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Towards *Critical Studies of Disabilities*: engaging Latin American theoretical perspectives on Congenital Zika Syndrome

Rumo aos estudos críticos da deficiência: engajando perspectivas teóricas latino-americanas sobre a Síndrome Congênita do Zika

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Abstract

Infection with the Zika virus during pregnancy can cause disability, yet disability remains under theorised in studies on Congenital Zika Syndrome (CZS). Existing studies are largely exploratory and descriptive in nature, and thus a deeper analysis is needed. Where theory has been applied, there is limited engagement with Latin American theoretical perspectives. The social construction of disability, and of caregiver identity in particular warrant further analysis. Understanding that disability is constructed through an 'ideology of normality' can help make sense of parents' reactions to a diagnosis of CZS. Caregivers resistance to biomedical narratives about disability is apparent in the case of CZS and deserves further attention. Consideration has been given to the ways that social location and shared temporality in relationships of care shape caregiver identity. Here I read these together to reach a fuller understanding of how caregivers and the people they care for develop a shared embodiment. An analysis bringing together Latin American Critical Disability Studies with other critical theoretical perspectives can advance theorisations of disability and the experiences of caregivers in their social, political, economic and historical contexts.

Keywords: identity, parent, carer, disability.

Resumo

A infecção pelo vírus Zika durante a gravidez pode causar deficiência. No entanto, são poucos os estudos que aprofundam uma teorização da deficiência nas pesquisas sobre a Síndrome Congênita do Zika (SCZ). Percebe-se que os estudos existentes são em grande parte de natureza exploratória e descritiva e carecem de uma análise mais profunda, em particular sobre a construção social da deficiência e da identidade do cuidador. A resistência dos cuidadores às narrativas biomédicas sobre deficiência é aparente no caso da SCZ e merece maior atenção. Além disso, nos poucos textos que apresentam um maior debate teórico, há um diálogo limitado com as perspectivas teóricas latino-americanas. Compreender, por exemplo, que a deficiência é construída através de uma "ideologia da normalidade" pode ajudar a entender as reações dos pais ao diagnóstico de SCZ. Também analiso como a localização social e a temporalidade compartilhada nas relações de cuidado moldam a identidade do cuidador. Neste texto, conjugam-se estes dois elementos para alcançar uma compreensão mais completa de como os cuidadores e as pessoas de quem cuidam desenvolvem uma corporificação compartilhada. Uma análise reunindo os estudos críticos da deficiência da América Latina com outras perspectivas teóricas críticas pode avançar nas teorizações da deficiência e das experiências dos cuidadores em seus contextos sociais, políticos, econômicos e históricos.

Palavras-chave: identidade; pais; cuidador; deficiência.

Introduction

The Zika virus transitioned from a little-known tropical disease to a Public Health Emergency of International Concern as it spread across Central and South America in 2015, and the association between in-utero infection with Zika virus and congenital disabilities in children was established. Qualitative and ethnographic research has brought much needed understanding to the social impacts of the Zika epidemic in Latin America. Feminist analyses have been particularly instructive for informing our understanding of how maternal experiences of the Zika epidemic were interlinked with gendered inequalities, sexual and reproductive health policy, and what it meant to be a mother and a caregiver. However, as Barros (2021, p. 152) finds, ethnographic knowledge production related to Zika and Congenital Zika Syndrome (CZS) has remained "maternocêntrica" (maternocentric). Relatedly, I argue that much of the existing research on Zika and CZS lacks adequate theorisation of disability. The construction of disability as a social category and the construction of the caregivers identity in particular remain under-addressed. Where disability does receive theoretical attention, critical perspectives from Latin American Disability Studies are seldom applied.

Thus, in this paper I set out to highlight two interlinked issues: the under-theorization of disability in ethnographic examinations of CZS, and the relative lack of engagement with critical theoretical perspectives on disability developed in Latin America. In doing so I hope to highlight the importance of theorising disability within anthropological studies, and demonstrate how Latin American Critical Disability Studies theory can deepen our understanding of CZS.

Background

Zika virus first received international attention when the connection was made between the virus and unusually high rates of microcephaly in Brazil (Diniz, 2017). In utero Zika infection has been shown to result in a number of symptoms including microcephaly, visual and hearing impairments, seizures, irritability, difficulty sleeping and swallowing, motor and cognitive impairment (Gordon-Lipkin; Peacock, 2019). This collection of symptoms has come to be known in the medical community as Congenial Zika Syndrome, and often to parents of children affected by Zika simply as microcephaly or micro (Diniz, 2016).

Attention to Zika has waned in recent years, especially in the light of the COVID-19 pandemic (Belluck; Franco, 2017; Magalhaes; Pearson, 2020). However, Zika continues to circulate and thousands of children are living with CZS (Magalhaes; Pearson, 2020; Pan American Health Organization; World Health Organization, 2021). Access to services for these children did not appear to be prioritised in national responses to CZS, and the lack of specialist services, long distances to referral centres, fragmentation of services, difficulty obtaining referrals and lack of information for caregivers have been well documented (Albuquerque *et al.*, 2019; Center for Reproductive Rights, 2018a, 2018b). The COVID-19 pandemic has interrupted services further, disrupting the therapeutic routines of children with CZS, particularly for families with limited access to resources (Magalhaes; Pearson, 2020; Williamson, 2020).

The arrival of Zika in Brazil, and it's spread to neighbouring countries, led to an initial boom of clinical and epidemiological research. Qualitative perspectives have added a great deal to our understanding of the experiences of communities at risk of Zika infection, pregnant women infected with Zika, and the families of children with CZS. Qualitative studies of parents of children with CZS are largely self-described as 'descriptive' and 'exploratory', and as such have limited engagement with theory (Albuquerque *et al.*, 2019; Calazans *et al.*, 2020; Duarte *et al.*, 2019; Félix; Farias, 2018; Freitas *et al.*, 2020; Junqueira *et al.*, 2020; Lima *et al.*, 2020; Marbán-Castro *et al.*, 2020; Mocelin *et al.*, 2021; Oliveira, B. *et al.*, 2019; Oliveira, P. *et al.*, 2019; Sá *et al.*, 2017; Sousa *et al.*, 2018). A small number of ethnographic studies applying critical theory, in particular feminist theory, have been conducted. These have been particularly valuable in illuminating how experiences of the epidemic and aftermath were shaped by unequal relationships of power on the individual, community and state level.

Patchin (2020b) applies an intersectional feminist lens to Zika in Puerto Rico. She situates the Zika epidemic in the context of the island's colonial relationship with the USA in order to explain why the bodies and reproductive potential of women on the island became the focal point for US fears of the virus (Patchin, 2020b). She found that the Zika prevention strategy implemented in Puerto Rico was underpinned by neo-liberal attitudes to population and "eugenicist impulses" (Patchin, 2020a, p. 1). The provision of long-acting contraceptives was not in line with women's preferences but was instead based on effectiveness and cost-benefit considerations, with the aim of averting potentially "costly" births of children who would require life-long care (Patchin, 2020a, p. 8). Rivera-Amarillo and Camargo (2018) also bring a multi-level spatial analysis to Zika in their feminist critique of the Colombian public health response to the virus. They found that women's bodies and the domestic spaces they inhabited became key sites in which government responses sought to control the spread of the virus (Rivera-Amarillo; Camargo, 2018). They found that state concerns with the prevention of "'anomalous' births" were projected on to low-income women with high risk of exposure and limited ability to prevent the virus (Rivera-Amarillo; Camargo, 2018, p. 2). Both they and Patchin caution that women's bodies and reproductive capacity will continue to be targeted as sites of intervention and control as interrelated concerns over population, environment and climate change continue to grow (Patchin, 2020a; Rivera-Amarillo; Camargo, 2018). Through a feminist analysis of reproductive decision making among Brazilian women infected with Zika during pregnancy, Williamson (2021) advanced conceptions of care and agency. She found that agency is not necessarily defined by individual decision making power, and that particularly in times of uncertainty like the Zika epidemic, health care providers and family members intervene in reproductive decision making as a means of caring for the pregnant woman and alleviating uncertainty (Williamson, 2021). By bringing together women's everyday lives and their interpretations with feminist theory, these feminist ethnographies have contributed a deeper understanding of the gendered impacts of the epidemic and situated Zika and CZS in their social and historical context.

While gender has received much needed attention, analyses of Zika and CZS based in Disability Studies are less common. This is in line with Barros' (2021, p. 152) assertion that ethnographic knowledge production related to Zika and CZS has remained "maternocêntrica" (maternocentric). Indeed, the majority of the qualitative literature on the experience of families of children with CZS lacks a clear conceptualisation of disability altogether. A minority of studies outline a socio-cultural understanding of disability, calling for inclusion and independence for children with CZS in the future and for their inclusion in future research (Campos *et al.*, 2020; Melo *et al.*, 2020; Scott, 2020), and a small number refer to the social model of disability by name (Félix; Farias, 2018;

Sá; Pletsch, 2021; Scott *et al.*, 2018). A small number of researchers have employed more critical approaches to disability, and these will be discussed in more detail later in this article. Few published ethnographic studies have applied perspectives on disability developed in the Global South or Latin America specifically. With this in mind, I will proceed to give an overview of a number of approaches to conceptualising disability, and discuss the coloniality of knowledge in Disability Studies.

"Disabilities Studies, in plural"

Mainstream models

A number of models of disability have been developed over time that guide how disability is defined and understood, and thus the way that people with disabilities are treated in society. The models of disability that currently dominate Western institutions are the biomedical model, the social model, and the biopsycho-social model. The biomedical model frames disability as an individual deficit that is classified in relation to the "normal", and as something to be overcome through medical rehabilitation (Llewellyn; Hogan, 2000; Smart, 2009). In contrast, the social model finds that the deficiency is with a society that discriminates against and excludes people with mental or physical impairments, and thus that disability itself is socially constructed (Llewellyn; Hogan, 2000). The biopsychosocial model is a broader model of health and disease which situates disability as an interaction between the individual's physiology and psychology and the social world (Borrell-Carrió; Suchman; Epstein, 2004).

The movement for disability rights that emerged in the second half of the 20th century in the UK and USA led to a number of important legal changes that advanced the rights of people with disabilities (Hinton, 2021). The movement also brought about the development of the academic field of Disability Studies, and the mainstreaming of the social model of disability (Hinton, 2021). The WHO International Classification of Functioning, Disability and Health (ICF) and UN Convention on the Rights of People with Disabilities (CRPD) acknowledge the role of the environment and social context in the construction of disability, and call for an end to discrimination, enabling participation and independence, and inclusion for people with disabilities (Equality and Human Rights Commission, 2020; Jette; Martin; Field, 2006). Activist demands for recognition of the role that social construction plays in disability have brought about changes to law and policy that aim to reduce exclusion and facilitate participation for people with disabilities. As the social model of disability has become mainstream, a number of critical approaches to Disability Studies have also been developed. A comprehensive review of each of these critical interventions is beyond the scope of this paper, but a number of key developments are outlined to demonstrate how the field has progressed beyond the social model.

Critical approaches

The development of the social model of disability and its adoption as a mainstream approach represented an important shift away from the deficit centred medical understandings of disability and towards social justice. However, a feminist critique reveals that the social model centres particular subjective experiences of independence and participation as they might exist for a white, adult male subject living with a physical disability or otherwise limited mobility (Valim, 2020). Such an framework marginalises the experiences of women, children, and those with complex and cognitive disabilities, for whom the type of independence that the social model prioritises may not be possible or desirable (Valim, 2020). Placing such value on the pursuit of independence not only forecloses consideration of what social justice might look like when dependence is an inevitability, but in so doing, also devalues relationships of care (Kittay, 2011).

Evident in the critique that the social model privileges white male experiences is the fact that early Global North Disability Studies (sometimes termed white Disability Studies) were overwhelmingly white and lacked an analysis of race in relation to the construction and experience of disability (Hinton, 2021). Black Disability Studies has a long history in its own right and more recently has also put forward important critiques of mainstream white Disability Studies (Bell, 2006; Hinton, 2021; Miles; Nishida; Forber-Pratt, 2017). Black Feminist Disability Studies have been particularly instrumental in the development of intersectional analyses that examine race, gender and disability as inter-related and co-constitutive systems of oppression that have their roots in colonisation and slavery (Bailey; Mobley, 2019; Hinton, 2021).

Considerations of the political economy of gender, sexuality, and disability in the context of a neoliberal global economic system by queer theorists has resulted in the development of Crip theory (Bennett, 2007; McRuer, 2006). Crip theorists offer robust critiques of normative expectations of gender expression, sexuality, and bodily form and function (McRuer, 2006; Sandahl, 2003). Crip theory has been particularly influential in offering a critique of normative notions of time in relation to disability (Kafer, 2013b). The concept of "crip time", which asks us to consider how experiences of disability alter the subject's experience of time, has been widely adopted (Kafer, 2013c). Kafer (2013a) also invites us to consider the idea of the future as it relates to disability, which is so often neglected or denied. Applications of crip time to the case of CZS will be discussed later in this article.

Indigenous scholars and those based in or originating from the Global South have highlighted that considerations of colonisation and coloniality are missing from mainstream models of disability. This is a glaring omission for two interrelated reasons. Firstly, colonisation was a major cause of impairment, through armed conflict, subjugation and punishment, disease, environmental destruction, malnourishment and poverty (Grech, 2015; Meekosha, 2008; Parra, 2020; Soldatic; Grech, 2014). Furthermore, the imposition of the *category* of disability as it was understood in the colonising countries (as a negative trait based in personal deficit) was part of the process of subjugation of indigenous populations (Ineese-Nash, 2020). Thus, the Eurocentric models of white Disability Studies are limited in their ability to provide a full and rich understanding of constructions and experiences of disability in post-colonial settings (Ferrari, 2020; Grech, 2015; Parra, 2020; Yarza de los Ríos; Sosa; Pérez Ramírez, 2020b). Despite this, they are often treated as universal and uncritically applied to contexts other than those in which they were developed (Ferrari, 2020; Yarza de los Ríos; Sosa; Pérez Ramírez, 2020a).

As already noted, the shift from medical to social understandings of disability by supranational organisations was a step in the right direction, but uncritical reliance on the social model risks reproducing some of the very same dynamics it was intended to subvert. Policies that aim to improve workplace participation as a means to achieving 'independence' fall back on capitalist logic that assigns value to individuals based on their productivity (Ferrari, 2020; Parra, 2020). Desires to 'normalise' disabled bodies, driven by a biomedical, deficiency-based understanding of disability, have been replaced by more subtle modes of control and the need for conformity (Parra, 2020). Furthermore, international conventions rely on the assumption that rights on paper create paradigm shifts that in turn transform systems of oppression and advance equality, which cannot be taken for granted in societies marked by severe inequality and political instability (Yarza de los Ríos *et al.*, 2020).

Latin American Critical Disability Studies

Latin American scholars working in the field of Disability Studies have developed a distinct branch of Critical Disability Studies. They explicitly acknowledge that the development of the social model of disability opened up discussions of the social construction of disability (Rojas Campos, 2020; Yarza de los Ríos *et al.*, 2020). Despite the critique that mainstream models of disability are Eurocentric, the aim is not to disparage or discount existing contributions, but to enter in to a "critical dialogue" that creates space for other experiences and interpretations (Ferrari, 2020; Parra, 2020; Yarza de los Ríos; Sosa; Pérez Ramírez, 2020b, p. 10). This includes drawing on other critical traditions, Global South Disability Studies and alternate epistemologies (Munévar; Fernández Moreno; Gómez Castro, 2020). Indeed, there is a hope that such dialogues will create space "to speak and think in terms of Disabilities Studies, in plural, or better yet Critical Studies in Disabilities" (Yarza de los Ríos *et al.*, 2020, p. 37).

What distinguishes Latin American Critical Disability Studies from other Global South Disability Studies is the use of Latin American decolonial and feminist perspectives on power, race, gender and knowledge. Drawing on decolonial theory helps to situate the production and construction of disability within the specific historical context with regards to early colonisation by European countries and the proceeding 500 years of exploitation.

Quijano (2007) finds that the naturalisation of racial hierarchy was essential to the construction of a social hierarchy that enabled colonisation and ordered colonial labour relations. The two inseparable axes of racialisation and capitalist exploitation that have outlived the physical act of territorial colonisation established what Quijano (2000b) refers to as the "coloniality of power". Lugones (2007, 2016) brings together the coloniality of power with intersectionality to develop the coloniality of gender. She argues that colonisation did not simply impose the European gender order on to the colonised people, but “imposed a new gender system” that ordered relations among the colonizers and the Indigenous peoples as well as between them, and that the constructions of gender is thus inseparable from the constructions of race (Lugones, 2007, p. 1, 2012). The coloniality of power shaped the development of a dominant worldview and system of knowledge production born out of “the fusing of the experiences of colonialism and coloniality with the necessities of capitalism” (Lugones, 2007; Quijano, 2007, 2000a, p. 343). Serving the needs of capitalism involves the measurement and classification of both people and nature in order to maintain social hierarchies (Quijano, 2000a). This system, that serves the needs of capitalism, privileges Western methods of inquiry and ways of knowing, establishes Westerners as those capable of ‘knowing’ and non-Western people as only able to be the object of study and thus be ‘known’ as an Other constitutes the coloniality of knowledge (Alonso Bejarano *et al.*, 2019; Quijano, 2007).

Decolonial perspectives on power, race and gender lay the groundwork for Latin American Critical Disability Studies by inviting debate “about possible ruptures with the coloniality of power, capitalism and Eurocentrism” (Danel, 2020, p. 77). However, they fail to adequately consider disability as an organising principle in the social hierarchization that was essential to the colonial project and is constitutive of and perpetuates the coloniality of power (Morán; Tiseyra, 2019; Parra, 2020). Through the dominance of models of disability developed by white Disability Studies, and the lack of consideration of disability in decolonial thought, understandings of disability have come to be “dominated by hegemonic matrices of thought from the Global North” and thus unable to account for the historically situated experiences of people with disabilities in Latin America (Danel, 2020; Ferrari, 2020; Parra, 2020, p. 63). In order to “generate a better understanding of the situation of people with disability in the context of Latin America” (Morán; Tiseyra, 2019, p. 504) Latin American Critical Disability Studies brings together Latin American decolonial theory, global south feminisms, and contributions from Critical Disability Studies. This facilitates an elaboration on the coloniality of (dis)ability and furthers our understanding of processes of subjugation of certain bodies, and subjugation based on bodily difference (Ferrari, 2020; Morán; Tiseyra, 2019; Munévar; Fernández Moreno; Gómez Castro, 2020; Parra, 2020).

Latin American Critical Disability Studies acknowledges a diverse lineage and calls for multiple Disabilities Studies and dialogue with other critical traditions. Thus, to argue for engagement with Latin American Critical Disability Studies is to argue for an approach that draws on critical approaches to gender, race and sexuality, while keeping in mind how Latin America's history of colonisation and present day social, political and economic conditions create and shape experiences and constructions of disability in the region.

I proceed to apply some insights from multiple Critical Disability Studies to the case of CZS, giving some examples from the literature examining the experiences of those affected by the condition and their families. I pay particular attention to how this perspective can provide elaboration on the processes through which identities are constructed – the construction of disability, and the construction of the caregiver's identity in relation to their role.

The construction of disability

The ideology of normality

Latin American scholars of Critical Disability Studies find that disability as a colonial concept is constructed through an "ideology of normality" (Rosato *et al.*, 2009; Yarza de los Ríos *et al.*, 2020). This ideology depends on the creation of binaries, in which a singular desirable or 'normal' state of being is constructed in opposition to the undesirable or 'abnormal' (Rosato *et al.*, 2009). The subjugation and othering of the 'abnormal' are essential in the construction of the 'normal' and in naturalising inequalities between the two (Rosato *et al.*, 2009). The abnormal is defined as something possessing characteristics deemed to be undesirable or lacking those deemed to be desirable in the given context (Rosato *et al.*, 2009). Colonisation and coloniality have shaped labour relations and established the global capitalist system (Quijano, 2000b). Under this system, "ability is synonymous with productivity, effectiveness, efficiency" and those who cannot produce capital are labelled as deficient (Ferrante, 2009; Ferrari, 2020, p. 125). Disability framed by the ideology of normality becomes defined by "lack, deficit, deviation, absence", and it becomes imperative that people with disabilities strive to achieve 'normality' through rehabilitation, even when reversal of the impairment is impossible (Rosato *et al.*, 2009, p. 99).

In the case of CZS, the construction of a desirable, ‘normal’ child began during pregnancy. Parents began to construct an image of an idealised baby that upon confirmation of a pregnancy, which was typically healthy and able-bodied (Carneiro; Fleischer, 2018; Melo *et al.*, 2020; Félix; Farias, 2018; Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020; Laza-Vásquez *et al.*, 2021; Mendes *et al.*, 2020; Sá *et al.*, 2017; Silva; Silva, 2020; Williamson, 2018, 2021). Parents expressed a desire for a ‘normal’ child, which, in light of the risk of infection with Zika, they framed in opposition to a child with CZS (Campos *et al.*, 2020; Félix; Farias, 2018). The diagnosis of CZS represented a disruption to their relationship to the imagined baby and caused shock and distress to the parents (Carneiro; Fleischer, 2018; Melo *et al.*, 2020; Félix; Farias, 2018; Hamad; Souza, 2020; Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020; Laza-Vásquez *et al.*, 2021; Mendes *et al.*, 2020; Sá *et al.*, 2017; Silva; Silva, 2020; Williamson, 2018, 2021). It was common for parents to experience a period of denial about the diagnosis, and for them to struggle to accept the news (Dias *et al.*, 2021; Félix; Farias, 2018; Laza-Vásquez *et al.*, 2021; Romero-Acosta *et al.*, 2020). Many parents’ worry and distress appeared to be focused on whether their child would be, or appear, ‘normal’ (Duarte *et al.*, 2019; Félix; Farias, 2018; Laza-Vásquez *et al.*, 2021; Oliveira, P. *et al.*, 2019). Some pregnant women sought a second opinion of the diagnosis and the healthcare professionals they approached with this request sustained the idealised image of the expected baby, downplaying the diagnosis and creating false hope (Laza-Vásquez *et al.*, 2021; Simas *et al.*, 2020). Others prayed for the child to be healthy, and wondered if they were being punished by God for some perceived or actual past sin (Melo *et al.*, 2020; Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020; Laza-Vásquez *et al.*, 2021; Romero-Acosta *et al.*, 2020).

The birth made the extent of the child’s physical symptoms apparent, but in some cases parents were *only* able to accept their child’s physical appearance – mothers still expected their child to be otherwise ‘normal’ and were in denial about their cognitive development (Laza-Vásquez *et al.*, 2021). Comparing their child to ‘typical’ child development milestones caused further distress, and a sense that their child would never measure up (Williamson, 2018). Parents clearly formed a view of their child’s condition that was constructed in opposition to the ‘normal’ child which they had imagined. Their conflation of able-bodiedness with ‘normality’ and CZS with ‘abnormality’ and deficit contributed to their emotional distress and denial about the diagnosis and prognosis. Pava-Ripoll (2020) explains that in the case of disability discrimination, the ideology of normality is made visible to parents through its interaction with and imposition on their child’s embodied being. This may inform their understanding that cognitive and physical differences represent something to be hidden or corrected.

One of the central contradictions created by a view of disability framed by the ideology of normality is that at the same time that disability is naturalised and inscribed as an inherent deficit, interventions and discourses around disability are orientated towards rehabilitation, ‘correction’ and cures (Rosato *et al.*, 2009). Some parents understood their child’s disability as a deficiency to be overcome through treatments, therapies, stimulation or an as-yet undiscovered cure (Campos *et al.*, 2020; Duarte *et al.*, 2019; Félix; Farias, 2018; Junqueira *et al.*, 2020; Laza-Vásquez *et al.*, 2021; Oliveira, B. *et al.*, 2019). They had unrealistic expectations of the extent to which available treatments could contribute to the child’s development and ability to ‘overcome’ their symptoms (Félix; Farias, 2018; Junqueira *et al.*, 2020; Laza-Vásquez *et al.*, 2021).

Understanding the ideology of normality and its colonial roots gives us the tools necessary to analyse and contextualise parental preoccupations with having a ‘normal’ child. Discourses that centre normality and rely on the construction of binaries between children with CZS and those without appear to contribute to parental distress and inability to adjust to the news of the diagnosis. Identifying and analysing these harmful narratives enables us to identify counter-narratives constructed by parents that resist pathologizing their child based on their condition. Such narratives may enable them to accept that their child’s differences are not inherently deficits or flaws, and thus help them process their distress and denial.

Developing counter-narratives

While biomedical narratives of disability dominated, parents also found ways to counter these. Some parents viewed their child’s disability as a “bodily way of being in the world” rather than a biomedical state of sickness (Scott, 2020, p. 20).

They countered the biomedical narratives put forward by healthcare professionals and policy makers by making explicit the distinction between illness and disability – their children need (lifelong) therapy but are not 'sick' and cannot be cured (Scott, 2020). This aligns with findings from a study of parents in Chile with various impairments, who made a similar distinction between sickness and disability, enabling them to relate to their child on the child's own terms rather than holding them to an unrealistic standard (Giaconi Moris; Pedrero Sanhueza; San Martín Peñailillo, 2017).

Fisher and Goodley (2007) point to the Western, modern notion that the human life course should follow a linear trajectory of continual progress and development as an underlying principle of the biomedical model of disability and the preoccupation with rehabilitation. Among mothers of children with disabilities in England, they found that such narratives "can obstruct the development of positive discourses around disability" as the expected life trajectory may not be possible for people with certain impairments, and thus their lives are constructed as deficient, lacking in potential and inherently tragic (Fisher; Goodley, 2007, p. 78). Countering these narratives, as some of the mothers they encountered were able to do, enabled parents to engage with the child on their own terms and see their child's strengths and positive attributes more clearly (Fisher; Goodley, 2007).

In her ethnography of mothers of children with CZS in Bahia, Brazil, Williamson (2018) identified similar counter-narratives based on rejecting linearity and developmental 'progress'. She draws on the notion of crip time to interpret the construction of these counter-narratives (Williamson, 2018). In line with Kafer's call for attention to disabled futures, she found that parents respond to uncertainty not by abandoning hope for the future but by practicing hope in the present (Williamson, 2018). Mothers responded to the unpredictability of their child's condition by developing "alternative forms of thinking about, interacting with, and appreciating the child in her or his own terms" rather than feeling beholden to developmental milestones that may never be met (Williamson, 2018, p. 2). In doing so, they reject normative time and construct "temporal trajectories that conform to the child, and not the other way around" (Williamson, 2018, p. 12).

The counter-narratives that parents employ to push back against biomedical narratives of disability that centre the pursuit of rehabilitation and cure are likely to vary significantly across different contexts. However, as demonstrated by the accounts in Williamson (2018) and Fisher and Goodley (2007), narratives of progress and linear development are widespread, and thus resistance to these biomedical understandings of disability share some core features across diverse contexts.

Religious belief and prayer played a role in the parents initial denial about the diagnosis, but the will of God may also offer a powerful counter-narrative to the pathologizing discourses around CZS and disability more broadly. Some parents believed that their child's condition was a challenge or a gift sent by God, and that they had been chosen specifically to receive this "special" child (Carneiro; Fleischer, 2018; Diniz, 2016, p. 2; Laza-Vásquez *et al.*, 2021; Lima *et al.*, 2020; Simas *et al.*, 2020). They believed that if God had chosen them in this way, that he knew that they were able to cope, or that he would prepare them and equip them to deal with the challenge he had sent (Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020; Laza-Vásquez *et al.*, 2021; Mendes *et al.*, 2020; Simas *et al.*, 2020). They also expressed that God would take care of the child, or that only he could decide whether the child survived (Félix; Farias, 2018; Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020). This fed in to parental resistance to one of the most explicit manifestations of the pathologizing narrative of disability, which was the suggestion from healthcare providers to abort the foetus based on the diagnosis. In some instances, the possibility of obtaining an abortion was raised by the pregnant woman. In others, however, it was the health care providers who raised the possibility of abortion. Some did so in a more neutral tone (Carneiro; Fleischer, 2018), but in some cases pregnant women felt pressure from their provider to consider an abortion (Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020). Many pregnant women, including some of those who raised the possibility of seeking an abortion themselves, reported being opposed to abortion on the basis of religion prior to the diagnosis (Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020; Laza-Vásquez *et al.*, 2021; Silva; Silva, 2020; Tirado *et al.*, 2020). The belief that the child's diagnosis was God's will appeared to strengthen their opposition to seeking an abortion in this specific case (Carneiro; Fleischer, 2018; Laza-Vásquez; Cortés-Martínez; Cano-Rivillas, 2020; Laza-Vásquez *et al.*, 2021). This demonstrates the role of religious narratives in countering a specific manifestation of the deficit driven discourse of disability inherent to the biomedical model that arose during the pregnancy.

Further research exploring the role of religious narratives in countering biomedical constructions of disability that resonate not only during the pregnancy but after the birth and throughout the experience of parenting would be welcome.

Adopting a critical stance allow us to identify how parents develop alternative narratives that resist pathologizing their child. Future ethnographies of children with CZS and their families must continue to allow space for the expression of resistance to dominant narratives about disability, and continue engage with perspectives from critical theory to better understand this phenomenon.

The construction of the caregivers identity

Much of the empirical research on people affected by Zika focused on the caregivers of children with CZS. Contributions from Latin American Critical Disability Studies can help us understand how the caring relationship influences the construction of the caregivers identity. Other authors have expanded on the social and political identity developed among mothers of children with CZS in particular (often referring to themselves as "Zika moms" or "micro moms") (Carneiro; Fleischer, 2018; Melo *et al.*, 2020; Sá; Pletsch, 2021; Simas *et al.*, 2020; Smythe *et al.*, 2020; Vale; Alves; Carvalho, 2020), and on the stigma and prejudice women experienced as a result of being blamed for the child's condition (Albuquerque *et al.*, 2019; Carneiro; Fleischer, 2018; Freitas *et al.*, 2020; Laza-Vásquez *et al.*, 2021; Silva; Silva, 2020). However, I am interested in how perspectives from Latin American Critical Disability Studies can help us to interpret the findings that some parents felt they also "acquired the social position of a person with a disability" (Melo *et al.*, 2020, p. 10; Félix; Farias, 2018).

The "social position" that people with disabilities occupy is contingent on the ways in which disability intersects with other axes of oppression within the given social, historical and political context. Thus in order to understand how someone may come to acquire a particular social position, we must consider how that social position, as part of a matrix of social hierarchies, is created and reinforced (Ferrari, 2020) and how identity and the self are constructed within that matrix.

An analysis based on the biomedical model of disability does not allow for meaningful consideration of the social position of people with disabilities, let alone the possibility that an able-bodied caregiver may come to share that position. Applying the social model of disability, we find that the social position of a person with a disability is a product of societal structures and processes whose design excludes and marginalises people with disabilities. Family caregivers may also find their activities restricted by these societal barriers (Dowling; Dolan, 2001). However, an analysis that begins and ends with the social model may lead us to believe that the removal of societal barriers creates independence for the person with a disability, and results in caregivers no longer occupying this position. A more critical approach is essential to analysing this phenomenon. Crip theory specifically dwells on the possibility of a "nondisabled claim to be crip" (Kafer, 2013b, p. 13; McRuer, 2006, p. 36; Sandahl, 2003, p. 27), and Latin American perspectives invite us to unsettle our understanding of independence as it relates to disability (Munévar, 2021; Rodríguez, 2020).

Rodríguez (2020) and Munévar (2021) share a scepticism for narratives that centre independence as the most socially desirable outcome for people with disabilities. Munévar (2021) points to the individualism and capitalist logics that underpin emphasis on independence, as well as highlighting the marginalisation of individuals with multiple and severe disabilities (for whom a socially acceptable level of independence may never be achieved) within this framing. Rodríguez (2020) finds that relationships of care shape the caregiver, the cared for and the assembly of the two, creating embodied connections between people and rending independence an impossibility. Adopting a perspective that allows us to de-centre the ideal of independence can help us to better understand how caregiver identity is constructed through the relationship of care and lived experience that they share with their child. The ways in which relationships of care contribute to the development of the caregivers identity can be seen in the narratives of parents of children with CZS.

Félix and Farias (2018) interviewed five, mainly rural and low-income, fathers of children with CZS in Paraíba, northeast Brazil. The fathers were involved in the children's everyday care, and the researchers sought to understand their perspectives on the arrival of the child (Félix; Farias, 2018). They reported feeling fearful, worried and discouraged by the diagnosis, and experienced denial about the child's condition when they were born (Félix; Farias, 2018).

The fathers experienced prejudice and discrimination while out in public with their child, to the extent that the child’s disability came to be viewed as if it were “partially that of the father” (Félix; Farias, 2018, p. 6). Mothers and other female caregivers in a study in Pernambuco, Brazil had similar feelings (Melo *et al.*, 2020). The caregivers lived in urban settings and were mainly from low-income families (Melo *et al.*, 2020). They felt that their social position came to mirror that of a person with a disability, based on their experiences of not only stigma and discrimination from others directed at their child (and indirectly affecting them) but due to the daily “limitations… social struggle, demand to rights and health services” they experienced first-hand (Melo *et al.*, 2020, p. 10). A grandmother who had a child with Downs syndrome and cared for her grandchild with CZS drew parallels between the challenges she experienced in gaining access to services, and the prejudice she experienced from others based on the children’s disabilities (Melo *et al.*, 2020). Thus, relationships of care contributed to the development of a socially constructed identity for the caregiver that was shaped by the experiences of discrimination and exclusion directed at the child they cared for. Even if barriers to accessing services were reduced or removed, children with cognitive and physical disabilities due to CZS would not be able to access them independently, and their caregivers would continue to face disproportionate “limitations” on their activities.

Scott (2020) followed the trajectories of three mothers of children with CZS in Pernambuco, northeast Brazil as they navigated motherhood and mobilised themselves to gain access to the fragmented services their children required. For these women, rather than the identity of disability being expanded to include the parent, a new identity was formed which was made up of the “mother-child dyad” (Scott, 2020). This was driven by social expectations of the mothers role, along with specific policy responses to CZS.

Within families, the expectation was that mothers would dedicate themselves fully to caring for their child with CZS at home, demanding rights and services and attending appointments, on top of the other household chores and childcare activities (Scott, 2020). Mothers were seen as the natural caregiver and female relatives were expected to be willing and able to help with care (Scott, 2020). Fathers, on the other hand, faced no such expectation and their contributions, when they did occur, were seen as unexpected acts of heroism rather than everyday activities of a father (Scott, 2020). Other studies have found that that mothers of children with CZS, lacking the support of others, sacrificed their own health, leisure and identities to care for their child (Calazans *et al.*, 2020; Duarte *et al.*, 2019; Freitas *et al.*, 2020; Mendes *et al.*, 2020; Sá *et al.*, 2017; Vale; Alves; Carvalho, 2020; Williamson, 2018). Scott (2020) finds that an even deeper interconnection is formed through the provision of care, in which the mothers lent their bodies to their child, forming "a multiple body" that was capable of leveraging care and solidarity.

In terms of policy, the mothers were granted access to free transportation (Scott, 2020). This was a great source of assistance given the high frequency of appointments at venues dispersed around the city of Recife, however, it was only valid when they were accompanied by the child with CZS, and could be revoked if this condition was not met (Scott, 2020). Through this policy, the 'dyad' became a more powerful symbolic force for accessing services than the mother or child alone (Scott, 2020).

The evolution of this new singular, embodied identity represents one form of the "co-extensions of one body into another" that Rodríguez (2020, p. 209), putting feminist theory in dialogue with Critical Disability Studies from a Latin American perspective, argues are produced through relationships of care. Rodríguez (2020) also argues that the perspective of the person receiving care has been neglected, and calls for considerations of both the giver and receiver of care. Seeking to understand the shared identity of the person giving and the person receiving care together, and viewing them as actively shaping one another, may serve as a strategy to counter the marginalisation of the recipient in considering how relationships of care shape identity. This would make space for both parties to be understood as the active subject, rather than rendering one a passive through objectification. De-centring the ideal of independence, as Munévar (2021) and Rodríguez (2020) suggest, may also represent an effective counter-narrative to biomedical discourses about disability, especially for the parents of children with severe CZS symptoms who are likely to require life-long care. Despite placing deserved importance on the permanence of many disabilities, Rodríguez does not address everyday experiences of time in her theorisation of shared embodiment. Consideration of how the temporality of relationships of care influences caregiver identity is necessary.

Williamson (2018) makes clear that family members who are heavily involved in caring for children with CZS experience crip time along with their child.

Caregivers are made responsible for promoting and monitoring their child's 'progress' through therapeutic and medical interventions, and thus experience stops and starts, pauses, reversals and repetitions along with them (Williamson, 2018). Reflecting on his experiences as a caregiver to a son with disabilities, Davidson (2020, p. 2) finds that his life "displays the marks of disability" through the shared experience of "the social stigma, the disenfranchisement, and the personal struggle" and by the shared experience of crip time. Reading these analyses together with the finding that parents of children with CZS felt that that came to occupy the social position of a person with a disability, we can find that inter-embodiment is not only spatial but also temporal. Caregivers are not only socially re-located in the position of a person with disability through the relationship of care but are also temporally re-located from normative time to crip time. Through an analysis that brings together Crip theory with feminist Latin American Critical Disability Studies, we find that caregiver identity is shaped through shared daily experiences, sharing their body, and sharing crip time with their child (Davidson, 2020; Scott, 2020; Williamson, 2018).

Concluding remarks

Applying Southern theory is essential to enable a rich interpretation of complex biosocial phenomena such as disability as they are constructed and experienced in post-colonial settings (Connell, 2007; Ferrari, 2020). Furthermore, drawing on diverse theoretical contributions is essential to advance our understanding of disability as a context-dependent, situated experience that overlaps with and is co-constitutive of other structures of oppression. Anglo-American contributions have been vital in opening up the field to alternatives to the biomedical model of disability, namely through the development of the social and bio-psycho-social models of disability (Rojas Campos, 2020; Yarza de los Ríos *et al.*, 2020). However, we must resist "scholarly colonialism" by refusing to uncritically transplant theories to contexts for which they were not developed and are not adequate to explain (Ferrari, 2020; Meekosha, 2008, p. 2). By engaging in to critical conversations with other branches of Disability Studies, along with feminist and decolonial theory, Latin American Critical Disability Studies scholars avoid the Eurocentrism of white Disability Studies (Yarza de los Ríos; Sosa; Pérez Ramírez, 2020b). At the same time they highlight and work to rectify the relative neglect of disability within Latin American decolonial theory (Yarza de los Ríos; Sosa; Pérez Ramírez, 2020b). Understanding the context-specific ways in which biomedical, deficit based, pathologizing narratives about disability develop and manifest is essential as it enables us to recognise counter-narratives that resonate with parents. A number of studies give a descriptive account of parents reactions to the diagnosis of CZS, but further analysis and engagement with theory is less common. Here, I have shown that the "ideology of normality" shaped how expectant parents interpreted the diagnosis of CZS and related to their child in their early years. Adopting this critical frame allowed me to identify how parental narratives abut their child demonstrate resistance to this ideology. Such narratives appear to play a role in improving the relationship between the parent and child and alleviating the burden of expectation and pressure that parents feel when engaging with their child (Williamson, 2018). Further empirical work exploring how parents develop counter-narratives to biomedical narratives about disability is warranted. Children born during the Zika epidemic of 2015-2017 are now aged between five and seven years old. The same attention that has been paid in existing research to how parents interpret, respond to, and resist early childhood development markers may now be turned towards normative trajectories based on educational and childhood milestones.

The relationship of care between caregivers and children with CZS mediates the experiences of discrimination and exclusion that they share, shaping a caregiver identity that is intwined with the identity and social position of the child. Bringing together queer theory with Latin American contributions to Disability Studies, particularly those that draw on feminist theories of care, can be applied to facilitate a deeper understanding of how caregivers identities are constructed. By demonstrating how the shared experience of crip time contributes to the development of inter-embodiment between the caregiver and the cared for, I have shown that dialogue between critical traditions can be generative in terms of furthering our understanding of how caregiver identity develops. Further considerations of ableism and stigma would be welcome when considering how disability is constructed. While stigma and discrimination evidently play a role in the construction of the caregivers identity, less attention has been paid to how experiences of ableism at different levels shape the construction of disability itself in this context.

Further research on fatherhood, masculinity and care in relation to CZS would be welcome. The existing research focuses largely on mothers and other female caregivers. Care work is highly gendered, and performing that work appears to be essential to the formation of identity for parental caregivers. In spite of this, male caregivers experiences and empirically grounded theory development about masculinity and care remain underexplored.

I have demonstrated how engagement with Latin American and critical perspectives on disability can deepen our understanding of disability in the case of CZS. Latin American Disability Studies specifically call for dialogue between multiple Disabilities Studies. I have found embracing this plural approach to 'Critical Studies in Disabilities' to be generative in understanding both the construction of disability and formation of caregiver identity. I have laid out future directions for empirical ethnographic research and theory development in this area, and shown that contributions from Latin American Critical Disability Studies can advance our understanding of how disability is and has been constructed in the specific historical context of colonisation, domination and coloniality.

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