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Invisible barriers: Examining the role of disability in transnational families

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Author:
Maria C. Marchetti-Mercer[1] ⓘ

Affiliation:
[1]Department of Psychology, School of Human and Community Development, Faculty of Humanities, University of the Witwatersrand, Johannesburg, South Africa

Corresponding author:
Maria Marchetti-Mercer, Maria.Marchetti-Mercer@wits.ac.za

Many narratives have shaped the course of my life. However, two seemingly unrelated ones strongly influenced my professional and personal lives in the last two decades: migration and running. I emigrated from Italy as a child. When I returned to Italy to pursue my family therapy training in the early 2000s, I saw work on migrant families in parts of Rome. I then realised that the systemic impact of migration, especially emigration, on South African families needed to be explored, and this steered the direction of my research since then. A few years earlier, I had begun jogging around the block in an attempt to deal with the stress of completing a Doctor of Philosophy (PhD). Over the years, as my fitness improved, I participated in ultramarathons, finally obtaining a 'green number' for completing more than 10 Comrades marathons. Running became a big part of my life – the time pounding the road became a space in which I conceptualised many of my research plans.

My shift into migration research was primarily self-driven. My PhD at the Milan School of Family Therapy left me well versed in systemic theory, but I was by no means a scholar of migration theory. My most relevant point of reference was my own personal story of migration as a child. I was not part of a research team where I was mentored into the seminal works of significant figures in the field, so I read the works of family therapists working with migrant families, such as Carlos Sluzki and Celia Falicov. Eventually, I encountered the work of anthropologist and sociologist Loretta Baldassar, whose extensive research on transnational families has had a strong impact on my thinking. As I interviewed members of migrant families, I identified critical gaps in the field, such as the experiences of loss by older adults left behind by their migrant children and their challenges trying to stay in touch with children and grandchildren living abroad (Marchetti-Mercer 2012). It soon became clear that when adult children migrated, the burden of care of elderly parents was passed on exclusively to siblings or other family members left behind in the source country.

By this time, I had met Leslie Swartz, who served on a panel for a review of the University of Pretoria's Department of Psychology (which I headed at the time), and I was struck by his kindness and deep insights. During this period, we started discussing issues of care. Through our conversations, my thinking on the meaning of 'care' expanded and deepened, especially concerning the elderly. Leslie had already carried out extensive work on the topic and was dealing with it in his personal life, as he was intensely involved in the care of his mother. Those experiences led to his profoundly moving memoir *How I lost my mother* (Swartz 2021), which highlights with immense empathy the exacting care required and the intense experiences of those caring for the elderly. His work also showed deep insight into family dynamics, which influenced my next research study, on the care processes around elderly parents left behind by migrant children (Marchetti-Mercer & Swartz 2020; Marchetti-Mercer et al. 2020). It was then that Leslie and I started formally working and writing together.

I have many memories of these encounters, often sitting in his purple kitchen or in a coffee shop in Cape Town or Johannesburg. Working closely with Leslie, one cannot but be struck by his enormously wide-ranging intellect, fuelled by extensive reading, and his ability to write flawlessly, as well as his generous spirit. This translates into an ongoing process of encouragement for those with whom he works. He always made me feel as though my ideas were brilliant, even when they were clumsily formulated and needed much refining. In the highly competitive world of academia, it is rare to meet someone of his calibre who is genuinely modest and who is not threatened by those with whom he works or mentors and instead cheers their successes.

It was mostly because of this intellectual support that my research was able to grow. Coming back to our research projects, two events profoundly shaped my understanding of the experience of disability. The first was my encounter in Sydney with a migrant who is deaf and suffers from other impairments. I interviewed her as part of the care study. The second event was a bad fall and a meniscus operation, which incapacitated me for several months and has had a long-term impact on my running.

While I attended an academic conference in Sydney in 2017, I had an opportunity to interview the daughter of a woman I had previously interviewed in Johannesburg. The interviewee in Johannesburg had three daughters – one in Cape Town and two in Sydney. Emma, in Sydney, was born with Waardenburg syndrome, which resulted in deafness, visual impairment and a pigmentation deficiency similar to albinism. We met at the conference hotel. She arrived with a sign language interpreter who was part of the free support available to her as a person with a disability in Australia. Her life had improved significantly because she lived in Australia, where government support is available. She encountered difficulties when she went back to South Africa, where she was entirely dependent on her family to fulfil many activities of daily living because of the lack of support available there for deaf people. In Australia, she could pursue a high-flying career, since all the necessary technological support was provided to her in the workplace. When she returned to South Africa, she felt 'disabled'.

Until that stage in my career as a clinical psychologist, I had given little thought to the experience of disability and had not received any training in this area. This reflects a significant gap in the professional training of psychologists in South Africa, also noted by Harvey and Swartz (2024). The discussion I had with Emma around her experiences of disability in South Africa led to more conversations with Leslie and a joint article for *Disability Studies*, entitled 'Disabling Africa: The power of depiction and the benefits of discomfort' (Swartz & Marchetti-Mercer 2017). It is worth noting that Emma's perspective was that of a migrant from a privileged background whose quality of life had improved after relocation. It did not yet represent the experiences of most migrants in the Global South.

Disability can take many forms. I was personally unfamiliar with the embodied experience of my body not functioning as it used to. However, this was soon to change. In their discussion on the lack of inclusion of disability studies in South African psychology, Harvey and Swartz (2024) remind us that:

> … after all, it is the one minority group which we could all become a part of without our control – anyone could develop a disability via an illness, accident, or ageing. Acquired disability is a very real reality. (p. 534)

In July 2017, soon after returning from Australia, I tripped on an uneven pavement while running and tore my meniscus. I had to undergo surgery and to use crutches for weeks to move around and intensive rehabilitation. I relied extensively on others for many tasks, was unable to drive and found mobility frustrating and challenging. Psychologically, this was extremely difficult for someone accustomed to running every morning, driving to work and standing for hours to lecture. Both my professional and personal lives were suddenly greatly restricted.

I vividly recall feeling deeply embarrassed while hobbling around on crutches – awkward, slow and acutely aware of people's irritation as I navigated shops or the university campus. I wanted to hide away, uncomfortable with the perceived pity, which made me feel different and no longer 'normal'. I experienced practical frustrations such as discovering that the elevators up to my office were far from the entrance and often out of order. I remember losing my temper the first time I entered the disabled bathroom in the Psychology Clinic; it was pitch dark, and no one had even noticed that the light bulb did not work. How does a person with limited mobility navigate such a dark space? I quickly discovered that the so-called 'wheelchair' ramps in many campus buildings were extremely steep and challenging to negotiate on crutches, let alone in a wheelchair. My experience was, of course, time limited and nothing like that of people who struggle with a permanent physical disability. Eventually, I was able to walk without crutches and even started running again. Nevertheless, this period had a profound impact on me – it gave me a glimpse into what it means to navigate a world where there is little recognition or respect for those who may not be 'able-bodied', and how society can be disabling (Harvey & Swartz 2024; Thomas 2004). Admittedly, this was the experience of a privileged person with several support systems during a limited time of incapacity. What, then, might the experience be for people living with permanent disabilities?

It was during this time that Leslie and I wrote up the findings of the research project on the care of ageing parents (Marchetti-Mercer et al. 2020) using the theoretical framework of transnationalism, which is widely used in migration research. Transnationalism characterises a new type of migrating population that uses networks, activities and lifestyles reflecting both their host countries and their countries of origin (Schiller, Basch & Blanc-Szanton 1992). With the relative ease of international travel and increased availability of information and communication technologies (ICTs), migrant families are able to maintain relationships despite geographical distance, in ways that were not previously possible (Marchetti-Mercer 2017). Since the rise of the Internet in the 1990s, there has been growing excitement about the potential for technology to bring about the 'death of distance' (Baldassar 2007; Craincross 2001; Marchetti-Mercer, Swartz & Baldassar 2023b).

We were particularly moved by the story of Emma's family, described in 'Migration, technology and care: What happens to the body?' (Swartz & Marchetti-Mercer 2019). We concluded that the enthusiasm within the field of transnationalism about the positive aspects of ICTs for

maintaining family relationships may overlook the challenges associated with using technology in the context of disability, and when ageing, bodies experience physical decline, such as reduced vision.

As already mentioned, I received no specialised training in the field of disability as part of my professional training as a clinical psychologist, which sadly reflects the field of psychology at large in South Africa (Harvey & Swartz 2024). Leslie, on the other hand, had consistently shown his commitment through his scholarly work and activism to develop better conditions for people with disability in South Africa and elsewhere on our continent (see publications such as Swartz 2009, 2018, 2023). One way to achieve this outcome is to mentor, opening someone else's eyes to the debates at hand. 'Disability, as the notable disability studies scholar Rosemarie Garland-Thomson is often quoted as saying, is nowhere until you see it. Then, it is everywhere' (Harvey & Swartz 2024:538).

In the field of migration, the gap is similar. It has been argued that disability and migration studies are often poorly integrated, typically running parallel to each other, without addressing the need for a more cohesive approach (see, for example, Duda-Mikulin 2024). This lack of cohesion may lead to the fact that 'migration theory grows without the person with disability, disability studies without the migrant, and practice without the disabled migrant' (Pisani & Grech 2015:425).

This became more evident in another research project that Leslie and I led, together with Loretta Baldassar, between 2018 and 2023. It explored the experiences of transnational African migrant families (including rural-to-urban South African migrations) and their use of technology to maintain familial relationships (eds. Marchetti-Mercer, Swartz & Baldassar 2023a). The project's focus was not on disability; however, issues of inequality and marginalisation linked to physical impairment and ageing again emerged from the data analysis, primarily thanks to Leslie's keen attention. Examples included older rural South Africans whose poor eyesight made reading small letters on their cellphones difficult, forcing them to prefer direct call phone communication (which is more expensive) because of their inability to use the technology with ease. Josephine, a participant from rural Limpopo, shared the experience of many people in such circumstances: 'We have poor vision, and also we struggle about how to dial the numbers [on a smartphone]' (Maja et al. 2023:57). Economic disadvantages, which affect many African migrants to South Africa, also restrict access to advanced technological tools such as smartphones or laptops and funds to purchase data, making communication both difficult and costly. South Africa is characterised by severe socio-economic inequality. However, digital inequality, although perhaps less visible, is no less important (Maja et al. 2023). Although more affluent migrants are easily mobile and are able to benefit from the relatively easy access to international mobile, this is not the case for poorer migrants and even less for migrants with disabilities.

Hughes (2017:468) argues that '… in this contemporary tale – unmatched in scale – of diasporas and uprooted lives, disabled migrants are "the most invisible"'.

This invisibility was highlighted in our study's findings. We argue that 'geographical distance is socially constructed. By this, we mean that distance is experienced differently, depending on socio-economic status' (Marchetti-Mercer et al. 2023b:185). We focus on the social and economic conditions of migrants, as physical ability can also impact the ability to move. As Dunn (2010:1) points out, '[a]t the international level this involves the movement across national frontiers, and it is clearly easier for some bodies to negotiate those borders than it is for others'. What might seem a relatively short distance to someone with access to dependable transportation can feel insurmountable to someone who can only access unreliable and uncomfortable public transport, which is often the case in African countries (Mkabile & Swartz 2022). The experiences of many elderly participants in the rural areas of South Africa whose children had moved to the urban area of Gauteng reflected this challenge (eds. Marchetti-Mercer et al. 2023a). For example, many participants in our study rejected travelling in a minibus taxi because of the cost and because of the physical discomfort of being in such a tight physical space. Arguably, for someone in a wheelchair, for instance, travelling to another country would be extremely challenging. Whereas transnational migrants by definition easily cross borders, people with a disability may struggle to travel even within their own country, let alone internationally. Consequently, both migrants and people with disability may feel excluded and different, encountering additional barriers. As a result, migrants with disability may face a double disadvantage because of their minority identities (Duda-Mikulin 2024).

Economic disparities and the digital divide add to the experience of exclusion and marginalisation of migrants with physical impairments or disabilities. Bacigalupe and Cámara (2012:1434) offer some hope by arguing the potential of exploring the role of ICTs in keeping families connected 'for transforming the psychology of immigration', but this ignores the embodied differences when migration puts physical distance between bodies – that distance affects the possible modes of exchange and interchange. People are 'differentially located in space, with differential abilities and opportunities to overcome … the frictional effects of distance' (McDowell 1996:31; also cited in O'Connor 2010:76). The experiences of migrants from the Global South are more likely to be compounded by challenges linked to limited access to assistive technologies, inclusive infrastructure and digital literacy. These challenges may be further exacerbated for those migrants with disabilities. While transnationalism may have introduced new ways of thinking about mobility in our technology-driven world, we should not overlook those who encounter the invisible barriers of space and distance. Going forward, migration research should be strongly informed by intersectionality, recognising how disability intersects with other identities such as race, culture and

migration status. Digital tools should be developed that facilitate a sense of empowerment and inclusion. With regard to methodologies, the use of adaptable, participant-centred approaches that accommodate the different accessibility requirements of participants with disabilities should be foregrounded (Soldatic et al. 2025). Broadening the focus of research to include different types of migration, including regional and South-South migration, is further essential for reflecting the varied and diverse experiences of migrant populations (Izaguirre et al. 2025).

As Leslie's work has consistently demonstrated, inclusion must be intentional and intersectional while recognising the unique vulnerabilities and contributions of all individuals.

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