what it meant for her future.

Fatima, Anusheh's mother, was with her when the injury happened and has not left her side ever since. Fatima started her own business, earning money while working from home and taking care of her daughter. Fatima's parents also help provide care within the family unit.

Anusheh had always been a strong student, with high aspirations for a future in the healthcare profession. Anusheh's education remained the highest priority after her injury, even during rehabilitation. With the support of the rehabilitation centre and the principal of her school, Anusheh was able to continue her studies while in rehabilitation and sit for the annual exams. Mother and daughter both believe that Anusheh's education will empower her to earn a steady income and financially support her mother when she is older. The high level of community and school support they received, starting early in the rehabilitation process, helped Fatima and Anusheh develop a very hopeful and positive outlook for the future.

Anusheh's experiences of medical neglect and deprioritisation also call attention to beliefs surrounding gender. In Bangladeshi culture, as in most patriarchal societies, men carry the family name and continue the family legacy. For men with SCI, then, the main concern would be fertility. The situation for women, Sultana and Hoque report, is more complex. Families are often more concerned about a young woman's ability to get married than her overall health, education or career prospects. A woman who needs care, and cannot provide care, in turn, is culturally regarded as a burden to the family because women are valued primarily for the domestic labour they provide. Sons, by contrast, are an asset to the family even if they are disabled because they will inherit more property after the death of a family member than a daughter would, meaning their lives are literally valued more highly. However, Tupetz's original study also demonstrates how each family unit is different. In Anusheh's story we observe her mother, Fatima, taking risks on her daughter's behalf and advocating fearlessly for her needs. Anusheh may have been treated as low priority by the healthcare professionals she first encountered, but it is clear that she is not a low priority to her mother.

Including Fatima's perspective allows consideration of the caregiver's story. People with SCI typically require assistance with certain life activities on a daily basis, and in Bangladesh, this labour is absorbed within the family, almost always by women. In the example of Nazia, we observed her feelings that her need for care was causing her family to suffer, and these feelings contributed to suicidal ideation. In the example of Anusheh, her mother Fatima came up with a creative solution to the labour dilemma: by starting her own business, Fatima continues to earn an income from the home, where she can also care for Anusheh. Moreover, Anusheh herself is regarded as a giver as well as a receiver of care: there is an understanding that Anusheh will provide care for her mother, if not in a physical sense, then in a financial sense by

continuing her education and getting a job. Anusheh's perceived potential gives her a sense of purpose, which clearly has a positive impact on her mental health and self-esteem. Anusheh and Fatima's story is also exceptional for its transcendence of the gender norms of Bangladeshi culture. Fatima's status as a single mother means they were already breaking the norms of family order prior to the injury. Fatima's strong advocacy actions on behalf of her daughter throughout their long healthcare journey set an example that women are leaders, and voices of change.

Stories like Anusheh and Fatima's are the rare exception rather than the rule, however, and not all individuals can be expected to adapt to the challenges of a care economy that places unfair expectations on women in the family. Disability rights legislation such as the ADA and the CRPD should guarantee access to personal care attendants or home health aides from outside the family as a means of protecting the independence of disabled people, and enabling their family members to pursue their own interests and careers. However, economic concerns frequently prevent access to these important resources. Even in wealthy nations like the USA, essential care labour is undervalued, with home health aides making on average just \$24 200 a year, proving that the way capitalist economies value care work is in dire need of revision (U.S. BUREAU OF LABOR STATISTICS 2019). Because care work is so undervalued, there are not enough workers willing to do the job, which often leaves disabled and elderly people no choice but to live in institutionalised settings like nursing homes, which are actually more costly to the healthcare system (Graham 2017), (Osterman 2017).<sup>3</sup> Congregate living facilities, beyond robbing a person of their freedoms, also pose an increased risk of premature death, as the COVID-19 pandemic shows (Cameron 2020).

Contemplating the survivors of scarf injury in Bangladesh and their families, who double as care providers, we return to the questions we raised about the responsibilities of the international community, and the embeddedness of these women's stories within the system of global capitalism. A recent report by Oxfam called 'Time to Care: Unpaid and Underpaid Care Work and the Global Inequality Crisis', provides the appropriate context:

Economic inequality is out of control. In 2019, the world's billionaires, only 2,153 people, had more wealth than 4.6 billion people. This great divide is based on a flawed and sexist economic system that values the wealth of the privileged few, mostly men, more than the billions of hours of the most essential work – the unpaid and underpaid care work done primarily by women and girls around the world. Tending to others, cooking, cleaning, and fetching water and firewood are essential daily tasks for the wellbeing of societies, communities and the functioning of the economy. The heavy and unequal responsibility of care work perpetuates gender and economic inequalities. (Coffey *et al.* 2020)

The report illuminates the troubling realities of wealth inequality and how it is supported and perpetuated by global injustices organised around hierarchies of gender, labour, class, race and disability. Care work is the most essential work, but it is also the least valued. Capitalism, white supremacy, and the patriarchy operate in lockstep and work designated 'women's work' often goes unpaid.

As long as these global economic injustices continue, a young disabled woman's best hope is in her own resilience. Anusheh is beating the odds, and with a strong, supportive role model for a mother, and the encouragement of key members of the community, such as a teacher who convinced Anusheh she could return to school with accommodations, she has a hopeful outlook for the future. Tupetz asked Anusheh if she had a message for other

young women survivors of the scarf injury. ‘Yes, I want to tell them not to lose hope,’ she said, ‘and to try to continue their education like me. There are lots of girls who stay at home always, stop working if they used to work before or stop going to school if they used to study after they had an accident like mine. I want to say to them, don’t stop going to school, your education should be continued’.

## INTERDISCIPLINARITY, THE MOVEMENT TO DECOLONISE GLOBAL HEALTH AND THE HUMANITIES

In addition to our interdisciplinary conversations around the rehabilitation and health policy implications of stories like Nazia’s and Anusheh’s, bringing the humanities into our conversations also pushed us to engage with the emerging ideas of the *Decolonize Global Health* movement, and laid bare our need to realign our relationship with our colleagues globally (Byatnal and Mihara 2020). What is/could be the role of the humanities in the nascent movement to decolonise global health as a discipline, a collaborative research partnership model, and a training ground, and how are the humanities reflected in our project? How do the colonial past and the neoliberal/neocolonial present shape both this project’s professional research partnerships and the relationship between the student trainee and the community collaborators who invited her into their homes? And what are the implications of these tensions for translating these results into actions that can contribute to both the lives of the young women who shared their stories and efforts to decolonise global health itself?

Recent papers argue that global health must begin to address its own implicit biases by confronting both its colonial legacy and the enduring impact of structural racism on the discipline and practice of global health. Calls for action include: acknowledging systems of privilege and practising critical allyship to transform those systems (Nixon 2019); increasing equitable recognition of authorship (Hedt-Gauthier *et al.* 2019), addressing unfair resource allocation in research partnerships (Boum Ii *et al.* 2018); improving reciprocity by addressing the disproportionate burden high-income country trainees often impose on majority world settings (Pai 2020) and interrogating the politics of knowledge production in global health research and publishing (Abimbola 2019). More directly related to the role of humanities in global health, Eichbaum *et al.* extend these efforts to decolonise global health research and practice to include actions to decolonise global health education by realigning storylines and narratives from ‘deficits of resource-limited settings (to) implicit strengths and assets’ (Eichbaum *et al.* 2020). We argue that humanities methods, content and pedagogies are essential to these efforts to decolonise global health practice, research and training.

The value of a fresh approach to collaboration, mediated through our humanities approach to *look first for the human story*, was clearly identified by our Bangladeshi colleagues in our postresearch conversations. For Hoque and Sultana, our qualitative study design provoked a new conversation that opened the door for their participation in interdisciplinary collaboration. According to Hoque and Sultana, a standard quantitative research design alone would have not revealed the depth of their patients’ and caregivers’ struggles, as every case they treat is unique. Hoque and Sultana attribute to our collaborative discussions an essential opportunity to learn new and different perspectives that go far beyond physical functioning, into the realm of contextual factors, such as human rights and basic education access. Hoque and Sultana believe our collaborative work will have a strong impact on SCI research in Bangladesh:

it can serve as an entry point for other rehabilitation professionals in Bangladesh to become aware of these issues, trigger self-reflection on the inadequacies of the way they conduct their rehabilitation work and ignite a desire to engage in such conversations themselves. The role of qualitative research, in particular, has proven to be exceptionally important for both Hoque and Sultana, as it not only allowed them a deeper understanding of ‘what we feel, what they feel, what other people feel’ (Hoque) it also allowed the research team in Bangladesh, in their role as practitioners, to gain a deeper understanding of the emergency care and challenges people suffering such injury face in accessing the care they need. According to Sultana, this information would not have become that evident to her, if she had only access to quantitative data. Our approach to this essay, informed by a historical-materialist critical disability studies framework (Erevelles 2011) and applying narrative and humanities methodologies to producing qualitative global health data, makes visible the many layers of each story, from the individual to the cultural, the structural and the global economic system. More importantly, it underlines our responsibilities to each other, and the urgency of collective struggle. Under current conditions of global inequality, such collective action is unlikely until we acknowledge that Nazia’s story, and Anusheh and Fatima’s stories, implicate all of us.

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**Contributors** All authors were actively involved in the conceptualisation, writing, review and editing of this manuscript. MS, KIH, ML, AT contributed to the conceptualisation, supervision, data collection, data analysis and data curation of the underlying primary data collection of this study. AT is the guarantor of the study.

**Funding** The underlying study was funded by the Duke Global Health Institute.

**Competing interests** None declared.

**Patient and public involvement** Similar to Strand’s work, this paper was inspired by the emotionally charged stories and voices that emerged from participants in the original study. Within the original study, it was the Bangladeshi physical therapist who first noticed and discovered the rising incidence of what has emerged to be known as scarf injuries, and who reached out to the investigator team based at Duke University with the request to collaborate on a study to explore the implications of the newly identified scarf injuries. This collaboration of researchers proved to be an essential factor towards the overall collaboration and interpretation of the results, both in the original study and in this essay. Patient representatives known as the peer-support network at the rehabilitation centre were involved at the beginning of the original study and were also involved in interpreting the assessment and interpretation in this paper. Their perspectives and voices serve to place critical context to this paper, and the ongoing research agenda to explore the perspective and meaning of disability in Bangladesh and beyond. All direct identifiers are removed from this manuscript and we use pseudonyms to further protect the identities of all local participants.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by the local Institutional Review Board (IRB) Bangladesh (CRP-R&E-0401-224) and Duke University School of Medicine IRB (Pro00092024). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article.

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## NOTES

1. In the 1990s, Bangladeshi photojournalist, activist, and now political prisoner Shahidul Alam began advocating use of the term ‘majority world’ rather than outdated, hierarchical language like ‘third world’. The majority of the world’s population lives in

the exploited lands of the Global South. Labels like 'developing nations' serve to 'hide [...] histories of oppression and continued exploitation'; whereas the term 'majority world', Alam argues, 'defines the community in terms of what it has, rather than what it lacks'. (Alam 2019)

2. Considering the circumstances that lead to scarf injury, these stories should also serve as an example to those who design wheelchairs. To design a wheelchair that is sensitive to cultural differences, designers should keep in mind the norms of dress in places like Bangladesh and ensure that an orna could not become entangled in the spokes of the wheels.
3. The Kaiser Family Foundation reported on the shortage of home health workers in the USA in April 2017, describing a situation of rising demand and stagnant wages due to the underfunding of Medicaid (Graham 2017). Paul Osterman of the MIT Sloan School of Management argues that 'expanding the role of direct care workers' will save the healthcare system money by keeping people out of hospitals and nursing homes (Osterman 2017).

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