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Complicating Mental Illness Stigma and Physical Disability Stigma Research: Centring Caribbean Women

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Abstract

This commentary paper presents key findings from a maternal depression research study conducted in Barbados and a global-health focused systematic review of stigma, both initiated by the author. These studies provide evidence that mental illness stigma amongst Caribbean women exists, but questions why so few retrievals from a systematic review of stigma focused on this group and this specific topic. It makes the case for increased research on mental illness stigma and physical disability stigma focused on Caribbean women across racial, linguistic, geographic, and ethnic differences.

Keywords: Mental Health, Disability, HIV/AIDS, Systematic Review, Caribbean

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In 2010 I left Toronto for Barbados with ambitions to conduct my PhD dissertation project on maternal depression. The year before I had visited Barbados and Jamaica using a travel bursary from the Centre for Addiction and Mental Health, a research and teaching hospital in Toronto, to scout research sites and begin to understand the landscape of mental healthcare on each island. During my trip to Jamaica I met a senior health official who drove me to public clinics in the northeast, and introduced me to people who were engaged in community mental health work. I recall telling this person that I was interested in doing a research project on postpartum depression,[1] and their reply was, "You won't find that here. Women have a lot of support; their sisters, mothers and grandmothers are there to help them after having a baby, so they don't get postpartum depression".

By the time I started data collection for my dissertation in Barbados in 2013, I had already heard doubts from people that women would admit to experiencing postpartum depression or the 'baby blues'[2] out loud, much less agree to be interviewed about it for a research project. I was told that having these conditions and speaking about them went against everything women are expected to be after giving birth which is happy and feeling an immediate bond with her child. Reflecting on both narratives now, I realize they share an underlying theme, which is stigma. The senior health official in Jamaica (likely unknowingly) reinforced a particular kind of stigma that renders Black women's experiences with mental illness invisible as our physical strength, emotional fortitude or close family ties are seen as being a kind of armour that prevents us from experiencing deep emotional distress, sadness, and even depression (Schreiber, Stern and Wilson 2000; Etowa et al. 2007; Jackson and Naidoo 2012). Some of the people I spoke to about my PhD research ambitions in Barbados believed that social and cultural stigma about mental illness would prevent women from participating in my qualitative study. The issue of stigma followed me from Jamaica to Barbados, making me call into question the potential impact of my dissertation project even when I found research evidence that indicated Caribbean women show higher rates of conditions like postpartum depression and the 'baby blues' in comparison to rates amongst women living

in North America and Europe (see Davidson 1972; Palmer 1996; Wissart, Parshad and Kulkarni 2005; Galler et al. 1999; Jackson-Best 2016a).

Of course, the women who experienced postpartum depression and/or the 'baby blues' and participated in my dissertation project did describe experiences with stigma during the research interviews. Several women discussed how mental illness stigma prevented them from going to the local psychiatric hospital, colloquially called "The Mental", to be administered medication (Jackson-Best 2013). Women were also critical of stigmatizing beliefs about mental illness that were transmitted by their religious leaders, including one participant whose pastor encouraged her to substitute medication with prayer (Jackson-Best 2016b). And they were also vocal about establishing destigmatizing interventions such as support groups comprised of women who were currently experiencing or had previously experienced postpartum depression or the 'baby blues' (Jackson-Best 2016b).

Encouraged by these findings and spurred by lingering questions about stigma raised in my dissertation project, I initiated a global health-focused systematic review of systematic reviews on stigma across HIV/AIDS, mental illness, and physical disability during my postdoctoral fellowship which began in 2015. Systematic reviews are a research approach that require the identification, appraisal, and synthesis of high quality data related to a specific research question (Jirojwong, Johnson and Welch 2013). Focusing my review on other systematic reviews of stigma allowed me to glean a better understanding of the scope and landscape of stigma research across the three health conditions on a global scale.

I also extracted data about intersectionality from the systematic review studies to ascertain how stigma research has incorporated this concept into its approach or analysis, and to learn if there were any reviews of stigma that used the concept to analyze primary studies of stigma conducted with Black women and Caribbean women, respectively. Admittedly, I was also interested in

intersectionality in my systematic review because it has become a buzzword across academic and social spheres, and its uptake has drawn both praise and critique. My work has engaged with intersectionality by first acknowledging that the concept is about power, and this facilitates better understandings about how co-occurring social identities like race, gender, and sexuality are intrinsically connected to and mediated by dynamics of power which deeply impact Black women's lives (Crenshaw 1989).[3] In my systematic review of stigma, extracting data about intersectionality also led to an important finding: while there was some research on Black women and HIV stigma in the United States which used intersectionality frameworks (see Loutfy et al. 2015; Darlington 2017), there was none about Caribbean women specifically. Also, research on mental illness stigma and physical disability stigma that focused on Caribbean women of any racial or ethnic background was less common across the body of work.

These findings were particularly surprising because of the extensive work that has been done and is being produced in the Caribbean and the Diaspora on topics that centre Caribbean women, privilege their experiences, and amplify their voices (see Massiah 1986; Mohammed and Perkins 1999; Rowley 2002; Hosein and Outar 2012; Crawford 2012; Haynes 2016). However, my review showed that systematic reviews focused on Caribbean women and mental illness stigma and/or physical disability stigma was less likely to be included in the retrievals. Some primary studies that informed the systematic reviews included in my review as well as some of the Caribbean-focused research that informed my dissertation provide context for this assertion. For example, little acknowledgment is given to the phenomenon of stigma or its effect on women who experience maternal depression in research dating back to the 1970's which explored conditions like postpartum depression and the "blues" amongst women in Jamaica (Davidson 1972), and in more recent studies on the incidence and prevalence of these conditions in Barbados and Jamaica (see Wissart et al. 2005; Palmer 1996; Galler et al. 1999; Jackson-Best 2016a). In fact, none of the Caribbean-based research that informed my doctoral research discussed, analysed, or even mentioned the term stigma[4] [5]. In my systematic review, across 60 reviews of mental illness stigma which included thousands of

primary studies from all over the world, only one review focused on the Caribbean and included primary research from the region alongside studies from Latin American nations (see Mascayano et al. 2016). The primary studies in that review included a study on internalized stigma from Jamaica (Gibson et al. 2008), and a study on deinstitutionalization in Jamaica (Hickling, Robertson-Hickling and Paisley 2011). While both primary studies included Jamaican women in their samples, each explored social and public stigma in the country more generally as opposed to mental illness stigma enacted or experienced by women specifically. The reviews on physical disability stigma were significantly less in number (three) in comparison to the work on HIV/AIDS and mental illness stigma, and just one had primary studies that included women in Haiti and the Dominican Republic who experienced physical disability related to lymphatic filariasis (Zeldenryk et al. (2011). This highlights a gap in the literature, and this gap begs the question: where is the research on mental illness stigma and physical disability stigma that is for and about Caribbean women?

It is apt to pose this question in a journal that is focused on gender, disability, mental health and disablement in Caribbean and Diasporic contexts. A core ambition of this project has been to amplify the voices of individuals and groups that have been historically silenced and centre them in discussions about these conditions. Importantly, this work is made possible by conversations on these topics that have taken place previously and are currently being had in activist, academic, and non-academic spaces. Works like Michelle Rowley's (2003) which points to the simultaneous lack of attention to emotional and mental health needs of poor Caribbean women, and hyper-focus on economic indicators by the Trinidadian state. Research like Dawn Edge's (2008) in the UK which focuses on Black Caribbean-descent women's experiences with postpartum depression as they overlap with cultural beliefs about Black womanhood and their inherent strength. Academic-community collaborations like the Livity Project initiated by the Institute for Gender and Development Studies: Nita Barrow Unit which seeks to address stigma and marginalization experienced by people living with disabilities, LGBTQ groups, women, girls, youth, and seniors in the Eastern Caribbean (*The Livity Project Launched,* 2018).

Community-generated data collected through an interactive mental health workshop at the annual Caribbean Women and Sexual Diversity Conference (CWSDC), and which is centred on exploring how LGBTQIA communities experience challenges like stigma and use coping mechanisms to deal with them across the English, French, Spanish, and Dutch-speaking islands (*We are LBTQIA*, 2018). And of course, the discourse produced every day through Caribbean music, talk, and gossip that people engage in have also made this journal possible because the shifts that we have been experiencing in the region and in communities in the Diaspora reflect a growing international shift towards acknowledging and addressing disability, mental health, and mental illness in our communities (Jackson-Best and Edwards 2018). The work in this journal contributes to knowledge-building and generates information that can be used by people to inform their activism, teaching, policy-making, and research. It is also firmly grounded in the scholarship and work of previous Caribbean scholars.

It must also be reiterated that the research gaps described in this commentary paper should concern us all, regardless of gender, geographic, class, racial, and ethnic differences. It is imperative that we work to fill them with high quality data that is informed by and conducted in collaboration with communities and groups of women in the Caribbean and Diaspora. This could take the form of a regional Caribbean mental health stigma project focused on women, and more research and work generated about women's experiences with physical disability to continue building this field of data. Regardless of the forms and methods of knowledge production we engage in we must remember that in order to see a change in the existing data on physical disability stigma and mental illness stigma, and more diverse retrievals in systematic reviews then Caribbean researchers, activists, and academics must be at the forefront of this work and drive it towards being better reflective of the people it is focused on, and of the pressing issues affecting Caribbean women.

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[1] Postpartum depression is a major form of depression which may share similar characteristics of other depression, and typically occurs 4-6 weeks after birth and can last for weeks, months, and even years (O'Hara 1987; Cole 2009). Symptoms of the condition may include "sleep disturbance, poor functioning, thoughts of self-harm or harming one's child, low mood, and anxiety (Halbreich and Karkun 2006; Fritz and McGregor 2013).

[2] The 'baby blues' is a mild affective syndrome common among women after childbirth whose symptoms include despondency, irritability, difficulty bonding with one's baby, mood swings, crying, and feelings of isolation which can last up to 10 days (O'Hara 1987; Cole 2009; Halbreich and Karkun 2006; Rondon 2003).

[3] Kimberlee Crenshaw (1989) coined the term Intersectionality, but it builds on a long history of Black activist women and Black feminists who have theorized about the multiple forms of oppression we experience due to our overlapping identities and which inherently shape our relationships with structures like healthcare, housing, and the law (Truth 1995; Cooper 1995; Terrell 1995; Combahee 1995; Hill-Collins 2000).

[4] Stigma was not a term commonly used in research published before 2006 (Jackson-Best and Edwards 2018), so in addition to doing a keyword search using the term "stigma" in Caribbean-based research on maternal depression, I also included alternative terms such as "stereotyping", "discrimination", and "prejudice". The same results were received.

[5] Some of the work on postpartum depression amongst Caribbean-descent women living in the Diaspora explored stigma and found that it was a barrier for help-seeking amongst Black Caribbean women (Edge 2008).

http://sta.uwi.edu/crgs/index.asp