Atlantis
Critical Studies in Gender, Culture, and Social Justice

Self-Evolution by Jessica Jerome

Issue 47.1 (2026)

"Healing is an Act of Communion": Critical Perspectives on Women's Health, Wellness, and Disease

Self-Evolution: Artist Statement

by Jessica Jerome

My paintings have always come to me in the form of dreams, images that appear to me in times of transition in my life. I painted some of my best work during times of change. As a two-spirited woman, a wife and mother, throughout this journey of coming into my own skin, art has always been healing. Releasing emotions into a painting, so that I am not carrying those anymore, is a part of the healing process. This portrait of a two-spirited woman highlights resilience, evolution, and spiritual connection between self and culture. Who I have become today is written all over her skin, carrying her culture and teachings forward, through movement and color.

Symbolic Mi'kmaw petroglyphs are displayed on the woman's skin, a message of the woman she has become. The Mi'kmaw symbols on her shoulders are a traditional L'nu hieroglyph representing "Spirit" in its plural form, which is why the two symbols are together. Sweetgrass presented in this portrait is giving strength and healing through challenges; it was one of the first medicines given to the Mi'kmaq people. Covering one eye gives strength to the other. I also wanted to showcase this painting because it is important to have more diverse representation of Mi'kmaq people, including those who are fair-skinned and have lighter eyes and hair: we are all different. I want this piece to speak to all those who don't feel that they are seen because of the colour of their skin and eyes.

Two-spirited people are knowledge keepers, artists who play a significant role in each community. Blessed by the creator, these beautiful people are cherished by the community. The teachings passed down to me, with knowledge and experience, I now pass along to my sons and to all those who want to learn more about our culture.

Jessica Jerome: Artist Profile

Background and Heritage

Jessica Jerome (Two-Spirited) is Mi'kmaq, originating from the district of Gespegewagi. She was born in Listuguj Mi'gmaq First Nation and was later adopted by the Jerome family in Gesgapegiag. Jessica is a member of the Micmacs of Gesgapegiag Band, which is situated along the banks of the Gaspé Peninsula in Quebec. Jessica moved to Nova Scotia and married to her wife Diane. Together, they are raising two wonderful sons, Elijah and Colin.

Artistic Inspiration and Family Influence

Jessica's biological mother, Linda Barnaby, was a hobbyist artist who primarily used simple tools such as a pencil or a homemade wood-burning pen to create her works. Linda even designed the logo for Listuguj Haven House using these basic materials. Her mother's creative approach and dedication to art inspired Jessica to pursue her own artistic journey. Unfortunately, just three years after reconnecting, Linda passed away from cervical cancer.

Art as Healing

To help Jessica cope with the loss of her mother, her father enrolled her in an oil painting course. This creative outlet became a vital tool for healing, bolstering Jessica's resilienc and supporting her mental health.

Artistic Development and Mediums

Jessica began her artistic practice by learning to paint landscapes. Over time, her work evolved to incorporate traditional Indigenous imagery, which she interprets through her own contemporary perspective. Today, Jessica creates in a variety of mediums, including oils, printmaking, wood burning, beadwork design, and digital art.

Education and Professional Training

Jessica's professional art education includes studies at the New Brunswick College of Craft and Design, where she earned a Certificate in Foundation of Visual Arts. She furthered her education with a Certificate in Applied Media and Communication Arts and obtained a Graphic Design Diploma from the Waterfront Campus of Nova Scotia Community College.

Exhibitions and Artistic Contributions

Jessica's artwork has been exhibited in several galleries and juried shows across Quebec, New Brunswick, and Nova Scotia. Her pieces are part of permanent displays at the Cancer Centre in Kingston, Ontario, as well as in her home community. She has also contributed graphics and logo design work for Mi'kmaq communities throughout Quebec, New Brunswick, and Nova Scotia, supporting First Nation community and economic development initiatives.

Illustration and Collaborative Projects

Jessica is the illustrator of two Mi'kmaw children's books, "Sweetgrass" and "The Creator's Plan." She has also collaborated with Brandon Mitchell on the Turtle Island educational book series, which focuses on teaching children.

Education, Mentorship, and Community Engagement

Jessica's career as a designer has expanded to include consultation work in education and culture. She o[ers workshops on Mi'kmaw culture, working with participants aged eight and older, and leads teaching sessions on art and cultural topics. Recently, she has mentored Indigenous youth in creating a mural at Mount Saint Vincent University, with Two Eyed Seeing Program, with the support of The Natural Sciences and Engineering Research Council of Canada (NSERC) PromoScience.

Ongoing Education and Future Goals

Jessica is currently completing her degree in Adult Education at the University of New Brunswick, driven by her strong commitment to working with Indigenous students. Artwork can be seen on Facebook Fanpage Jessica Jerome Artwork, also she can be reached by message or email Ruhkah@hotmail.com Website https://ruhkah-designs.odoo.com/about-me

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Special Issue: "Healing is an Act of Communion": Critical Perspectives on Women's Health, Wellness, and Disease
Editorial

"Healing is an Act of Communion": Critical Perspectives on Women's Health, Wellness, and Disease

Co-written by the editorial committee and cover artist: Shannan Grant, Barbara Hamilton-Hinch, Irene Ogada, Dayna Lee-Baggley, Tara Pride, Clare Goulet, Maggie MacIntyre, Tammy Bernasky, and Jessica Jerome

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Atlantis Journal was established in 1975. While it was founded at Acadia University, it became a publication of Mount Saint Vincent University (MSVU) in 1980. A publication aimed at supporting critical studies in gender, culture, and social justice, named for the lost city of Atlantis, and based at a university known for its strong history of advancing women's education and commitment to social responsibility, *Atlantis* was the obvious home for this project and associated special edition. The editorial committee was confident that this journal, and the people who make it possible, would help us co-create a space in which the editors, authors, reviewers, and readers could co-learn, heal, and grow together.

"Healing is an act of communion" is a quote by bell hooks that motivates reflection on healing as a profound connection with ourselves, each other, and the natural world.

Healing is often understood as returning to a prior state, health, or peace, or engaging in therapy or treatment that can be self-facilitated and/or facilitated by others. In agreement with this perspective, western and complementary medical practices are often used to heal or treat diseases. This model of treatment is often described as evidence-based and patient-focused (or person-focused) and is grounded in systems biology. However, women's and gender-inclusive health research and practices remain limited and underfunded, while existing approaches are often homogeneous, focusing more on medical interventions, methods, and outcomes that are frequently *done to* women rather than *with* women. While current research and practices are beginning to address these gaps, much work remains. The patriarchy and its manifestations remain strong and, on the counter-offensive, ranging from overt political action to subtle cultural and social and, on the counter-offensive, or reasserting traditional gender hierarchies (e.g., shaming, stigmatization, gaslighting of women public figures, violence against women, algorithmic bias—relevant with growing application of Artificial Intelligence or AI).

This special edition and collaboration are a peaceful stand and an act of communion. We view this special addition as a beacon and an invitation to engage in counterculture and in collective healing. With this piece, we wish to counter dominant norms in academic publishing, which serve to privilege the voices of a dominant few, and challenge people to broaden their perspectives on evidence in health and wellness. Admitting bias (every human being has bias), we think this edition is special for several reasons, including the art, research, and narrative that make it up. But, the real "special sauce," if you will, is the people who made this happen, those who are actively addressing the gaps, individually and collectively.

For instance, the *Atlantis* team supported us in our efforts to make space for participatory action and engagement with authors, reviewers, and community, from the beginning of the process to its completion and beyond. This manifested in several ways, including a recent invitation we received to speak about this edition at the 50th anniversary celebration and conference of "Atlantis: Revolution and Resurgence: Celebrating Feminist Publishing Registration." Other forms of participatory action included, for example, allowing flexibility for authors, in terms of timelines. Many of our contributors are caretakers and/or parents, work multiple jobs, engage in community, and/or participated in work strikes during edition preparation. For women, our work is never purely academic and many people benefit from our labour. We believe that in relation to academic work and collective action/protest, a dichotomy of and/or is not appropriate and does not warrant academic penalization.

To challenge traditional colonial and patriarchal publishing models, we took a co-learning approach to publication. For instance, an editorial group, composed of nine women, representing several perspectives, professions, fields of study, and experiences, created a review group composed of 20 women from across Canada (Cape Breton to British Columbia). We provided authors with feedback and mentorship and an opportunity to resubmit, as desired and needed. The publication process was a discussion, rather than a transaction. The literature identifies several overlapping structures that define the patriarchal system, which manifests differently across cultures and times. One we are particularly interested in is information management (e.g., flow, vetting, capture, sharing, and storage). Great care was taken by the reviewers and editors to not edit the authors' voices away.

For this edition, we invited interdisciplinary and intersectional feminist analyses that consider race, ethnicity, gender, sexuality, disability, socioeconomic status, and/or other dimensions of identity and social justice. Our goal was to foster a vibrant dialogue that reflects the range and diversity of experiences, welcoming holistic approaches to health and healing. The collective works represented in this edition span several topics and geographies, ranging from Nepal, to India, Thailand, to Canada, from public health policies, perspectives on aging, body size, health care accessibility, birth practices, mothering, vaccination, and grief. They represent original research, commentaries, reflections, literary work, and graphic art.

"Healing as an act of communion" acknowledges that, as humans, we rarely heal alone but through connection, community, and sharing, finding wholeness through relationships, shared experiences, and mutual care, whether it's spiritual communion or communal support in friendship and social justice movements. It emphasizes interdependence, where we support others' healing and receive support in return, recognizing liberation and wellness not as isolation but as belonging to one another. The call for submissions for this special edition spoke to those who submitted, identifying a commonality among us all. Even if we did not first see the alignment with the call, we explored each submission with an open mind, and authentic curiosity. We grew forward together, collectively, co-creating this edition, and are hopeful that this work resonates with the reader, and larger community, and ultimately that subsequent special editions focused on women's health and wellness will grow out of this. We hope that it will bring editors, gatekeepers of knowledge, to examine their practices for exclusionary habits, processes, and bias, and change them. To engage in best practice, to address "isms" and to decolonize our systems, we need to work together to ensure everyone is at the table.

Thank you for reading.

Acknowledgements

The special edition editors would like to thank the authors, reviewers, participants, and muses for this special edition. Special thanks to Katherine Barett, Managing Editor of *Atlantis*, and Tegan Journal Editor of *Atlantis*, and three brilliant scholars and advocates who contributed to the idea/seed that became/grew into this special issue, Maki Motapanyane, Jacqueline Gahagan, and Marnina Gonick.

Special Issue Co-Editors

Shannan Grant is an adjunct professor in the Department of Women's Studies at Mount Saint Vincent University and in Dalhousie University's Faculty of Medicine, Department of Obstetrics and Gynecology. She is especially proud of her work with The Alexa McDonough Institute for Women, Gender and Social Justice, and *Atlantis: Critical Studies in Gender, Culture & Social Justice*. She is also an affiliate scientist at IWK, Department of Obstetrics and Gynecology, where she continues to engage in practice-based research, and education.

Barbara-Ann Hamilton-Hinch, is a Professor in the School of Health and Human Performance at Dalhousie University in the faculty of Health and the Assistant Vice-Provost Equity and Inclusion. Her research exams the structural, institutional, and systemic racism and oppression that exists for populations that have been marginalized but particularly people of African descent. Her work looks closely at the social determinants of health and crosses all disciplines from education to health to justice. Barb identifies as an 8th generation African Nova Scotian and is the first African Nova Scotian to graduate with a PhD from Dalhousie University.

Irene Ogada is an educator and researcher in women and children's health and nutrition. She is committed to community-led inquiry, action, and transformation. Applying intersectionality and socio-ecological lenses she collaborates to co-facilitate participatory platforms for women and children in equity-seeking communities to articulate their health and nutrition experiences and needs; co-facilitate collaborative health and nutrition actions that foster sustainable and equitable communities; contribute to development of culturally safe resources and processes in health and nutrition programs for women and children; and enhance the capacity of future researchers/mentees to contribute to sustainable and equitable communities.

Dayna Lee-Baggley is a Registered Clinical Psychologist in British Columbia, Alberta, Ontario and Nova Scotia. Her registrations include clinical psychology, health psychology, and organizational psychology. She is the founder and CEO of Dr. Lee-Baggley and Associates, which provides evidence-based workplace wellness solutions. She is the creator of the "Dr. Dayna Method" which is a science backed system to equip leaders with people leadership skills and to equip employees with skills to flourish. She also conducts research at Dalhousie University and at Saint Mary's University. She is the author of the book *Healthy Habits Suck: How to get off the couch & live a healthy life…even if you don't want to*.

Tara Pride is of mixed Mi'kmaw and settler ancestry and member of Sipekne'katik First Nation in Mi'kma'ki. She is an Assistant Professor in the School of Occupational Therapy at Dalhousie University where her research focuses on Indigenous health and wellbeing, Indigenous mentorship, Indigenous community engaged and driven research, and advancing Indigenous excellence in occupational therapy.

Clare Goulet lives in Halifax/Kjipuktuk, Nova Scotia, where she teaches and publishes creative, scholarly, and hybrid forms of writing and interdisciplinary research and directs the Writing Centre at MSVU. Her book *Graphis scripta: writing lichen* was shortlisted for the J. M. Abraham Atlantic Poetry Award and the Raymond Souster Award; she co-edited *Lyric Ecology,* essays on the work of Jan Zwicky. *Future Past Tense* is out late 2026.

Maggie MacIntyre is a writer, editor and visual artist with decades of lived experience navigating healthcare and other systems in pursuit of support for chronic and acute conditions of the menstrual body.

Tammy Bernasky is an Assistant Professor of Political Science at Cape Breton University and teaches in areas of public policy, gender and women studies, and stigma. She has life-long experience of disability and more than 25 years of experience working on disability inclusion efforts at local, national, and international levels. Using an intersectional lens, she centres the stories of diverse people with disabilities in her research. In 2022, she published the book *Working to End Gender-Based Violence in the Disability Community: International Perspectives*.

Jessica Jerome (Two-Spirited) is Mi'kmaq, originating from the district of Gespegewagi. She was born in Listuguj Mi'gmaq First Nation and was later adopted by the Jerome family in Gesgapegiag. Jessica is a member of the Micmacs of Gesgapegiag Band, which is situated along the banks of the Gaspé Peninsula in Quebec. Jessica's professional art education includes studies at the New Brunswick College of Craft and Design, where she earned a Certificate in Foundation of Visual Arts. She furthered her education with a Certificate in Applied Media and Communication Arts and obtained a Graphic Design Diploma from the Waterfront Campus of Nova Scotia Community College. Jessica's artwork has been exhibited in several galleries and juried shows across Quebec, New Brunswick, and Nova Scotia. Her pieces are part of permanent displays at the Cancer Centre in Kingston, Ontario, as well as in her home community. She has also contributed graphics and logo design work for Mi'kmaq communities throughout Quebec, New Brunswick, and Nova Scotia, supporting First Nation community and economic development initiatives.

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Literary

The Canvas Remembers: Spirit and Skin

by Jessica Jerome

The brushes sat idle, the colors ran dry,
As seasons of projects kept hurrying by.
All my light was poured into pixels and the screen,
Leaving little for spaces where *self* once had been.
A friend whispered when darkness was stark:
"Make room for the flame. Find time for the spark."
A dream once awakened in two-thousand-four,
When I first let the shadows slip out through the door.
A two-spirited woman, a mother, a wife,
I paint transitions that flow through my life.
Releasing these feelings is how I stay whole,
Moving weight from my heart to the depth of the scroll.
Now Mi'kmaw petroglyphs bloom bright on my skin,
A message of who I have grown from within.
Two-Spirited symbols rest firm on each shoulder.
Growing in power as the years make me older.
With one eye covered to strengthen the other,
I paint as a keeper, a daughter, a mother.
Sweetgrass is present to heal and to hold,
A medicine gift from the stories of old.
Through paint, I show kin in their beautiful span,
The light in the eyes and the fairness of the skin.
So all our people feel seen in the light,
Through movement of colour that breaks through the night.
Blessed by Creator, I carry the flame,
Passing down teachings and honouring a name.
I give to my sons what was gifted to me /
The art of a journey, the soul set free.

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Mother, Mutter, Matter

by Nancy Kang

A circle of smeared butter melts a fading smile on a hot pan
when we ate her sweet rice pancakes studded with raisins,
dusted with cinnamon like a spray of perfume or a sloppy subway sneeze.
Cold rice, clumped like prayers, made our lunches stick to the bones.
Mingling rough laughter and small fears on a savage tender tongue
she tasted the tasks she scraped out of each day like melon rinds
or cataracts grown over eyes that turned away from sirens, street fights,
and pricey organic berries in stiff paper bags that looked so good she cried.
So tired, the bottoms fell out of words some days, most dinners felt like
chewing newspaper, the bed an antiseptic tank in which floated
her body, serenely tethered to those butterfly blue pills the doctor
said would "lift her spirits" like cellophane crackling between skilled hands
when a gift is wrapped and tied in a taut, taught bow. Her limbs
would kick out suddenly like octopus tendrils in the night, oozing black ink
like the signatures she made on all our forms, permissions, detention slips,
forgeries, admissions trips, and the wondrous arabesques of small power
and willful presence she never knew she had in her hands or the
woodpecker red head she carried high even though it was us who bought
the wrong color to cover her greys and whites and dim flakes of passing seasons.

Nancy Kang teaches at the University of Manitoba where she is Associate Professor of Women's and Gender Studies and Canada Research Chair in Transnational Feminisms and Gender-Based Violence. Her books include *The Once and Future Muse: The Poetry and Poetics of Rhina P. Espaillat* (University of Pittsburgh Press 2018), co-authored with Silvio Torres-Saillant, and *Problematic Paradigms and the Contours of US Latinidad* (Univeristy of Texas Press 2026), co-edited with Michael N. Garcia.

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Impairments in Proprioception/ Stillness in Motion

by Jessica Oler

Eyes closed equate to misbalances, movements I cannot control.
Falling.
A feeling from the interior.
Like a cylinder rotating in a circle as it rolls up my body from the inside.
Off-putting.
Like a bunch of strangeness.
Like an unknown, uncontrollable aliveness inside of me.
Like my ancestors who have come and gone before me.
Forced movement.
My body sways, becomes ruckus, unsettled.
Pulls and leans to seemingly find a safe center.

Impairments in Proprioception/Stillness in Motion, photographic collage by author, 2025

Jessica Oler is a visual artist, writer, poet, and scholar from Northern California. She is currently a third year PhD student in the Gender Studies Program at Queen's University in Kingston, Ontario. Her photography, photographic collage, poetry, autoethnographic writing, and painting explore themes of meaning-making, memory, and abstraction as method. Oler's personhood and artistic practice continues to be grounded in transgressive Black feminist thought. Her work has been shown at California College of the Arts; Lewis-Clark State College Center for Arts and History; Chautauqua, Rochester, and Brooklyn, New York; Philadelphia, Pennsylvania; Miami, Florida; Lawrenceville and Atlanta, Georgia; Alameda, Oakland, and San Francisco, California; and Alexandria, New South Wales, Australia.

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Sari not Sorry

by Rohini Bannerjee

I remember the first time I draped one. It had a teal blue hue to it and a wide border. I was slimmer then, just having celebrated the beginning of my Chapter 19. There was a wedding in our small community, and I was tired of wearing the same overly beaded '90s-inspired kurta and pajama bottoms that the White girls in high school called "MC Hammer pants." The extra material did make me feel dowdy, my thick waist expanding as the folds of material were bulky around my midsection. I wanted to wear a sari.

"I think you are old enough now. This will make you officially a woman." Mom squeezed the body fat under my armpit, eyeing which sari blouse from her collection would fit my chest.

"Your breasts are separated, like your father's mother. No actual cleavage. So strange," she added.

We Christian Punjabis here in Halifax are a siloed group within the South Asian diaspora. Without a gurdwara, a mandir, or a masjid to meet, weddings were often where we found fellowship. And where the Aunties found an opportunity to gawk and comment on the next generation of young girls.

The blouse fit. And so, we began to drape.

Mom was pulling and tugging, her long nails scratching my navel as she tucked my pleats, her sapphire ring digging into the flesh of my hips.

"There is just not enough material here for you," she sighed, tucking strategically to cover my exposed midsection. "These saris look better on more slender girls." My chest pinched, as it had the previous night at the pre-wedding mehndi celebration when Lila Auntie remarked on my wide shoulders.

"For our type of women, we need more than the average six yards," Mom muttered with three safety pins in her mouth. I could see beads of sweat on her forehead and her freshly-out-of-the-drugstore boxed hair colour was a couple of shades too dark for her copper skin.

"Ouch. Please Mom, maybe I'll just pin it." My voice shaking a little with apprehension, I couldn't believe my own audacity. Fueled with this newfound confidence, I squinted into the mirror guessing how much material to pull so that the paloo of my sari would land softly but firmly on my shoulder. I gestured to Mom to let me take a safety pin out from her mouth. Instead, she took out all three and closed her fist.

"You need many pins, bacha. Once we start dancing at the wedding, this will unravel. Remember that James Bond film *Octopussy*? Let me do it." Grabbing my bra strap through my blouse, Mom pinned the border of my paloo onto my shoulder. I closed my eyes as I could feel the cold metal of the safety pin on my skin. She placed a second one for good luck, she said.

"Don't move or I'll prick you." I held my breath. Done.

Shifting the fabric so both my breasts were completely covered, the pleats on the bottom were simultaneously yanked and smoothed. I could hear murmurings from my mother of how the back of my sari was riding too high. Standing as still as possible, I felt like a marionette having her strings adjusted for a debut performance.

Beside each other, shoulder to shoulder, Mom looked at me through the mirror, realizing this was the best she could do, and softly whispered, "Go, go show your father."

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#sarinotsorry, I saw you Dr. David

I was just a kid, circa 1980, walking near the Children's hospital

I saw you, Doc Sahib

tall torso heavy hips, a salaam alekum

thin sari wrapping each curve of you

Your crisp white lab coat, stethoscope albatross sun shining

I saw you, Dr. David

I saw hope

I saw me

/

I remember getting out of my vehicle in the bitter cold of late January, thick boots on my feet, my oversized winter coat barely closing, relying on a zipper that had clearly given up two winters ago. I placed my feet out the door and gently held up my sari pleats from the wet snow. Never let your sari drag on the ground, I could hear my mother whispering in my head. I sausage-walked into the side door of my building, hoping the elevator wouldn't take long. As much as I liked wearing a sari out and about, I didn't like how it drew attention from nearly everyone on campus. But something in me was determined to normalize wearing saris to work.

"Is there some kind of event today Rohini?"

"Oh, that's pretty. You look nice. A bit fancy though. And kind of too much for class, isn't it?"

"So, you are Hindu then. But didn't you go to Catholic school? And isn't your husband Muslim? Are the saris cultural or religious? Maybe just a blazer and skirt would be better?"

I dropped my bags in my office and found my heels, the ringing of the comments from the White staff and faculty still persistent in my ear. Most of my empty answers to their judgements resulted in nervous laughter or shrugged shoulders. Decolonizing my profession meant showing up to class outside of a Western dress code. However, what about decolonizing my own mindset? Why did I have this sudden urge to explain my choice of clothing? I did no such thing when I wore a pencil skirt and a blouse. Well, except if the blouse had a paisley print and was a bright orange. Then I was told by White women that I was so courageous to wear colour and all those exotic prints which they wouldn't dare to wear.

I didn't have the capacity to simply say to all fashion police officers around me that I just wanted to feel and look pretty, and saris made me feel this way. These saris were so patient too, waiting in my closet to be selected. They came out at Christmas or Easter dinner but often felt neglected against my A-line skirts and blazer collection which were my usual university teaching attire.

I slipped into my Sacha London black pumps and noticed that the sari pleats were now uneven. The change in height from winter boots to heels altered how the sari fell. The back of my sari was not dragging but instead it was riding too high, and the blue petticoat underneath was peeking through the border. I took a long breath and tugged and tucked. I looked at my watch, and I had to get to class in ten minutes.

Shoulders back, remember Rohini, you are your Ancestors.

I stopped in the washroom near the classroom where I was teaching that morning's second-year French grammar class. I intended to use the toilet, but I knew that if I rustled the pleats, there was the likelihood I would bugger it all up. I checked my hair and walked out.

Maybe wearing saris to teach is not a good idea, I mumbled to myself. And then I walked into class, and I saw my students smiling.

"Alors, ça va tout le monde?"

I walked around the classroom, asking the students to sign the attendance sheet, my paloo sometimes brushing up against a chair or table, the sounds of the embroidered border muffling my negative thoughts.

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#sarinotsorry, I saw you Dr. Devi.

I was an untenured professor, circa 2008, in Louvain-la-Neuve, Belgium

I saw you, Dr. Devi

tresses tucked behind the ear, crimson lips aglow, ki manière

cotton sari, an everyday, I just found this and thew it on, kind of look

Refreshing, really.

I held your novel in my hand; I wrote a paper on it and was about to speak

and then

I saw you, Dr. Devi

and you gave me permission to wear a sari too

And so, I did

/

Going to coffee shops to answer emails, meet up with colleagues or friends, or simply to find a quite space to be, has been a regular practice for me. The week Vice-President Kamala Harris was sworn into office I consequently swore to myself, and to my small Instagram following, that I would wear a sari every day for seven days. Seeing someone with the same name as my own auntie, someone who had roots in South Asia but also was born on Turtle Island, someone who had Brown skin like me, that had a special zing to it.

I showed up at my favourite café a couple of days in a row. I wore an orange daywear sari, as my mother would call it. It was light, nothing too shiny or bright, a bit more on the plain side, no design or beadwork. The second day I planned a phulkari lime green cotton sari I had bought in Mumbai. On day three of my Kamala Sari Week, I chose a jewel-toned teal silk sari. I walked into the café and ordered my usual. The baristas have known me since my children were little and always expect me to order the Americano and so I did. As I walked with my filled mug to a small table, another patron approached me.

“I have to say this. You look stunning.” Her left hand held her latte, the other a pen.

“I’m from the UK and am visiting Halifax. I have been coming in every day, and I look for you. I look to see if you will wear a sari and what colour you will go for, and I’m like, she did it again.”

I scanned her face to see if I could discern her ethnicity. I desperately wanted her to be Brown. I wanted her kind words to feel real, less like the dominant culture pointing out my otherness. Her amandine eyes and high cheekbones led me to believe she had South Asian roots. Her hair was lush and as she approached, I could perceive the scent of incense from her.

“That’s kind, thank you.” My voice was trembling. I didn’t know why.

“In London, it’s normal to see women wearing saris but here not so much. You remind me of my aunt when she was younger. She would just wear saris on the Tube, back in the ’70s, and not give a shit. I feel like you are kind of the same.” She looked me in the eyes, barely blinking, like she had rehearsed this soliloquy.

“Thank you.”

I wanted to say more. I wanted to thank her for taking the time to come over to me and share her heart. I instead was processing the compliment, the observation, the connection, the beauty of the moment. I brought my gaze down to my feet as she walked away. She turned and added, “Keep it up. You’re making a difference. I know you don’t know it, but people are looking at you, and in a good way, if that makes sense.”

She walked back to her table where a tall, slender White man waited for her; he was busy picking at a cinnamon bun with generous icing. I think it was the same one I had contemplated purchasing myself but told myself it would be too much.

Instead of returning to my emails, I got up from my seat, gathered my paloo, the part of the sari I let drape past my shoulders, scanned the room for any other Brown faces, and, seeing none, ordered a cinnamon bun.

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#sarinotsorry, I saw you Madam Ji

I was on my way to France, circa 1995, with a connection at Heathrow

I saw you, Madam Ji

Toes forward as you walked, the pleats of your sari gliding, namaskar

rushing to your gate, handkerchief in your hand

I didn't care that your sari was dragging on the ground and

Neither did you.

maybe your name is Kamala, and you

took the Tube in the '70s and didn't give a shit

I saw you, Madam Ji

Or maybe it's Maharani

/

I remember hearing Ustad Nusrat Fateh Ali Khan playing in the background. His qawwali melody echoing in the apartment, the tabla so fierce. The lighting was set up, and the photo shoot was about to begin.

I had been professionally draped in a thick magenta and gold silk sari. My belly rolls were all covered, and I was embodying the sari; it had molded onto and into and through my body, a fusion of sort. Pins were everywhere but instead of feeling restricted, I felt free. My chest had been deemed ample and inviting under the blouse that was sparkling à la Bollywood red carpet vibes. My eye makeup was sultry, hair unpinned and shiny.

Considering that all my life I had ached to have White skin, blue eyes, and blonde hair, today was a miracle. April 14, 2023, I relished in my caramel Brown skin, my dark, diamond eyes, and rich chocolate hair. I smiled with my backside filling out the sari. I treasured my strong inner thighs touching when I stood. I knew who I was.

"Dr. Rohini, are you ready?" Sara had her camera in hand.

"One second, I have to send a quick photo to my parents."

Ela, who had so patiently draped me, took the photo for me on my cell phone. I sent it to my parents with the caption, "Look what your daughter is up to today."

Mom responded within seconds, "I showed your father. He said you look beautiful. I think you are like a professional model or something. Good job bacha."

Later in the local park, I joined a professional model, twenty years younger than me, and we took shots near rhododendrons and tulips. We moved in sync and in contrast.

"Dr. Rohini you seem so comfortable. Are you sure you haven't done this before?"

"Just in my dreams," I giggled.

We took more shots near the waterfront and by a local art gallery. The wind was in my hair.

My phone was ringing incessantly. I was in the moment, making art, in public, in a sari, in my Brown skin. My brother kept ringing and so did my husband. I finally answered.

"It's your dad. You need to talk to your brother, right now." I trusted his voice.

The ambulance had already loaded Dad when I arrived at my family home. He had a faint heartbeat. An hour later, he did not. I am glad the last image Dad saw of me was in a sari, free and beautiful, making art, because art is whatever reminds you to stay alive, if not in this life, in the next.

/

#sarinotsorry, I will keep seeing you Rohini

I was on my way to myself, circa 2024, my full-length mirror

I saw you, Rohini

Smile full, the lines of your neck lifting your chin with pride, Bonjour

Paloo dancing on your arm

You chose a sleeveless blouse because your arms are

Robust, like your heart.

I saw you, Rohini

And I won't look away anymore

/

Daughter of Indian immigrant Settlers on unceded Mi'kmaki territory, **Rohini Bannerjee** is a scholar, translator and creative writer. Chevalière de l'Ordre de la Pléiade and Full Professor of French, with research focusing on the literatures and cultures of the Francophone Indian Ocean at Saint Mary's University (Halifax), Rohini is published in India, Canada, France and Spain, in both English and French. Her short stories and poetry explore themes of belonging, identity and body image.

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Grief as Communion: Honouring Collective Grief Through a Black Feminist Ethic of Care

by Crystal-Jade Cargill

Author: Crystal-Jade Cargill is a PhD student in the School of Public Health Sciences at the University of Waterloo in Waterloo, Ontario, Canada. Her research seeks to understand the impact of grief, bereavement, and loss on the health and wellbeing of healthcare workers in Long-Term Care Homes (LTCHs).

Introduction

Grief is understood as one's response to loss (Breen et al. 2020; Cadell 2022). In my own experience with grief, I have come to understand it as a deep wave. A tide. We cannot determine or even predict the extent to which our grief will captivate us, flip life on its head, and force us to confront the many unknowns within ourselves and the world around us. While grief is often associated with the death of a human or animal that is in close relationship to us, we will come to face many forms of loss and grief in our lifetime (Frommer 2019). This includes ongoing climate grief, political grief, grief associated with change, and the loss of control (Cadell 2022; Cunsolo and Ellis 2018). Grief is a profound reflection of stories told, words left unsaid, and the uncertainty of what remains. Grief is collective. Yet, the productivity-oriented culture of western society largely disconnects us from the personal and collective embodiments of grief that arise in and through our experiences of bereavement.

When my great-grandmother died, we held a "nine night." This ritual, which brings family and friends together over the course of nine nights through food, shared story, weeping, singing, mourning, and service is of deep sacredness to Jamaican culture. Through this ritual, we hold space for one another to mourn, remember the deceased, and ponder how life continues in their absence. We sat in my grandmother's living room and we mourned, together. However, in western society, grief and cultural grief practices are rarely discussed outside of the home, due to the presence of ongoing silence and denial which continue to pervade the acknowledgement and acceptance of grief and death.

In this article, I begin by providing an overview of grief in western society, outlining the systems of oppression currently utilized to disconnect us from our grief and our ability to heal in communion with others. I then lean into the ongoing medicalization of grief in western society and its implications for navigating and healing grief. I end this piece by situating a Black feminist ethic of care as a portal that unearths new possibilities for grief and bereavement care. I offer no tangible solution but rather an opening towards new ways of knowing, sitting with, and living in our grief.

Grief in Western Society

One's experience with grief is deeply embedded within larger webs of identity, including race, gender, sex, age, (dis)ability, religion, migration, and socioeconomic status (Neimeyer et al. 2014). Further influencing these entanglements are systems of capitalism, neoliberalism, and pathologization that serve as mechanisms of disconnection, both between the mind and body, and between the body and others. The pressure to achieve in order to attain social status reinforces barriers to our wholeness. Thus, we are reduced to our outputs, silenced in our embodied unraveling, and denied the right to exist fully within the broad spectrum of the affective economy (Ahmed 2004; Harris 2009). Further, in western society grief is often contained within the rigid boundaries of time and the pressure to return to normal. Bereaved individuals often feel pressure to "get over" their grief while drawing as little attention to their mourning as possible. The invisibility of grief is also demonstrated by workplace bereavement policies which provide employees with only three days to mourn the loss of a loved one. Bereavement involves identifying, acknowledging, and *sitting with* the emotional and embodied manifestations of loss. With little time and space provided to grieve and mourn, bereaved individuals are unable to fully engage with their collective experiences.

It is impossible to determine the exact timeline for grieving. Historically, staged grief models, including Kubler-Ross's widely regarded "five stages of grief" model, have emphasized that healing, in fact, does follow specific staged processes and encourages traditional healthcare practitioners to guide bereaved individuals through these stages in a specific order. However, Kubler-Ross's and similar models fail to make room for the personal and nuanced intricacies of grief that are often invisible to the naked eye, including intimate memories of the deceased, the journey of making meaning from loss, reconstructing one's identity after loss, and adjusting to the absence of presence post-loss. In fact, staged models are "epistemologically unified as they frame grief within an empiricist postpositivist paradigm. As such, they deny the ontological possibility and importance of other ways of living grief that are present in the stories of bereaved people (Macdonald 2019, 127). Due to the neoliberal and capitalistic culture that dominates western society, communal approaches to care are not prioritized. The pressure to produce has resulted in a resounding silence around death and grief, abruptly disrupting the natural pace and journey of grief and bereavement. This leaves the bereaved malnourished of soul-nourishing bereavement care.

Medicalization of Grief as Hindrance

The medicalization of grief problematizes its natural course and contributes to harmful stigma that reduces grief to a condition requiring medical attention. Undoubtedly, grief causes significant pain, lament, and melancholy. Should the pain of grief persist, one may be encouraged to seek medical attention to address its intensity. The blurred boundary of medicalization in grief care stems from an ongoing history of grief-colonization in which approaches to grief of the Global South become sanitized and publicly discouraged (Jacobsen and Petersen 2019). Grief-colonization is especially salient in the ways that grief is tended to in the Global North where medicalization and pathologization are salient. Those unable to "return to normal" after experiencing grief may be categorized as mentally ill and in need of treatment. However, is grief itself inherently abnormal? One may argue that lament, melancholy, fear, and sorrow are natural and appropriate responses to personal grief as well as responses to the ongoing despair in our world. In thinking through the medicalization of grief and bereavement, I pose this question: How does the pathologization of grief hinder its full and total unravelling? In what ways does it disrupt liberation and rapture (hooks 2001).

Experiences of grief and bereavement have long been dominated by medical discourse. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has included experiences of bereavement as a subset of Major Depressive Disorder since 1980. This has contributed to significant confusion regarding the natural manifestations of grief and loss including sadness, rumination, lament, and acute mental illness (Horwitz 2019). Additional mental health conditions relevant to grief and bereavement are now prevalent in the DSM-5 and International Classification of Diseases (ICD-10), including prolonged grief disorder (PGD). The standard classification for PGD include "(1) identity disruption (2) marked sense of disbelief about the [loss] (3) intense emotional pain (such as anger, bitterness, sorrow) related to the death (4) difficulty with reintegration (5) emotional numbness (6) feeling that life is meaningless (6) intense loneliness" (APA 2022, n.p.). According to both classification tools, the manifestations of PGD must be persistent for 12 or more months. Potential treatment modalities include Cognitive Behavioural Therapy and bereavement support groups (as per the APA 2022). While I agree that enduring unbearable pain related to bereavement warrants support and attention, little acknowledgement is made of the powerful role of communal care and interdependence as supportive mechanisms for bereavement and grief. Within the medicalized realm of grief care, a shift to interdependence and communal care becomes a radical portal towards (re)turning to grief as a sacred practice.

Black Feminist Ethic of Care as Portal to Communal Grief

What truths does grief reveal when it is fully allowed to unravel? Grief serves as a portal guiding us towards a deeper sense of love and care within ourselves and our communities. As bell hooks reminds us, "communities sustain life—not nuclear families, or the 'couple,' and certainly not the rugged individualist. There is no better place to learn the art of loving than in community" (hooks 2001, 129). Black feminist epistemologies, including Black feminist ethic of care, can assist us in understanding the power of embodied relational care for one another. This ethic is grounded in the unique epistemological standpoint of Black women and their experiences of navigating constraint and invisibility (Collins 2000). It differs from other ethics of care epistemologies because it is rooted in the standpoint and shared lived experiences of oppression faced by Black women.

At its core, this ethic is grounded in affective relationality and the power of shared story. As bell hooks and other Black pedagogues describe, love—for ourselves and our communities—is central to a Black feminist ethic of care (Nash 2020). In her essay "Practicing Love," Nash discusses the private/public dichotomy and articulates the role of Black feminist epistemology in making expressions of love a public act. The notion of public feelings "problematizes the boundaries between private and public, and draws intimate connections between the subjective and the social, between the emotional and the political" (Nash 2020, 442). I extend this notion to include public mourning as a radical display of love; which is necessary to engage in collective grief.

Black feminist ethic of care is also demonstrated through the ethics of *ubuntu.* Ubuntu, which refers to humanity towards others, and the notion that "I am because we are," can serve as a tool for understanding the power of collective care as an act of communion. It articulates the integral role of affective and embodied relationships in our collective well-being and honours the position of care as "the symbol for communal relationships representing reciprocal responsibilities" (Gouws and van Zyl 2015). Our ability to grieve in communion with others is a direct result of the permission we receive to become entangled in moral relationships that uphold our need for individual nurturing as integral to nurturing our collective roots. In the context of grief, our relationships, which are "bound into community through relationships of care and obligation" (Gouws and van Zyl 2015, 174) honour our mourning, lament, and anguish, and actively seek ways to carry us through our pain- rather than rendering it invisible.

During the COVID-19 pandemic, the world witnessed millions of deaths due to the vicious virus. Along with this, the world witnessed the death of George Floyd and the ultimate conviction of his murderer, Derek Chauvin, a former Minneapolis police officer. What came after the death of Floyd was a public embodiment of Black feminist ethic of care in a time of insurmountable grief. Black and brown bodies held each other collectively through rallies and protests to mourn not only the loss of George Floyd but the terrifying reminder that Black lives are often undervalued and uncared for in the Global North. This embodied relation speaks to Sara Ahmed's notion about affective economies and the movement of bodies between contexts and social constructs, as well as an ethic of care that is not always spoken about but deeply felt by those who are a similar lived experience. This type of collective mourning does not require explanation, as it is deeply felt daily amongst Black bodies.

Conclusion

Grief in Western society demonstrates an unparalleled ethnology of disconnection. The ongoing use of capitalism, neoliberalism, and medicalization as mechanisms for disconnection and silence have harmful implications for bereaved individuals. Amidst pervading silences around grief, Black feminist care offers a portal to revelation, liberation, and rapture for the bereaved. Through affective and embodied relationships, Black feminist ethic of care, including Ubuntu, offer ways of being in caring relations with others that are grounded in a shared standpoint. Thus, offering collective insight into grief as an act of communion.

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Healing in Unexpected Spaces: A Reflection of the Care Assemblage of My Master's Thesis

by Sarah Costantini

Author: Sarah Costantini is a doctoral candidate at the University of Guelph. She holds a Master of Science from the University of Guelph and an Honours Bachelors of Arts from the University of Toronto. Her research focuses on exploring avenues for care justice and challenging normative ways of approaching care and treatment for those living with and/or healing from eating disorders.

Introduction

In a time where limitations abound, standardized bio-psychiatric models dominate, and harm so often occurs in the eating disorder (ED) treatment system (e.g., Holmes, Mason, and Semlyen 2021; Lester 2019), alternative avenues for healing need to be explored. As an ex-patient and now researcher in the ED field, I have found myself reflecting on my healing journey, troubled by how the space conventionally deemed healing (formalized ED hospital programs) caused harm to me that remains viscerally evident today.

In this reflection, I speak back to the (un)care I experienced during an inpatient ED treatment admission in 2021, illustrating how possibilities of care, supportive of my healing, expanded unexpectedly in the subsequent research space of my master's degree project. I begin by highlighting literature that complicates care in conventional ED treatment and follow with a brief description of care during my thesis. I then bring you to a specific treatment moment to introduce how my master's research resulted in a radical alteration to the care assemblage surrounding my healing. Thinking through care as an assemblage enables attendance to the human and non-human factors and forces—such as treatment guidelines, clinician actions, emotional responses to distress, and physical spaces—which become implicated in care and also enable recognition that altering these connections changes the whole assemblage (Jackson and Mazzei 2013). Healing is a deeply personal experience. Thus, in reflecting on the altered care assemblage surrounding my healing, I provide only a snapshot of how unexpected spaces can facilitate healing journeys, pulling into view the critical need to re-envision the conceptualization of healing spaces and resist the dominant bio-psychiatric focus in ED treatment, which can be deeply limiting, and, at times, harmful.

Care and Eating Disorders

Care, as a concept and practice, has been taken up in relation to EDs in ways that challenge care as inherently good (LaMarre et al. 2023; Lester 2019; Musolino et al. 2016). For example, Lester (2019) depicts how tensions faced by clinicians due to insurance requirements and treatment mandates result in providers adopting strategies to withhold care while construing this as a therapeutic act. Care, here, becomes restricted to those who comply and "willingly" engage in recovery. Exploring care for individuals with EDs deemed "resistant," Musolino et al. (2016) highlight that when practitioners attend to how individuals experience care, they can open possibilities of care, expand relationality, and move beyond bio-psychiatric models.

Despite some acknowledgement of the vast complexity of care in ED treatment (LaMarre and Rice 2021), "good care" in ED treatment remains centred on medical stabilization, nutritional rehabilitation, weight restoration, symptom intervention, and behavioural change (American Psychological Association [APA] 2023). Strategies to achieve these aims typically follow a standardized, problem-focused, time-limited, and adherence-based approach heavily rooted in cognitive-behavioural therapy (CBT), with change measured through biometric data (Geller et al. 2021; Lester 2019). Both service users and clinicians feel the effects. Treatment protocols expect patients to adhere to stringent rules, resulting in a denial or minimization of their specific needs, as their experiences become decontextualized within the treatment space. Clinicians must enforce standardized treatment practices to meet required goals under institutional pressures, regardless of what their training and experience tells them (Costantini 2024). Literature indicates that such institutional pressure drives high rates of clinician turnover and burnout (Accurso et al. 2024).

Exploring the Ruling Relations of Carework

Care took a central role in my thesis. Taking an institutional ethnographic approach, I explored how the carework of clinicians is shaped and coordinated by broader institutional processes of administration, management, professional authority, and cultural discourses—the "ruling relations" (Smith 1987; 2005)—in inpatient, day-patient, and live-in ED treatment programs in Ontario. My work explicates how institutional discourses of care-as-cure and gold standard (evidence-based) treatment come to organize clinicians' carework in moments of treatment non-adherence—when clients struggle to adhere to ED treatment directives (Costantini 2024). As clinicians elaborated on carework, it became apparent that a misfit exists between their desires for collaborative care and institutional pressures to follow increasingly standardized treatment directives, resulting, at times, in informally coercive practices.

Care was also integral to how I engaged in research and self-reflection, becoming more than strictly an orienting concept for data collection and analysis. Brannelly and Barnes's (2023) book *Researching with Care* offered a starting point for embedding care in my research. Drawing on the feminist ethic of care, Brannelly and Barnes (2023), attend to the relationality of the research process, illustrating how research goes beyond technicality of methodology, creating and re-creating relationships to participants, to experience, and to literature. In turn, thinking about why I undertook this research, my relationship to the research topic, and how this differs from the clinician participants, became a starting point for me to centre care in the research process (Brannelly and Barnes 2023).

The Care Assemblage

The Memory

On December 2, 2021, I was barely four hours into an inpatient admission for the eating disorder that had come to consume my life. Both relieved and scared to be there, knowing without major intervention my life was in danger, I was also terrified for the changes to come. Deeply distressed, paralyzed by fear and racing thoughts, I struggled with my first meal, shutting down and refusing to engage. Right after this meal, the psychiatrist, the "expert" in treatment, standing outside my room, said, "You can either eat or go home and die." It slammed into me like a truck, the response visceral, simultaneously increasing my self-hatred, strengthening my desire to give up, and diminishing all hope that I could ever be free of my eating disorder. This moment, when I needed care and kindness, I was starkly dismissed, threatened, hurt, and denied care.

Four years later, this moment remains crystallized in my memory, continuing to evoke a strong reaction. While I recognize how critically I needed treatment to sustain my life at the time, I do not view that time or space as supportive of my healing. As this memory has continued to resurface, it has driven my path into ED scholarship, motivating my desire to explore avenues that complicate the practice, regulation, and experience of care in ED treatment.

What I experienced as deeply uncaring at a time when I was seeking care contrasts sharply to the alternate care relations I experienced throughout my master's degree research. Reflecting throughout, and particularly in the final writing stages, it became increasingly clear how healing the research had been. I could quite distinctly see where drastic strides in my healing took root—from engaging in more food challenges to increased flexibility in eating and life to engaging more socially—as I found a research space to which I felt deeply connected and that provided support along the way.

In one of the final meetings with my advisory committee, I shared how doing this work had driven a level of healing I never thought possible, nurturing my life in entirely unexpected ways. As my advisor shared, a care assemblage had (re)formed, driving a project that held care in all elements—from thinking about the topic to engaging with clinicians (participants) to the analysis and writing to my own personal ED healing. Thinking of my research process and of my healing journey as an assemblage deeply resonated. This allowed me to recognize and engage with how research processes and technicalities, emotions and emotional responses, and relationships with myself and my history, research participants, my committee and others connected, dis-connected, and re-connected in complex and multi-directional ways.

Considering the research space as a care assemblage allowed me to reflect on how the alteration of connections within this assemblage—from my treatment admission to the end of my master's—had shifted and changed the assemblage (Jackson and Mazzei 2013). Specifically, I think of the alteration of my sense of safety in the care assemblage of the research space in comparison to that of treatment. The care assemblage of treatment, formed by stringent rules, confinement to a hospital ward, threats, intense anxiety, and distrust in providers vastly impacted my (un)care experience. There, my struggle to comply with the mandatory rule of meal completion was met with anger, punishment, threats, and loss of the freedom of movement. Where compassion, understanding, and empathy held minimal space, a deep sense of distrust, lack of safety, and sense of unworthiness emerged. When I think of this, and the connections of relationships that formed this, I question how healing could have possible when some of the core components of care—interdependency, compassion, and safety—were so starkly missing. This question goes beyond my experience to that of the larger ED system, which is marked by bio-psychiatry, minimal resources, and long waitlists that likely create pressure for clinicians to engage in such threatening statements to enforce symptom abstinence and move people through treatment quickly such that those waiting for life-saving treatment can gain access.

The care I experienced in the research space greatly differed, as collaboration and connection stood strong in this assemblage. Any struggle I faced was met with understanding and willingness to work collaboratively to find a solution. A deep level of care for the participants, their voices, and their raw honestly came from all who engaged. Finally, my connection to the research topic, honest conversations with participants, and sense of support through each stage from those involved, facilitated a commitment and motivation to my personal healing that I had never experienced, nor thought possible in the past.

My research taught me the depth of the importance of care for healing, as well as how healing involves a complex array of relationships from a multitude of different forces. This reflection is my personal example of finding healing in unexpected spaces. For many, the academic space, too, can be harmful, yet through my master's research, surrounded by a group of critical scholars, a support system, and sense of finding space in research, I found myself healing in ways I once did not see as possible. While this is my personal journey, I believe it can offer a lens for exploring care assemblages and their complex relationships that can both infringe upon and facilitate healing beyond conventional treatment spaces.

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Bodies in Conflict: Understanding Women's Experiences of Polycystic Ovarian Syndrome

by Samadrita Chowdhuri

Abstract: Polycystic Ovarian Syndrome (PCOS) is a complex medical condition that impacts women's bodies and identities, especially in relation to gendered expectations of health and femininity. Drawing on feminist and social constructionist frameworks, this study uses ideas of "doing gender" and "undoing gender," in connection with the concept of medicalization, to investigate the relationship between self-perception, medical authority, and gender norms. This qualitative study examined the embodied experiences of Indian and Indo-Canadian women living with PCOS in Edmonton, Canada, using semi-structured interviews, focus group discussions, and body mapping as the primary methods of data collection. According to the findings, women establish a hierarchy of symptoms, giving external symptoms like acne and hirsutism precedence over issues about fertility. This hierarchy is a reflection of internalized ideas of feminine appearance and also a rejection of feminine functionality focused on reproductivity. The women's choices of treatment, especially with regard to hormonal contraceptives, reflect a negotiation between defying and adhering to sociocultural and biological standards of womanhood. This study challenges conventional medicalized discourses on PCOS by emphasizing women's narratives, and advances a more comprehensive understanding of gender, health, and embodiment. It emphasizes the necessity of more patient-centered approaches to recognize and validate opportunities for healing that are not based on predetermined and essentialist notions of health and femininity.

Keywords: Polycystic Ovarian Syndrome; healing; femininity; health; gender; body-mapping

Résumé : Le syndrome des ovaires polykystiques (SOPK) est une maladie complexe qui affecte le corps et l'identité des femmes, en particulier en raison des attentes liées au genre en matière de santé et de féminité. S'appuyant sur des cadres théoriques féministes et constructionnistes sociaux, cette étude s'intéresse aux notions de « faire le genre » et de « défaire le genre », en lien avec la médicalisation, afin d'analyser les liens entre la perception de soi, l'autorité médicale et les normes de genre. Cette étude qualitative a examiné les expériences vécues par des femmes indiennes et indo-canadiennes atteintes du SOPK à Edmonton, au Canada, à l'aide d'entretiens semi-structurés, de groupes de discussion et de la cartographie corporelle comme principales méthodes de collecte de données. D'après les résultats, les femmes hiérarchisent les symptômes, privilégiant les manifestations visibles, comme l'acné et l'hirsutisme, plutôt que les problèmes liés à la fertilité. Cette hiérarchie témoigne de représentations intériorisées de l'apparence féminine, ainsi que du rejet d'une féminité définie par sa fonction reproductive. Les choix de traitement des femmes, notamment en ce qui concerne les contraceptifs hormonaux, reflètent une négociation entre la remise en question et l'adhésion aux normes socioculturelles et biologiques de la féminité. Cette étude remet en question les discours médicaux conventionnels sur le SOPK en valorisant les récits des femmes, et contribue à une compréhension plus approfondie du genre, de la santé et de l'expérience vécue. Elle souligne la nécessité d'adopter des approches plus centrées sur les patientes afin de reconnaître et de valider les possibilités de guérison qui ne reposent pas sur des concepts prédéterminés et essentialistes de la santé et de la féminité.

Mots clés : syndrome des ovaires polykystiques; guérison; féminité; santé; genre; cartographie corporelle

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Introduction

Polycystic ovarian syndrome (PCOS) is a complex medical condition that significantly affects women's identities and bodies. This research deploys body mapping, focus groups, and in-depth interviewing to look at how women with PCOS deal with the gendered aspects of living with the disorder. Grounding my work in a feminist and social constructionist theoretical framework, I incorporate theories of both "doing gender" (West and Zimmerman 1987) and "undoing gender" (Butler 2004; Deutsch 2007), while also drawing on Foucault's (1973) conceptualization of "medicalization." Used together, these theoretical viewpoints help to shed light on how women with PCOS navigate their identities and treatment choices by both complying to and defying gender norms.

This qualitative research aims to get a more nuanced knowledge of the experiences of Indian and Indo-Canadian women with PCOS living in Edmonton by examining how women identify their bodies in response to living with a gendered disease. In this study, I explored illness experience with regards to symptoms but also illuminated treatment approaches and perspectives to understand the reasons why women go through treatments, whether and why they prefer certain forms of treatments, or if they are challenging conventional forms of the same. Building on previous research done on PCOS that has focused on experiences of women, this study explored how "health" is connected to the construction of a "normative female body." The research questions were as follows:

1. What are the treatments Indo-Canadian women prefer with regards to PCOS?
2. How do these preferences arise from their lived experience of PCOS?

My research found that the narratives of the 18 women in this study established a hierarchy of symptoms, giving visible symptoms precedence over less visible issues with reproductive function. This prioritization of symptoms highlights a complex dynamic between internalized ideas of womanhood and external gendered expectations. Furthermore, the treatment decisions made by these women, especially with relation to hormonal contraceptives, suggests a conflict between defying and fitting into different ideals of femininity. Women accept or reject hormonal treatment (referred to as birth control) based on whether their physical/visible symptoms get better and they prioritize these symptoms over reproductivity.

By elevating the perspectives of women, this research challenges traditional narratives about the female body and advances a more comprehensive understanding of the intersections of gender, health, and embodiment in the lived realities of people with PCOS. My positionality as an Indian immigrant woman with PCOS helped me approach this study with both empathy and a critical eye because of my lived experience which acknowledges how intersecting medical, cultural, and social influences affect the experience of PCOS. In this article, I argue that my participants are enmeshed in prevailing webs of medicalized and gendered discourses while I also highlight their resilience and places of resistance.

Polycystic Ovarian Syndrome

Polycystic Ovarian Syndrome or PCOS is a condition characterized by different symptoms of menstrual abnormalities, weight gain and obesity, acne, hair loss, and hirsutism (male hair growth pattern) based on the key feature of an increase in androgen synthesis by the ovaries. It has been stated that this condition is incurable and treatments are mostly directed at masking the symptoms and regulating hormonal functionality (Vrbikova 2012). PCOS is the most frequent endocrinopathy among premenopausal women, the major cause of infertility, and is the most widespread endocrine disorder affecting women (Vrbikova 2012). The diagnosis of androgen excess, which centers on clinical indicators of "increased" male hormones, suggests a problem with PCOS patients' bodies since they depart from normal gender embodiment.

Oral contraceptive pills, insulin stimulation medicine, and antiandrogens are the most commonly used treatments (Witchel et al. 2019). The first-line treatment options for the clinical signs of PCOS are combined hormonal contraceptives (CHCs). CHCs are believed to help regulate the clinical symptoms of hyperandrogenism and menstrual cycles because they include both an oestrogen and a progestogen component (de Melo et al. 2017). The side effects of routine intake of birth control include mental health problems, high blood pressure, and hypertension (Lucidi 2016). These medicines and lines of treatments are mainly focused on masking symptoms that manifest the dominance of male hormones, which makes this syndrome even more complex. These gendered aspects of treatment suggest that the pathologization and construction of this syndrome is another example of the perpetuation of essentialized ideals of femininity within established medicalized frameworks. Thus, it is important to consider women's narratives of this condition and their expectations with regards to treatment.

In recent years, PCOS has become a very common "disease" among Indian women (Pruthi 2019) but it is still a condition most people are not aware of and it has been under-explored in research initiatives (Ellerman 2012).. The high incidence of PCOS among Indian women was one of the primary reasons this exploratory research was focused on their experiences.

Research on PCOS

This study explicitly builds on previous research that concentrates on women's voices to understand what living with PCOS looks like, with an emphasis on studies that have explored how femininity has played out in those experiences.

Studies that focus on how physical symptoms of PCOS affect women's ideas of femininity mostly observed that participants were concerned about their appearance as a woman. Research on experiences associated with hirsutism highlighted that body and facial hair led to social isolation and rejection by intimate partners and people around the participants (Kitzinger and Willmott 2002; Meyer and Zerssen 1960). Studies that focused on hirsutism highlighted that women were preoccupied with restoring a feminine (hair-free) appearance. For instance, women in Pfister and Rømer's (2017, 180) study expressed that they feel more feminine when they remove their body hair, as they perceive the hairless body as a symbol of "proper" femininity.

Along with physical appearance, internal functionality was also an important factor for women in various studies. Kitzinger and Willmott conducted interviews with women in the UK and concluded that they were "challenged in their perceptions of themselves as feminine and as women" because of issues with hirsutism, irregular menstruation, and infertility (Kitzinger and Willmott 2002, 358). They also noted that women were also extremely concerned if there were menstrual problems. They either felt different from other women or were worried that their present issues with menstruation may affect their fertility in the future, since regular menstruation is one of the essential definitive elements of a female body (Hennegan et al. 2019). Snyder (2006) investigated experiences of American women with PCOS and discovered that her interviewees believed their PCOS symptoms made them different from other women. The participants said that they had always yearned to be "normal" which they defined as having a regular menstrual cycle and seeming more feminine. In their study, Meyer and Zerssen (1960) claimed that women with polycystic ovaries had a deep-seated uneasiness about a feminine sex role. In the Kitzinger and Willmott (2002) study, the majority of women discussed not feeling normal and expressed a sense of social separation brought on by irregular or non-existent periods.

Across these various studies, participants prioritized concerns related to their gendered identity, with limited emphasis placed on health as the primary focus. Inspired by these findings, my research explored the common themes that came up, especially feminine appearance, fertility, and treatment. I examined how these themes were viewed by my participants to understand the complexities of femininity for women experiencing a health condition like PCOS.

Theoretical Framework

The theoretical structure in this study was influenced by a social constructionist lens. It utilized a feminist framework to understand gender and bodies. I primarily used theories of "doing" (West and Zimmerman 1987) and "(un)doing gender" (Deutsch 2007; Butler 2004) to understand how women negotiate their gender identities and navigate the treatment process with regards to femininity norms. West and Zimmerman (1987) argue that the social construction of gender is continuous, taking into account "normative conceptions" of men and women (Deutsch 2007, 106). Deutsch (2007) states that people act in certain ways knowing that they will be evaluated based on standards that are applied to their sex category, which dictate what is considered proper for either gender. Deutsch argues that, according to West and Zimmerman, both conforming to and resisting gender norms are examples of doing gender since, by definition, doing gender means behaving "at risk" of being evaluated in accordance with those standards (Deutsch 2007, 109). According to this notion, resistance is rendered invisible by highlighting the definitional similarity of compliance and resistance, where the focus is on the maintenance of the gender order.

Deutsch (2007) questions the application of West and Zimmerman's theory since it ignores situations when gender is being undone, such as when people's identities and behaviours undermine gender hierarchies and binaries. The concept of "doing gender" suggests that gender is created through ubiquitous social interactions, but it may also be dismantled and deconstructed (Pecis 2016). As noted by Deutsch (2007), an ethnomethodological approach to gender also entails comprehending the resistance to gendering activities: "It is time to put the spotlight squarely on the social processes that underlie resistance against conventional gender relations and on how successful change in the power dynamics and inequities between men and women can be accomplished" (Deutsch 2007, 107).

Building on Deutsch's need to recognize the subversive potential of doing gender, this research was also influenced by Butler's framework of "undoing gender" which contextualizes the complexity of embodied experiences (Butler 2004). In her book *Undoing Gender*, Butler poses a question, or more specifically calls it "a question for ethics," when one considers not only what makes their own life bearable but also what makes the lives of others bearable. This question illustrates how, for Butler, bodies are not entirely our own and also belong to the social sphere (Butler 2004, 17). The body becomes a social reality which is not only a medium that is used to adapt to the current socio-political and economic conditions but also is used to maintain medicalized and essentialist ideas of female bodies. However, Butler also asserts that while gender serves as the locus for the formation and normalization of the normative binary of masculine and feminine, it can also function as a site for the dismantling and deconstruction of these constructions. In this study, I adopt Butler's framing of "doing gender" to understand the experiences and decisions of women with PCOS and how they are following and/or rejecting specific ideals of femininity.

To understand the complexity of women's conformity and resistance to the gendered nature of PCOS, I used Foucault's concept of medicalization as a guiding framework to understand the construction of the disease and how medical discourses impact women's decisions (Foucault 1973). Through instruments of femininity and medical management, women with PCOS are persistently forced into surveillance and management of their bodies. Foucault argued extensively that knowledge emanating from social relationships and interaction implicitly promotes behaviours, relationships, and beliefs that lead to creation of discourses in society. These discourses are enhanced by various forms of regulatory processes that ensure that people conform (Frank 2020).

According to Foucault (1973), the normalizing gaze is always at work in an ongoing assessment of one's conformity to these regulatory factors, whether it comes from other people or from one's own self-normalization. McNay (2013) emphasizes that Foucault's concept of disciplinary power helps explain how individuals internalize and enact their own subjugation by embodying social norms. The effectiveness of the normalizing gaze lies in its subtlety; it operates without the need for an external observer, as individuals take on the role of monitoring and regulating themselves. Women with PCOS are often exposed to this normalizing gaze. On one hand they are stigmatized because of visible symptoms or the diagnosis and on the other hand they self-regulate their bodies through different cosmetic or medical solutions.

PCOS bodies are exposed to regulation wherein the conventional treatment consists of inducing artificial hormones into the body. In the study presented here, the notion that the female body is not merely a biological fact but a socially constructed condition shaped by medical interpretations of womanhood serves as a critical framework for examining the treatment-seeking behaviours of women. At the same time, I ask not only on how women are internalizing medicalized and essentialist notions but also whether and how they challenge or resist them.

Methods and Methodology

This qualitative study was informed by a narrative research approach combined with aspects of feminist methodology. By giving voice to women's bodily experience, it served as a platform for feminist research techniques and, in the process, produced experiential knowledge that might broaden this particular area of study. I studied how identity conflicts and treatment choices are created as distinctive parts of the PCOS experience with a focus on personal narratives and perceptions obtained through interviews and focus group discussions (Jarvis 2021). In its most basic form, narrative inquiry starts "with experience as expressed in lived and told stories" and employs narrative as a research methodological tool (Clandinin and Connelly 2000, 40).

As part of my data collection instruments, I conducted in-depth face-to-face semi-structured individual interviews (both in person and virtual) that lasted for an hour. These were followed by a virtual focus group session (comprising six participants) that lasted for ninety minutes, with women who were not part of the interviews. In-depth interviewing helps "to gain insight into how people interpret and order the world" (Milena et al. 2008, 1279). The focus group was useful in "providing in-depth information in a relatively short period of time" (Gundumogula 2020, 299). For both, I used semi-structured questionnaires that focused extensively on women's experiences regarding symptoms, treatments, and relationships. I also used a supplementary method of data collection through a short body mapping exercise which sought to understand participants' experiences of their bodies and lives as well as the significance they attach to these experiences (Lys et al. 2018). At the end of the interviews and the focus group, a body outline was given to the participants, and they were informed that they had complete freedom to add to or draw on it. Participants were asked to associate any kind of feelings, thoughts, or memories they have with their bodies in terms of their PCOS journeys. For virtual interviews and the focus group, the outline was shared through a whiteboard on Zoom.

The sample included a total of 18 Indian and Indo-Canadian women living in Canada within the age category of 20-30 years. The sample focused on women who have been diagnosed with PCOS within the last ten years, to control for the diagnosis time period. Recruitment was done through posters at the campus of University of Alberta to reach out to women who have been diagnosed with PCOS. In addition, social media platforms, Facebook and Instagram were used for recruitment. Most women identified as immigrant Indians from various parts of the world (India, USA, UAE, and Kenya) however, five women identified as Indo-Canadians who were either born in Canada or have been living in Canada for most of their life and also identified as Canadian citizens.

I used thematic analysis to structure my findings, which allowed me to methodically examine narrative content in order to identify underlying themes that arise from people's stories (Creswell and Poth 2018). All recorded interviews and the focus group discussion were transcribed. Data from the interviews were analyzed first to shape the focus group discussion. Based on the transcripts and the body maps, I extracted themes from the data, which included both open and axial coding. This helped me form categories based on emerging patterns in the data which eventually led to higher-level themes.

Owing to ethical considerations, informed consent was obtained from all the participants after they were given a thorough explanation of the study (Government of Canada 2022). For the focus group, participants signed a confidentiality agreement. The participants were given the opportunity to review the interview transcripts for clarification and to ensure fair representation. I have used pseudonyms to present their narratives to ensure that confidentiality and anonymity of participants was strictly maintained (Government of Canada 2022). All the participants were also informed about the positionality of the researcher and my connection to the research topic. The study was approved by Research Ethics Board 1 at the University of Alberta (ID: Pro 00132200).

Findings: Hierarchies and Priorities

The main finding was that women unconsciously create a symptom hierarchy; they prioritize symptoms of the present—those that are visible to everyone—based on internalized ideas about the female body. They simultaneously do and (un)do gender by prioritizing visible symptoms (conforming to gender norms to look more feminine) over reproductivity (not focusing or conforming to the idea of female functionality). This hierarchy is based on which symptoms they want gone first. Interestingly, women did not wish to conform to the expected norms of being fertile and reproductive for now and were more concerned about looking more "womanly." The following sections explore three main themes: embodied experiences, experiences in relationships and social interactions, and experiences in medical encounters. These are interrelated and illuminate how my participants view their bodies and make decisions about treatment based on their own embodied experiences and through interactions with others.

Embodied Experiences

According to Bartky (2010, 91), a woman's identity is often closely linked to ideas of femininity and that it takes "skill" to sustain gender normativity. Since people are usually only perceived as male or female, having a body that is perceived as "feminine"—that is, a body that has been socially constructed through appropriate practices—is typically essential to a woman's sense of herself.

Participants in this study express their struggles to become "normal" and the need to correct their bodies. This coincided with Shildrick's (2002) concept of a "differential body," defined as a body that defies norms in some manner, either in terms of appearance or functionality. Thompson and Stice (2001) discuss how young women with PCOS started pathologizing their experiences by claiming that they were abnormal and needed to be fixed. The idea of "fixing" "differential bodies" was also expressed by participants of this study (Janki and Bhoomika) and was connected to ideas of having a more "feminine" appearance. Women mostly used negative connotations to describe their bodily symptoms. They viewed their body as "different," which revealed how women had internalized standards of gendered embodiment. Their approach to treatment (discussed below) was influenced by these standards which reveal how these are attempts to adhere to gender norms in terms of physical appearance.

Most participants discussed that they wanted to get rid of the bodily manifestations, specifically hirsutism, acne, and weight gain. For instance, as Anika expressed,

> These are like all my problem areas of having facial or like, like my arms here. Like I have a lot of arm hair. And I think it's a bit more than like, my friends. I like would always cover my arms since junior high. I think even now I still like cover my arms. And my legs are also very hairy. I think my legs are like two shades or three shades lighter than the rest of my body because I never show it … makes me very insecure.

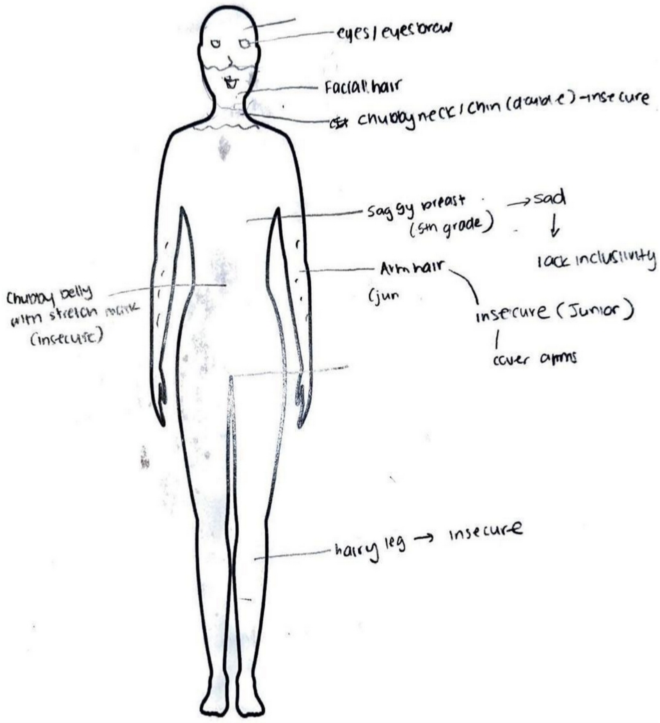

Figure 1: Body map created by Asmi after the in-person interview in response to what she associateswith her body in terms of her PCOS journey.

Women were upset since they could not experience "normal" womanhood. Asmi reflects,

> Sometimes I feel so much like, I don't feel like a man ever in my life to be compensated, I don't feel like a man. But I also feel like less than a woman sometimes … I feel like oh, like my hair's falling. Like, my face is like this, not well groomed and stuff. But then especially like, when it comes to shaving, I have to, like, almost shave like every day, just to keep it all.

The use of the word "have to," which came up in a lot of narratives, perpetuates the idea that women must live up to expectations out of fear of being rejected (Fahs 2014). In her study on women with PCOS, Fabricius claimed that medical discourses on PCOS and how knowledge is situated and internalized by women with PCOS "shape not only their social and material practices, but their very subjectivities" (Fabricius 2020, 110). West and Zimmerman (1987, 137) define "doing gender" as the behaviours, bodily comportments, and daily performances that seemingly establish distinctions between men and women, distinctions that are not inherent, necessary, or biological. For my participants, too, their perspectives were influenced by socio-cultural constructs of embodied femininity, which make them adopt coping strategies to avoid the risks of "gender assessment" (West and Zimmerman 1987, 13) and to mitigate perceptions about their incomplete femininity (Fabricius 2020). These strategies of doing gender can be complex and multidimensional, reflecting how the normalizing gaze works from the inside as well, necessitating a great deal of effort and adaptability from individuals.

In terms of PCOS, since the visible symptoms are clearly evident to everyone, these become significant for assessing if women's appearances conform to the expected gendered norms. When asked about what kind of treatment would be ideal for them, most participants in this study expressed that they wanted to "fix" their appearance. The external body is prioritized over the internal functionality—whether it be having regular menstrual cycles or getting pregnant in the future. Naina shared,

> As superficial as it sounds, I would want to fix the external part of it. Because my insecurity stems from very much being outward appearances of PCOS. So, if I could change that, if there was medication to change that I would probably take it in a heartbeat.

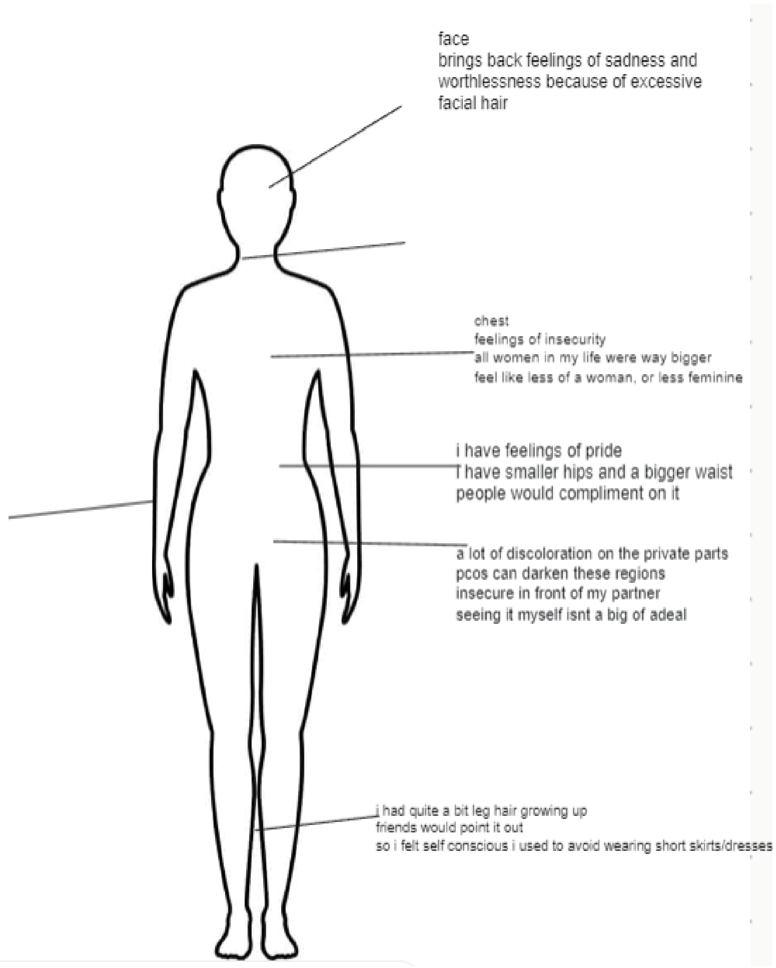

Figure 2: Body map created on the whiteboard by Bhoomika after the virtual interview on Zoom, in response to what she associates with her body in terms of her PCOS journey.

Fabricious' (2020) research shows how PCOS bodies are negotiated intersubjectively and are relational to others. The possibility of infertility is a concern for women in the current study but it is again something relational, i.e., for most of the women it is not a problem that they have to deal with now but in the future which would also impact people close to them. Symptoms that are visible to everyone become the locus of insecurity whereas future concerns become more relational. That is, future concerns will only matter to some people involved (like family and intimate partners) and might not be as evident as external symptoms. Hrithika says,

> I do want to have kids in the future. It's not that I don't want to, I feel like this is something I kind of go into denial about … it's a problem for the future, not now.

Another aspect of contradicting experiences of gender conformity was related to menstrual irregularities. Irregular menstrual cycles were an aspect of concern for most of my participants, which added to their doubts about the internal functionality of their bodies. However, not everyone had similar experiences. Some of my participants, for instance, said that they felt ashamed and believed that they are not feminine because their missed menstruation is a reflection on their gendered identity (Thorpe 2016). However, for Bhoomika and Clarissa, the absence was not a problem and they were more inclined to rectify the external symptoms. They stated how getting an IUD was a huge relief for them since they did not have to deal with the hassles of menstrual cycles or prolonged birth control. They were open to contraceptive methods for their convenience. Tandoğan et al. (2024, 2) argue that "regular menstruation is associated with femininity and fertility." But these two women resisted the idea of associating femininity with bleeding regularly. It was again based on their preference of dealing with visible symptomatic manifestations.

Experiences from Relationships and Social Interactions

Illness consists of experiences at "levels of self, others and society" (Wright et al. 2020, 1731) and the prevailing societal factors that shape people's understanding of illness also impact how people interpret, respond to, and act upon illness. In this section, I discuss how my participants' embodied experiences were also influenced by their relationships and other people's perspectives. Women shared that irrespective of whether people around them knew about their diagnosis, their physical symptoms like acne, hirsutism and even weight, had always been pointed out and were the subject of scrutiny and social rejection, especially by other women. Bhoomika shared,

> So, this brings back feelings of sadness and worthlessness because of like, excessive facial hair growing up, especially because not just once, like, a few times, growing ups, random aunties that we know would comment on it.

Most of the interactions about these physical symptoms circled around the topic of marriage or finding a partner based on how they looked.

> It makes things very hard because a lot of things are focused on appearance. It's always about what are people gonna say about you? Like, no one's gonna marry you, like marriage is not my only goal in life! (Mehekdeep)

Some women also reported that they were not concerned about fertility as much as other people were, but shared that there was a sudden pressure on them to be extra careful with their lifestyle.

> I have no thoughts about my uterus, man. But people have a lot of thoughts about my uterus. People love to make it my vending machine. (Ayana)

> Suddenly, I mattered to them [parents] more. My response wasn't that bad to getting that news. But my parents, they were more like taken aback about it. Because like, they went to all the depth like, oh my god, what if she's infertile? (Aishi)

These women were part of a minority among the participants, who were not worried about having a "functional" body for reproduction.

> Having kids is going to be a problem, which, you know what? That's okay. I've had a massive fear of childbirth since I was eight. So, I think it worked out for me in that case, I don't think I could ever physically want to be pregnant. I would give [sic] a surrogate if I had to or even adopt one frankly. (Asha)

These participants' approach to fertility and motherhood is influenced by choice and alternatives to conventional forms of motherhood; however, it is also affected by the stigma of infertility they might face later in their life. This results in an unconscious navigation to future plans to become a mother—the focus may not be on the internal or bodily functionality but is centered on the social role of becoming a mother. These women challenge norms about reproductivity but conform to norms of motherhood.

The women in this study elaborated on how interactions with other people "otherized" them since PCOS might disrupt normal expectations of how their bodies should be and how their life should unfold. First, the symptom manifestations do not align with the ideal image of what a woman should look like. Second, these women have a syndrome that might affect their fertility, and hence they get stigmatized even before they try to get pregnant. These interactions or the people in these interactions act as the "guardians of normalcy" who remind these women that there is something wrong with them, that they are incomplete as women.

Experiences from Medical Encounters and Consultation

Chrisler (2004) expands on Foucault's theory that medicalization defines and upholds standards of health and femininity by extending the power of medical authority into daily life. In alignment with Chrisler's argument, women in this study typically follow strict social norms in an effort to fulfil and maintain conventional notions of femininity which in turn make them prioritize certain health aspects when it comes to treatment for PCOS. In the following sections, I will illuminate how women in this study seek treatment through biomedicine to normalize their bodies according to the internalized gendered notions of femaleness. At the same time, most of the women resist some medicalized notions of femaleness. In other words, the processes of both doing and undoing gender are present in women's narratives.

Health Hierarchy in the Medical System

In this section, I elaborate on how a health hierarchy for the female body is pre-constructed in the medical world. By health hierarchy, I refer to patient-doctor interactions in which doctors focused on reproductivity as the only concern and dismissed all other concerns of my participants. The construction of health hierarchy typically happens because most illnesses or conditions are viewed from biomedical perspectives that perpetuate the standard of normalization (Foucault 1973).

All of the participants in this study expressed that they have been extremely frustrated, confused, and anxious because of their encounters with their doctors. Some participants complained that practitioners failed to appropriately address other symptoms because they placed too much attention on the issue of reproduction. Participants (un)do gender with regards to medicalized health expectations and state that they were more concerned about symptoms that currently affect them or their ability to relate to other women. Reiterating a similar observation made by Kitzinger and Wilmott (2002), some of the women in my research also reported that they believed their doctors either under- or over-diagnosed PCOS. For instance, Ayana shared how the doctor made her feel like a "baby producing machine" and talked about the trivialization of appearance-based symptoms like acne by the doctor.

> I went to see the university doctor and I told him that my PCOS is getting really flared up ... my chin hair just erupting, I started getting a lot of acne. And my periods were getting a bit irregular. And then he asked me, "Are you planning to get pregnant anytime soon?"... He was like, if you're not planning

> to get pregnant, then we don't need to do anything about it. That was very difficult, because it just made me feel like I'm like a baby producing machine.

Based on her experiences, Ayana read this interaction as one where the doctor's focus was on restoring fertility, which led to the dismissal of other health problems. She states, "At one point, honestly, I was thinking, should I tell him that I am thinking of getting a baby? Because then maybe he will treat it?"

Twenty-year-old Naina talked about how the negligence of the doctor led to her delayed diagnosis.

> I was pretty frustrated for the most part…. It just kind of sucked having to go through the Canadian healthcare as a woman because you are always brushed off as it's just stress, you're in school, like you're anxious, that's why you have irregular periods and all of this. But the main reason is that you are young and you don't need to get pregnant

A very clear health hierarchy was evident in the women's narratives about their interactions with doctors, where there was a prioritization of reproductivity. Women's voices remain excluded in the treatment process. The doctors' focus on pregnancy undermined all other problems these women reported and eventually shifted the responsibility of managing this syndrome to the women themselves.

The concepts of standardization, health, and abnormality that underpin biological understandings of PCOS were evident in these medical encounters. In the case of PCOS, it gets more complex since women are not only examined or judged as patients but also as female bodies. If pregnancy was not an issue that these women reported, all other symptom corrections were shifted to their own responsibility.

Navigating Treatment: Rejecting /Accepting Birth Control

As discussed in the previous sections, embodied experiences and interactions with other people influence women's perspective of their bodies and what is more important for them in terms of symptom treatment. In this study, the women rejected or accepted birth control based on how this treatment addressed the symptoms that they prioritized. It is important to note that I did not ask details or the dosage of the medication; however, all my participants used the word "birth control" or "contraceptives" to describe the hormonal treatment they were prescribed. Bhoomika rejected birth control stating that it did not help her the way she expected it to.

> Contraceptives were not really useful for me. I got laser treatment done ... that was quite expensive. But honestly, my mental health has really benefited from the lack of facial hair. Yeah, birth control, I was on it. But I found that it like, hindered my weight loss goals. I honestly don't mind spending money on something that actually does something with my symptoms rather than adding more problems in my body.

For the women who rejected birth control, when they were assessing the treatment, they stressed how their feminine appearance was not "fixed" by it. The only time they mentioned health was when they talked about side effects, which were again mostly future possibilities.

Just like the participants who expressed that birth control was not helpful, the participants who reported that birth control was a helpful treatment option in their PCOS journey focused on the femininity aspect more than health. For these women, the fact that the visible symptoms got "fixed" was the most important part. They were definitely satisfied that their menstrual cycles became regular but their contentment was more concentrated on visible physical symptoms. The focus was more on how these "markers" were lessened or absent and how that made them feel like a normal "woman" during these phases when they were on medication. For example, Janki said:

> I have a lot of acne, as soon as I leave the pill, like, or if I'm missing pills, I can see that, you know, those differences in my skin. So, now, if I have to take it, it's gonna fix my other problems as well. So, it's balancing the stuff that my body is not able [to do].

Women who took hormonal contraceptives accepted the risks of this treatment because it addressed symptoms they ranked as high priority. The side effects of hormonal pills were secondary to the regulation of womanhood inside the body. This can be related to Irni's approach of "relationality of risk," where the risk of not taking these pills supersedes the risks of taking them (Irni 2017).

Clarissa shared how she plans to remain on birth control in the future since it is an "easy option" for her and that "the only adverse effects would be I'd be hormonal or nauseous or have extreme mood swings for about a month or so until I settled, and then I'd be back at the normal." For her, less facial hair and having periods are more important than experiencing the negative side effects of birth control.

Although these women were (un)doing gender and rejected the idea of fertility and reproductive capacity, they still were doing gender to maintain their physical appearance. There was a conflation of health and femininity. The approach to treatment in these cases is not an attempt to get a healthy body but rather a body that is fulfilled in terms of femininity and womanhood. This is essentially based on ideas of feminine gendered embodiment.

Conclusion

In this article, I argue that women unconsciously create a symptom hierarchy, which has two separate aspects. They prioritize external symptoms of PCOS over reproductivity, which also makes these symptoms become more important than the potential or experienced side effects of taking birth control as a form of treatment. The majority of participants reported that they had faced prominent and sometimes severe side effects of taking birth control, but they still continued with it. In this study, women mostly struggle with phenotypical normative femininity norms (Esteban-Gonzalo et al. 2020). Phrases like "problem areas," "insecurity," "worthlessness," "less feminine" were part of the conversations when asked about specific labels that these women created in the body maps (presented earlier), especially based on symptoms that are visible to everyone. There was a clear prioritizing of less body and facial hair growth, less acne, a slimmer body, and regular menstrual cycles over the side effects and other health problems that could have been caused by the treatment. Women conform to gender norms and "do gender" through this prioritization by complying with ideas of how a female body should look. At the same time, they challenge the essentialized and medicalized norms of how a female body should function and, in that process, "undo gender." Hence, women's efforts to get rid of any "unfeminine" symptoms are about both conforming to and challenging gendered norms of the female body.

It is important to note that resistance becomes contextual for PCOS bodies. While women may internalize socially constructed narratives that objectify them through appearance-based ideals, some women actively reinterpret these ideals as strategies of resistance in relation to fertility and constructions of womanhood. Their narratives in this study show how the female body is a site of negotiation, contradiction, and agency. Women might fall into the cycle of reinforcing ideals of feminine appearance, but they resist the essentialization of their body just for procreation. The processes of doing and undoing gender are negotiated by the women through the conflation of femininity and health. In terms of identity, women in this study express that they always experience a state of liminality, a condition of ambiguity and uncertainty in which they feel difficult to categorize themselves. They are always trying to "be a woman" which suggests that, with the symptoms and treatment, they do not see themselves as a complete woman. This state of liminality can also be seen as an opportunity to resist gendered conceptions of bodies both in terms of health and femininity. It can lead to the questioning of the "ideal female body."

As Oksala asserts, “Power inscribes the limits of normal bodily experiences, but it is exactly the existence of these limits that makes their transgression possible” (Oksala 2004, 108) . This study argues that dominant views of the female body—where femininity is equated with reproductive norms and standards of feminine appearance—are challenged but also accepted by some women. The experiences of women with PCOS shows that they resist and reshape these norms, offering more complex understandings of womanhood. Illness narratives over the last few decades have demonstrated the importance of patient accounts in expanding the body of knowledge (Bennett et al. 2020). This research study provided a platform for self-reflection for these women and showed how experiential knowledge resists the medical paradigm and essentialized expectations of the female body. My participants’ notions of what is more important when it comes to identifying as a woman may serve as an analytical lens to reframe our understanding of gendered health conditions. These not only challenge medical norms but might also serve as a pathway for healing where women relate to others beyond their predetermined reproductive role.

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Toward Conceptual Clarity: Out-of-Hospital Birth Practices and Freebirth Entrepreneurialism

by Krista Johnston and Christiana MacDougall

Abstract: There is a growing interest in giving birth outside of hospitals and healthcare systems. In our analysis of more than five years of qualitative research, we have noted the conflation of unregulated birth care with regulated midwifery care, a concern also identified by several professional midwifery associations in Canada. This is particularly concerning in a national context where midwifery remains insufficiently integrated and understood. Growing healthcare dis/misinformation and increasing politicization around healthcare have led to confusion for those choosing among different forms of birth care. In this article we differentiate among birth workers and practices, focusing on unregulated forms of care, including doulas, lay or traditional midwives, and other kinds of birth workers, as well as freebirth, or unassisted birth. This analysis paper provides information on the range of practices that healthcare providers may encounter and articulates areas of difference and overlap among forms of birth care. It also highlights strategies to address some of the unmet needs that are leading people to choose unregulated birth care.

Keywords: regulated midwifery; unassisted birth; freebirth; birth justice; reproductive justice; birth care; New Brunswick; Canada

Résumé : On observe un intérêt croissant pour l'accouchement en dehors des hôpitaux et des systèmes de santé. Dans notre analyse de plus de cinq ans de recherche qualitative, nous avons constaté une confusion entre les soins liés à l'accouchement non réglementés et les soins de sage-femme réglementés, une préoccupation également soulevée par plusieurs associations professionnelles de sages-femmes au Canada. Ce constat est particulièrement préoccupant dans un contexte national où la profession de sage-femme demeure insuffisamment intégrée et mal comprise. La montée de la désinformation et de la politisation en santé a semé la confusion chez les personnes qui doivent choisir entre différentes formes de soins liés à l'accouchement. Dans cet article, nous faisons la distinction entre les professionnels et les pratiques liés à l'accouchement, en nous concentrant sur les formes de soins non réglementées, notamment les doulas, les sages-femmes laïques ou traditionnelles et d'autres types de professionnels de l'accouchement, ainsi que sur l'accouchement non assisté. Cet article d'analyse présente les diverses pratiques que les prestataires de soins de santé peuvent rencontrer et précise les différences et les chevauchements entre les différentes formes de soins liés à l'accouchement. Il présente également des stratégies visant à répondre à certains des besoins non satisfaits qui poussent les gens à choisir des soins liés à l'accouchement non réglementés.

Mots clés : profession sage-femme réglementée; accouchement non assisté; justice liée à l'accouchement; justice reproductive; soins liés à l'accouchement; Nouveau-Brunswick; Canada

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Introduction

While access to regulated midwifery care has contributed to the growth of home birth, a small—and growing—percentage of births intentionally take place outside of hospital and outside of the care of registered midwives. Such practices are referenced variously as unassisted birth, unattended birth, out-of-hospital birth, or out-of-system birth, but increasingly, they are called freebirth. There is growing scholarly interest in such practices, both because they seem to be increasing since the Covid-19 pandemic (Statistics Canada 2021) and because they reveal a great deal about potential gaps and shortcomings of existing pregnancy and birth care (Greenfield, Payne-Gifford, and McKenzie 2021; Shorey et al. 2023; Miani et al. 2021). Based on our research in New Brunswick, we identify shortcomings in emerging conceptualizations of this range of practices as "freebirth" and propose new approaches to differentiating among them. We argue that framing all out-of-system births as freebirth flattens various practices, orientations, and commitments of birth workers into an amorphous category that hides these important differences, with significant potential impacts for those seeking care, those providing care, and for those who are organizing around birth justice. We begin by differentiating between regulated and unregulated forms of out-of-hospital birth, describing birth practices that co-exist, overlap, and at times exist in tension, and demonstrate how different birth practices can be understood within the specific socioeconomic, geographic, and policy contexts in which they emerge. Furthermore, we develop a new conceptualization of freebirth entrepreneurialism to bring further specificity to the use of this term in the context of our study and more broadly. Given the ideological commitments of outspoken freebirth advocates, several of whom began their activism for alternative birth in New Brunswick, we demonstrate that conflating all alternative (to hospital) birth practices as freebirth risks undermining public understanding and assessment of medical advice and regulated midwifery. This confusion complicates attempts by those seeking care to navigate existing systems and may undermine fledging midwifery programs in provinces like New Brunswick.

Literature Review

There is a growing body of literature focused on birth practices that take place outside of hospital and outside of the established health care system. The most common term used for such practices is freebirth, which is consistently defined along the lines of the definition proposed by Velo Higueras, Douglas, and Kennedy (2024): "the deliberate decision to give birth at home without a regulated healthcare professional in countries where maternity care facilities are available and easily accessible" (for similar definitions, see McKenzie, Robert, and Montgomery 2020; LeBlanc and Kornelsen 2015; Feeley et al. 2015). Like many other scholars, Velo Higueras, Douglas, and Kennedy (2024) use the term freebirth interchangeably with unassisted birth (McKenzie, Robert, and Montgomery 2020; Feeley et al. 2015), arguing that these birth choices often look similar in practice. This definition effectively separates home birth with a regulated midwife from all other forms of home birth, but we argue that it does not provide sufficient conceptual clarity to fully capture the many kinds of birth practices, and different kinds of birth care practitioners, that may be involved in out-of-hospital (and outside of healthcare system) birth. Furthermore, the definition of freebirth proposed by Velo Higueras, Douglas, and Kennedy (2024) and others relies upon the existence of birth care facilities at the national level, which may misrepresent significant issues of availability and access to care impacted by geographical and socioeconomic location *within* national boundaries. In the broader literature on freebirth, many associate freebirth with high-income countries (HICs). For instance, Shorey et al. (2023) use the term freebirth to reference out-of-system births in high-income countries and use the term unassisted childbirth to reflect similar practices in low- and middle-income countries where professional maternity care is not widely available. This differentiation presumes that services available in one part of the country will be equally available and accessible across the country, which is not the case in Canada. As we have learned in our research with birth care clients, providers, advocates, and policy makers in New Brunswick, the absence of a robust and readily accessible regulated midwifery care program, combined with the challenges of rurality and geographic isolation as well as high rates of poverty and insufficient investments in reproductive healthcare has resulted in the growth of *both* unattended birth and freebirth in the province. Existing definitions that conflate these practices miss significant differences and further complicate attempts by those seeking birth care, as well as those providing birth care, to understand the differences and potential responses.

Theory and Methodology

The findings and analysis shared here are part of on-going research including two studies focused on the New Brunswick midwifery program, which began serving clients in one city in the province in 2017. Our work in this project has been governed by commitments to justice-oriented movements which centre racial, cultural, and gender diversity. Our thinking is informed by anti-colonial conceptualizations of bodily autonomy and sovereignty advanced by Indigenous theorists like Simpson (2017), Wilson (2015), and TallBear (2018), which direct us, as white settler scholars, to be led in this work by the Indigenous communities and activists doing this work and to continue to confront the ongoing violence of settler colonialism. Our work is also directed by the insights of Black feminist movements for reproductive justice and birth justice. As articulated by Loretta Ross and Rickie Solinger (2017, 9), "Reproductive justice is a contemporary framework for thinking about the experiences of reproduction. It is a political movment that splices reproductive rights with social justice to achieve reproductive justice… reproductive justice demands sexual autonomy and gender freedom for every human being." Core to the work of reproductive justice activists is confronting the violence of anti-Blackness and the pervasiveness of ideologies of white supremacy. Finally, recognizing our own social locations, our work is driven by a commitment to challenging the individualized frameworks common in liberal feminism. This shows up in our work below by exploring how ideas of body-sovereignty and individual choice in birth work can become co-opted by movements that actually serve to perpetuate dominant relationships of power.

In 2019 we conducted research on service user experiences of midwifery care, holding in-depth interviews with clients of the new midwifery program in Fredericton, New Brunswick (MacDougall and Johnston 2022). Early in the study, we noted that the midwives and many of the clients of the midwifery clinic espoused commitments to access and justice. The clinic employs a progressive screening tool to prioritize clients based on social and economic location, and midwives and many clients were intentional in their use of inclusive language around gender and sexuality. We recognized the midwives' emphasis on informed consent and bodily autonomy as core to midwifery and to birth justice. Initially, we understood comments by clients of the clinic in the context of this emphasis on autonomy. Our findings on the relationship between the regulated midwifery program and unregulated birth care practices were incidental; we were surprised to hear about freebirth at almost every interview. At first, these were subtle references, and we noted that participants often used the terms freebirth and unattended birth interchangeably. We became curious as interview participants told us about their consultations with freebirth attendants, relayed the stories of friends or acquaintances who had freebirths, and, eventually, some participants told us that they had also had freebirths with prior pregnancies. As we moved into the second phase of our research, tracing the development of the provincial midwifery program, we came to understand that the legal landscape for birth care in New Brunswick, the scarce access to regulated midwifery care, and the largely rural geography of the province have combined to create a particularly complex context for birth care. We also came to understand better that despite the emphasis on autonomy and freedom, some elements of freebirth movements directly counter the justice-oriented commitments of midwifery and birth justice.

Over the course of our research, we have completed 51 semi-structured interviews with birth care advocates, clients of midwifery services, regulated and unregulated birth workers, and those involved with policy development. Interviews were coded using Quirkos qualitative data analysis software during multiple rounds of qualitative analysis, moving from descriptive to analytical codes and themes through the many rounds of coding. The two authors each coded some transcripts individually, and then compared emerging codes and reached agreement on the codes we would use going forward. We then each coded the rest of the transcripts and repeated this process until we felt we had developed analytical codes that captured the nuance of the data with a reproductive justice focus. Following our informed consent process and the wishes of our participants, data is reported here using either pseudonyms chosen by participants or their real names; a small number asked not to be named or directly quoted (sometimes both), and their comments are paraphrased or included without attribution.

Birth Care in New Brunswick

Registered midwives provide prenatal and postpartum support as well as attending births in the hospital, at birthing centres (where these exist), and at home. Midwifery is regulated by provinces and territories across Canada, and midwives attended about 11% of births in 2021 (Canadian Association of Midwives 2021). In most provinces, the only way to have an out-of-hospital birth within the provisions of the healthcare system is with a registered midwife, but there is significant unevenness in access to midwifery care across Canada. In 2019 midwives attended 25% of births in British Columbia, compared to 15% in Ontario, 2.8% in Nova Scotia, and 0.7% in New Brunswick (Canadian Association of Midwives 2019).

New Brunswick was among the last Canadian provinces to implement midwifery care, opening one clinic within the anglophone health authority in 2017. Since then, the midwifery program remains available in only one clinic, located in the capital city of Fredericton, with a maximum equivalent of four full-time midwives. Clients must meet the criteria for a low-risk birth and live within the small catchment area of the clinic in order to receive care. Midwives are regulated as part of the provincial healthcare system, registered by the New Brunswick Midwifery Council, which is part of the Canadian Midwifery Regulators Council. They may attend births in the hospital or at their clients' homes, and they also provide follow up postpartum care both at their clinic and in clients' homes. Midwives in the New Brunswick program therefore provide hospital and home-based care, within the regulated health care system, operating at the interface of hospital and out-of-hospital care. Our 2017-2019 study with midwifery clients in the province found high levels of satisfaction with the program, as well as some structural and implementation challenges being faced by midwives and their clients (MacDougall and Johnston 2022). Since it opened, the clinic has maintained an extensive waiting list, and our ongoing research finds high levels of interest and desire for midwifery care.

The piecemeal, limited nature of the creation of the midwifery program and its implementation have had considerable impacts on the kinds of out-of-hospital and out-of-system birth practices we report on here. In addition, it is worth noting that the legal, socioeconomic, and geographic context of the province of New Brunswick present significant challenges for the provision of reproductive healthcare. New Brunswick is a small province in the Atlantic region with a rapidly aging population, a downward trending birth rate, and a largely rural geography, as well as income levels among the lowest in Canada (Government of New Brunswick 2023). In 2019, New Brunswick was recognized as the poorest province in Canada, garnering higher equalization payment rates from the federal government to cover healthcare, education, and other social services (Jones 2019). Although the province is located within one of the wealthiest nations, it is a low-income province. Like many provinces in the region, governments in New Brunswick have been reluctant, and at times hostile, to the expansion of many facets of reproductive health care, including abortion (Ackerman 2012; Foster et al. 2017). As we demonstrate below, these combined factors have had significant impacts on birth practices in the province.

Wolostoq, Passamaquoddy, and Mi'kmaw Nations have long-standing, ongoing, and sovereign traditions of welcoming new life into their communities through ancestral knowledge, land-based practices, and diverse medicine ways. Our research does not adequately reflect the breadth, depth, or lived realities of Indigenous midwifery and birth work in this region. Discussions around regulation, self-determination, and the reclamation of birth are not only ongoing—they are grounded in sovereignty, community priorities, and relational accountability. We acknowledge the limitations of our methodology and team in respectfully representing these Indigenous-led movements. Our initial findings reflect the ongoing emphasis among Indigenous communities on home and community-based birth, which is not new, but a continuation of long-standing practice that predates colonization. As one Indigenous interview participant explained:

> For Indigenous people, that is community … let us have our babies at home, let us have midwifery care so it doesn't feel like a clinical medical setting, which you know, a lot of people are curing some trauma with, and it's passed down trauma. We're hearing stories about young people now, and how they don't want to give birth because they heard about social services coming in and taking their parent's babies. Or, you know, just being in the system is a reminder of shitty things. (SP)

This powerful reflection echoes intergenerational experiences of medical colonialism, family separation, and state surveillance—realities that continue to shape Indigenous experiences with the healthcare system today. Returning birth to community is central to Indigenous midwifery resurgence and the "Birth Back" movement amplified by the National Council of Indigenous Midwives (NCIM) reflects the voices of Indigenous midwives and their communities (National Council of Indigenous Midwives 2014; 2019). This work is rooted in restoring wellness through body autonomy, returning culture to health practices, and centring family and community participation and care.

In the province of New Brunswick, this work of restoring Indigenous birth practices is underway. For example, the community of Pilick First Nation recently celebrated the first at-home birth in 85 years, guided by Elder Opolahsomuwehs and supported by the presence of registered midwives (Baker 2022). While significant, this milestone is also a reminder of the structural barriers that have interrupted Indigenous birth practices for generations—and of the ongoing resistance and leadership of communities reclaiming this inherent right. As Nathalie Pambrun, Michif midwife and Community Engagement Lead at NCIM notes,

> Further action—including Indigenous-led research, secure and long-term funding, legislative recognition of Indigenous midwifery authority, and full access to Indigenous-designed and -governed midwifery education—is urgently needed. This work must be directed by Indigenous communities, midwives, and knowledge keepers, not only supported by policy shifts but grounded in restitution and Nation-to-Nation accountability.

Moving between Regulated and Unregulated Birth Care

Much of the literature on unregulated birth care focuses on motivations to seek or provide alternative care, and while motivations do show up in our data, our aim here is to provide greater conceptual clarity on different birth practices and the relationships among them. We begin by problematizing the common conception that all out-of-hospital care is unregulated care, pointing out the many ways in which those seeking unregulated forms of care may also make use of various kinds of regulated birth care. Indeed, there are many kinds of unregulated birth care, and many interface with the existing provisions of the regulated health care system. In some ways, they might even be seen as complementary. In our data, a range of birth practices are evident, often negotiating the line between regulated hospital-based care, regulated out-of-hospital care, and unregulated care which takes place outside of hospital and often outside of the healthcare system. In problematizing the assumption of a clear division between unregulated and regulated care, we gain a more fulsome understanding of existing birth practices.

Doulas

As an unregulated health profession, there is no legal definition or required certification for doulas in the province of New Brunswick. Doulas of New Brunswick is a professional organization affiliated with DONA International, which provides doula training and its own accreditation (DONA International, np). Doulas are therefore not part of the regulated healthcare system in the province, and they are contracted and paid privately by clients. Like midwives, they may support clients at home or at hospital births. Unlike midwives, doulas are not medical professionals, and they are not legally empowered to be the primary attendant at births. While doulas are unregulated birth workers, they often work within the regulated system alongside physicians, nurses, and midwives at hospital births, and alongside regulated midwives at home births. Perhaps because they work closely with midwives and the midwifery model of care, doulas are often confused with midwives, as indicated by some interview participants:

> A lot of what I do is just explaining to people that I am not a midwife. This is what a doula is, this is what a midwife is. You know, they're [midwives are] clinical care practitioners, they can order tests. (SP)

> I do a lot of doula work and so I work closely with midwives, of course, but also with OBs, with hospital care. (Genvieve)

> The midwife takes more of the medical side, right. And the doula does more of the support. (Therese)

As discussed further below, some birth workers may call themselves doulas when they are actually attending births as unregulated (lay or traditional) midwives.

Lay Midwives and Unattended Birth

Home-based birth workers have a long history in New Brunswick. These kinds of birth workers are sometimes called traditional, lay, or independent midwives; they are usually trained through a combination of apprenticeship, self-education, and some formal education. Sometimes, lay midwives have received formal midwifery training at an accredited institution but their training does not meet the current standards for registration in the province; in other cases, they have decided not to obtain or maintain their registration. Lay midwifery is not included in the provincial health care system, and therefore clients of these services pay out of pocket. Under the New Brunswick Midwifery Act, only those registered with the Midwifery Council of New Brunswick may use the professional designation of midwife and attend home births. According to our interview participants, lay midwifery was widely practiced before the implementation of the Midwifery Act, and although the legal prohibition on this work has driven some lay midwives underground, the practice is still relatively common among those seeking alternatives to hospital-based birth.

> I was around women who are unattended birth assistants, they call themselves, or lay midwives. And women who have been birthing at home without any support other than maybe these women, these lay midwives. (Christina)

Some lay midwives do this work to fill a gap in the provision of home- and community-based care. Nathalie Pambrun, Michif Registered Midwife, former head of the Midwifery Council of New Brunswick, and Community Engagement Lead at NCIM explains:

> Lay midwives' work is a form of harm reduction to address critical gaps in regulated home- and community-based care. They're going to the margins to reach the folks who aren't being reached and that's where our health system transformation needs to go.

One participant saw her work in this capacity as a service to members of her community. Lisa explained: "You're serving women. They ask you to be with them when they birth: end of story."

In our interviews, participants sometimes expressed uncertainty about the nature of their care providers' training, or they were reluctant to talk in more detail about what they did know. One participant, seeking a midwife through people she knew "who were midwives but couldn't be actual midwives here" found care with a provider who was described as "more or less the same." In reflection, Danielle said: "So I trusted that opinion. I don't feel like I should have, but I did."

In the instance of lay and traditional midwives, there is less interplay with regulated and hospital-based forms of care, though some clients of lay midwives *also* access regulated forms of care, piecing together various provisions to obtain the kind of birth care they seek. Sometimes, lay midwives support clients at hospital births but downplay their role in the provision of birth care and call themselves friends or doulas instead of unregulated midwives. As Lisa explains:

> There were situations where we just get in the car 'cause she [the birthing person] decided she wants to go and you go and you know, she pretends that she had no intent to birth at home, and she's whatever. You lie. (Lisa)

In other instances, physicians may support their clients in seeking lay midwives to have a home birth. As one person told us,

> I know someone who had an unattended birth, and they were able to have a doctor who was familiar with midwifery and was just, like, "I will help you to know if you're at risk. And tell you if I don't think you should do it." (Erin)

In the comments of our participants, there is a great deal of conflation between lay midwifery, unattended birth, and freebirth. For instance, Genvieve explains:

> To answer your first question, whether or not unattended and freebirth is different, I use them in the same way. That being said, if I was a doula who was working in a kind of a freebirth capacity, I might have different—I might think about that differently, but in terms of what I've seen, unattended and freebirth are pretty similar. (Genvieve)

In other interviews, participants used the terms "unattended birth attendant," a confusing formulation which attempts to both hide and recognize the presence of an unregulated birth worker. Similarly, participants sometimes talked about a "radical" subset of lay midwives who eschewed regulation and regulated midwifery and worked in tension with those advocating for the implementation of a midwifery practice within the provincial healthcare system. While the birth practices themselves may look similar, we argue that orientation to regulation is a key factor differentiating between unattended birth (birth with a lay or traditional midwife) and freebirth, with most lay midwifery practitioners and clients exhibiting more readiness to negotiate across regulated and unregulated forms of care and freebirth practitioners taking a staunch anti-regulation position. Our data indicates that despite some confusion and obfuscation, freebirth is increasingly a form of birth care that falls completely outside of regulated healthcare systems and actively resists this negotiated relationship with regulation in many systems.

Free Market Freebirth: Against Regulation

In our research, it became evident that there was a stark difference among the forms of care we describe above as doula, lay midwifery, and unattended birth, and the kinds of birth work being offered by freebirth advocates. We refer to this group of birth workers as "freebirth entrepreneurs" and note that they combine free market monetization, aestheticization, and social media alongside an alignment with the unregulated wellness industry in the specific forms of care they provide. With roots in the region where this study took place, the Free Birth Society is one example of freebirth entrepreneurs, but there are many others (Dickson 2020; Butler 2020). In our study, people who wanted to birth outside of hospital but were unable to access regulated or unregulated midwifery care often found their way to the Free Birth Society and other freebirth entrepreneurs through word of mouth, internet searches, and social media. The principles of the Free Birth Society, including an active distrust and undermining of regulated midwifery in the region, may or may not have been what these people were originally seeking.[1]

We use the term freebirth entrepreneur as a catch-all for a group of practitioners who are not regulated healthcare professionals, and who claim expertise based primarily in lived experience and ideas about the naturalness of childbirth. Their services include the provision of various and often overlapping kinds of care such as information about pregnancy and birth (individually in-person, through online interactions, through virtual trainings, and in-person groups); prenatal care (visits with the pregnant person, virtual advice and check-ins, pregnancy support groups offered virtually or in person); being present at births; and other services of a similar nature.

While a suite of services is offered, by those with a variety of backgrounds, under the freebirth entrepreneur model, there are similarities across the types of care these communities and groups provide. Freebirth entrepreneurs often highlight the language of entrepreneurialism in their marketing, typically charging fees for service while operating completely outside of the formal healthcare system. These service providers frequently express low tolerance for pregnant people and other birth workers (e.g., doulas) who wish to interact with both the regulated and unregulated worlds of birth work. Indeed, the Free Birth Society specifically espouses ideas of birth as natural and cautions members that any involvement with regulated providers, from prenatal care to assistance at labour and delivery outside of their network, is antithetical to freebirth practices, insisting that members of their group fully reject the formal healthcare system to enter and stay within their community (Kale and Osborne 2025). This group, and others like it, represents a sector of unregulated birth workers where births may indeed be "unattended," and the aim is to remain entirely outside of existing healthcare systems. Thus, we argue, freebirth entrepreneurs take a position that is explicitly opposed to any forms of regulated care. That is, they espouse unregulated and out-of-system birth practices only, sometimes to extreme ends (Kale and Osborne 2025).

Free Market Monetization

The freebirth entrepreneur approach to birth care is commodified and commercialized. Before the Covid-19 pandemic, some freebirth entrepreneurs were providing birth support for a fee of $3000-5000; this included pre-natal support and information sharing and often being physically present at the birth but not intervening in any way. Judy explains the financial cost and lack of professional training associated with this kind of service:

> So, for my unattended birth, that's not available for people, I paid three thousand dollars to have my baby at home. That is not something that is possible for [many] women. (Judy)
>
> And they aren't as trained [as registered midwives], and they don't have the equipment, and all that stuff. (Judy)

In recent years, freebirth entrepreneurs have begun to organize and share information online, including fee-based training sessions and webinars. Those seeking advice have increasingly found support online, sharing information, resources, and experiences. Despite stated commitments to "a global sisterhood," "body sovereignty," and "the return of the matriarchy," the resources offered by freebirth entrepreneurs are accessed only through paid registration in closed trainings and private memberships accessed through paywalled websites (Free Birth Society 2025).

Aestheticization and Social Media

As part of the wellness industry, aesthetics surfaces as an important aspect of the freebirth entrepreneur narrative. And as freebirth entrepreneurs eschew any involvement with healthcare systems, they often deliver this highly aestheticized service through online social media platforms, YouTube, and Substack. One participant, who did not want to be directly quoted, talked about one of the main actors in the Free Birth Society, who was locally based at the time, as beautiful, charismatic, engaging, and radical.

As the region has been so poorly resourced with respect to regulated midwifery for so long, many participants discussed the role of the internet and social media in finding information about out-of-hospital and out-of-system birth and finding information from freebirth entrepreneurs about "do it yourself birth." Again, the aestheticized nature of this business model is evident in participants' comments:

> Before I got pregnant I was watching a YouTuber who had a home birth. And like I had followed them for a while and I had thought that it was a very like beautiful experience, you know, like the lights were dim, and she had her own clothes on, not like a hospital gown, and she had her family there, and the husband was super involved. I don't know if they had a midwife, but I… that was where the idea of a home birth came in. And so, when I did get pregnant, I really wanted that, and then I found out that we had midwives here, so home birth was available, which was surprising to me 'cause I hadn't heard of it around here before. (Liza)

> They know this [home birth] is what they want and then they get into the research rabbit hole where there was a huge world of unattended home births and a lot of times it is totally fine. I mean a lot of times people can give birth with no problems. But when there are those problems, we should have a midwife there. [Laughing] You know? Yeah, I think it's sad when there's somebody who wants a midwife and can't have one. (Margaret)

Freebirth entrepreneurs are ideologically anti-system and anti-institution and, as we demonstrate below, this also further extends toward positions best described as anti-science, with strong alliances with many of the health conspiracies that gained traction during the peak of the Covid-19 pandemic and that continue currently.

Wellness Industry and Conspiracies

Over the last several years the Free Birth Society has adopted views that are explicitly against regulated midwifery, gender essentialist (for example, statements such as women are closer to nature and are meant to give birth), and transphobic ("gender critical"), as well as espousing some ideas about Covid-19 and vaccines that align with various alt-right and Covid-19 conspiracy theories.

We see this freebirth movement as part of the wellness industry, associated with healthism discourses, and increasingly and overtly aligned with a gender essentialist orientation including promoting transphobic and homophobic beliefs. There are also elements of cultural appropriation and a language of freedom that is deeply individualized. Freebirth entrepreneurs are deeply anti-authoritarian, as evidenced by their hostility to regulated midwives, with a strong mistrust of the state. As one participant from our interviews explains:

> There's a sort of anti-vax, anti-medicine, anti-institution, anti- whatever sector that connects to this that I think can also undermine what I think needs to happen, for example. It's not just like, I want

> the right to have my baby at home and these are the reasons that it can be safe, or this is why I want to do it—it's the, like, I don't trust doctors they're gonna give us needles and all this stuff.

Due to the ambiguous legal status of unregulated birth work, those involved in freebirth practices and freebirth community were often reluctant to be directly quoted while sharing their information, fearing legal and social repercussions. One study participant, who did not want to be quoted directly, shared her concerns about people calling themselves lay midwives who were part of this freebirth community, stating that these providers are actively against regulation and are anti-education, using the word "radical" to describe their overall orientation to birth. Another participant, who also did not want to be quoted directly, shared her experience of attending a meeting with freebirth advocates, where there were discussions that she felt were very "anti-midwife," stating that those in attendance saw regulated midwives as a threat to those who wanted to birth outside the system.

While freebirth entrepreneurs often express commitments to evidence-based services and processes of informed consent using language similar to what one would expect from a regulated midwife, we argue that they are more aligned with the burgeoning wellness industry's orientation toward a for-profit, commodified, neoliberal version of healthcare and personal health responsibility. We see the increased profile of the freebirth entrepreneurs during the peak of the Covid-19 pandemic as an example of this, when many other ableist and eugenicist ideas about control of the body as a sign of a healthy/fit individual and narratives of personal responsibility circulated as part of an open distrust and undermining of government regulated and provided healthcare.

Consequences of the Lack of Conceptual Clarity

The lack of conceptual clarity about the various forms of birth care can be attributed to several factors. As demonstrated above, many forms of unregulated birth work intertwine with regulated forms of care offered within the healthcare system. Other forms of unregulated work exist completely outside of the system and the illicit nature of this work means that it may be difficult to discern exactly what kinds of training and experience care providers offer and what their central motivations and orientations for providing birth care might be. The consequences of the lack of conceptual clarity are myriad but are most worrisome for those seeking care. As one participant explained, "There's, again, not a strong understanding of what midwives are, what doulas are, what unattended births are."

The confusion is not just among those seeking care but extends to those practicing in the medical system and there is concern that this has negative consequences for regulated midwifery in an area where it has been insufficiently resourced and understood. As one participant explained:

> …there have been hospital transfers and that has coloured the perceptions of some health care providers in some centers as to midwifery care. Even though these individuals weren't using midwifery care, it's more in terms of home births. There's a fear of home births, I think, in some [health care] centers, just because they've seen these hospital transfers of those who have decided to freebirth at home and then something happens, and they go to the hospital and... they're seeing just what goes wrong. They're not seeing what goes right in terms of home birth. (Erin)

Recent data indicate that out-of-hospital births are likely to continue to increase, in both regulated and unregulated forms (McKenzie, Robert, and Montgomery 2020). As McKenzie, Robert and Montgomery (2020, 517) note, "the lack of appropriate midwifery services has been recognized as a factor in women's decisions to have UBWs [unregulated birth workers] at their births as opposed to regulated HCPs [health care professionals]". They go on to note: "Linked to this is the rurality of some women's homes" (2020, 517). The scholarly literature includes several recommendations for addressing the growth of unregulated birth work, including harm reduction strategies, shared decision-making and renewed attempts to connect with those considering unregulated forms of birth care (LeBlanc and Kornelsen 2015; Shorey et al. 2023). Perhaps most relevant to the context of our study however, the data also demonstrates that the expansion and fulsome integration of regulated midwifery will go a long way to mitigating the growth of organizations like the Free Birth Society. Indeed, many of the participants in our research who ended up having unassisted births indicated that they would have preferred a home birth with a registered midwife instead, a finding that echoes that of LeBlanc and Kornelsen (2015).

While we agree that out-of-hospital and out-of-system birth can be and often are part of a feminist commitment to community care and bodily autonomy, we are also concerned that freebirth entrepreneurs co-opt the history and language of feminist community-centered healthcare to align with specifically anti-feminist beliefs —especially those feminist beliefs and core comments that are based in justice-oriented approaches. A look at any of the Free Birth Society public facing pages will demonstrate commitments to the radical liberal feminism often perpetuated by white feminism. We argue that freebirth entrepreneurialism is an emergent source of birth information that may be attached to essentialist views about gender, hyper-individualism, and, at times, with conspiratorial orientations to medicine and science, and as such undermines the work that intersectional and Black feminists have advanced through the reproductive justice framework.

Conclusion

Clarifying the differences among forms of care is crucial to increasing informed decision making and safety and a crucial first step in undertaking further research on regulated and unregulated birth practices. Justice oriented frameworks for understanding the political nature of birth practices complicate how we think about choice. Rather than seeing choice as an individual level practice, reproductive justice and anti-colonial approaches emphasize that choice is always shaped by complex relationships of power and oppression. These justice-oriented approaches to thinking about birth allow us to understand how people make decisions about the type of birth care they will choose for many reasons and seek a variety of sources of information and care providers to support this choice. These choices are often based in difficult experiences with healthcare systems, including experiences of racism and violations of consent, sexual violence, and other traumas. A justice lens also allows us to see how centring individual choice can also contribute to maintaining relationships of power and oppression. The availability (or unavailability) of a range of forms of care will shape the extent to which people seek and consider alternative options.

The link between freebirth entrepreneurialism, conspiracy theories, and white, trans-exclusionary feminism has become particularly troubling. Based on this early analysis of incidental findings, we are concerned that freebirth entrepreneurialism lacks an analysis of power and gendered oppression and that, as a result, it could reinforce settler colonialism, white supremacy, gender essentialism, and other forms of oppression. For example, when freebirth entrepreneurs incorporate aestheticized aspects of Indigenous birth practices and appropriate the language of bodily sovereignty, they trivialize the ongoing and systemic harms of colonialism on Indigenous people and their birth experiences and practices, including a continued lack of access to Indigenous midwifery care, while benefiting from the harmful settler colonial romanticization of Indigenous cultural practices.

In the context of our research, we argue that rurality, the frequent closure of hospitals in smaller centres, and serious obstacles to widespread access to regulated midwifery care have fuelled the growth of a range of unregulated birth care practices, including freebirth. Some versions of unattended, out-of-system birth also undermine existing movements for regulated midwifery, birth justice, and reproductive justice in the region.

While motivations for out-of-system birth are being well studied, the possible relationship between motivating factors for out-of-system birth and choice of care provider (including no care provider) should also be explored more fully, particularly in the Canadian context. Motivations for providing out-of-system birth care should also be considered an important topic of investigation as this may point to problems and potential interventions in maternity care. Clarity on the various approaches of out-of-hospital birth and out-of-system birth that consider their core orientations, such as the conceptualization we have suggested here, will enable more analytical power in further studies in this area.

Finally, while we have attempted to clarify some of the forms of care that are typically conflated as freebirth in the extant literature, it is also clear that there is considerable movement across regulated and unregulated forms of care, which should be embraced in contexts such as movements for Indigenous birth work. Recognizing that people will make the best possible decisions given their own needs, experiences, and desires is crucial to destigmatizing the choices that people make about their birth experiences. Although freebirth entrepreneurs are ubiquitous in online spaces and in some physical spaces in the region where we have conducted our research, our data indicates that most of those who sought or engaged in forms of unregulated birth care were not seeking freebirth, and we have no evidence to suggest that participants in our study endorse the more extreme positions of freebirth entrepreneurs. To the contrary, a central finding in our research is a strong desire for access to home birth with regulated midwives, alongside a commitment to equity and inclusion. Building on the conceptualizations introduced here, we will continue to examine the relationships between regulated and unregulated birth practices, and the rapid growth of freebirth entrepreneurialism.

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Conflict of Interest

We have no conflicts of interest to declare.

Endnotes

As we were finalizing this article, *The Guardian* released a series of articles, podcasts, and videos detailing the damning findings of an in-depth investigation of the impact of the Free Birth Society. Descriptions of the FBS and the actions of its founders confirm our assertions about the distinct nature of freebirth entrepreneurialism. For more, see Kale and Osborne (2025).

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"I don't want to be a burden on others": Perspectives of "Young-old" Thai Women on Self-reliance, Wellness, and Aging

by Kullanit Nitiwarangkul

Abstract: This article examines the perspectives of middle- and upper-class "young-old" women (aged 60 to 69) in Thailand on "wellness" amidst the country's rapidly aging population. Drawing upon findings from my interviews with sixteen older women, it explores how self-reliance has become central to their pursuit of decent physical and mental health. Participants strived to maintain their health, preserve mobility, and reduce dependence on family members. At the same time, some served as caregivers for their families in a culture that emphasizes familial interdependence. Additionally, this paper analyzes how "mental wellness" is framed within self-reliance, shaped by Buddhist teachings and neoliberal ideals, as these women navigate life transitions and sustain their well-being amidst the disruptions of COVID-19. The study further demonstrates their rising concerns and demands for essential resources for their wellness, including health insurance, professional caregiving, and adequate housing, in the absence of sufficient public welfare. The paper offers a nuanced understanding of self-reliance and wellness in later life and promotes interventions to support older individuals. It does so by foregrounding the classed, gendered, and culturally specific experiences of aging women in the Global South, a topic rarely studied in fields such as gerontology and feminist studies.

Keywords: aging; self-reliance; wellness; intersectional identities; Global South

Résumé : Cet article s'intéresse au point de vue des « jeunes vieilles » (âgées de 60 à 69 ans) issues des classes moyenne et supérieure de Thaïlande sur le « mieux-être », dans un contexte de vieillissement accéléré de la population. Fondé sur des entretiens que j'ai menés auprès de seize femmes âgées, l'article montre comment l'autonomie est désormais au cœur de leur quête d'une bonne santé physique et mentale. Les participantes s'efforçaient de maintenir leur santé, de préserver leur mobilité et de réduire leur dépendance à l'égard des membres de leur famille. Parallèlement, certaines assumaient un rôle d'aidantes auprès de leur famille dans une culture qui valorise l'interdépendance familiale. De plus, cet article analyse comment le « bien-être mental » est envisagé sous l'angle de l'autonomie, influencée par les enseignements bouddhistes et les idéaux néolibéraux, alors que ces femmes traversent les transitions de vie et préservent leur mieux-être malgré les perturbations causées par la pandémie de COVID-19. L'étude révèle en outre qu'en l'absence d'une aide sociale suffisante, elles sont de plus en plus préoccupées par les ressources essentielles à leur mieux-être, notamment l'assurance maladie, les soins professionnels et un logement adéquat, et qu'elles les demandent de plus en plus. L'article apporte un regard nuancé sur l'autonomie et le mieux-être à un âge avancé, et encourage les interventions visant à soutenir les personnes âgées. Pour ce faire, il met en premier plan les expériences, marquées par la classe sociale, le genre et la culture, des femmes vieillissantes dans les pays du Sud, un sujet peu étudié dans des domaines tels que la gérontologie et les études féministes.

Mots clés : vieillissement; autonomie; bien-être; identités intersectionnelles; pays du Sud

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Background and Rationale

Thailand, a country "getting old before getting rich," faces increasing pressure to support its aging population (Zachau 2016). Life expectancy rose from 70 years in 2000 to 75 years in 2021, yet public welfare remains insufficient, especially amidst the COVID-19 pandemic, economic downturns, and political instability (WHO 2025). Government allowances for older individuals are as little as 600 to 1,000 THB (Thai baht; approximately 19 to 32 USD) monthly, per the exchange rate as of February 2026, with pensions only available to former government workers (Jumnianpol et al. 2023). Since 2022, budget cuts have restricted such allowances to vulnerable groups rather than all senior citizens (Arunmas 2023). Despite limited financial welfare, Thailand provides relatively broad healthcare access. By 2021, 80% of the population was covered under the Universal Healthcare Scheme, allowing treatment of all diseases and illnesses for 30 THB (approximately 1 USD) (Damrongplasit and Melnick 2024, 1). However, the rising demands on healthcare due to population aging and the pandemic have led to overcrowded facilities and inconsistent quality of care (Damrongplasit and Melnick 2024, 1).

Despite limited public welfare, the healthy and productive aging agendas, reflected in the United Nations' Sustainable Development Goals 2030 and Thailand's recent policies, are encouraging older people to age well with financial management, engagement in socioeconomic activities (such as lifelong learning, entrepreneurship, and employment), and maintenance of wellness in old age (DOP 2019; UNDP 2018). Political instability, economic crises, and the COVID-19 pandemic have further constrained resource distribution, reinforcing pressure on older individuals to reduce dependence on public welfare by prioritizing health, activeness, and financial security (Jensantikul 2022; Shimoni 2023). Such "successful aging" rhetoric particularly targets the "young-olds" (aged between 60 to 69), who are often regarded as having greater purchasing power and as healthier than older seniors (Kohlbacher and Chéron 2012, 179). Representing 60% of Thailand's over-60 population, this growing demographic is central to the country's aging society and policies (TGRI 2022, 23). Therefore, my research focuses on women in this age demographic in Thailand, who also face the "double standard of aging," which places higher expectations on them to maintain youthfulness and decent bodily conditions than their male counterparts, similar to those in the same age group in many other cultures, including Western countries (Sontag 1997, 19). Women's aging bodies are often pathologized through health and medical discourses, which pull them "into the cycle of consumption of anti-aging goods and services" (Niamsri and Boonmongkol 2017, 62). Thus, they are often required to regulate their lifestyles and engage in self-care practices to be healthy and self-reliant amidst the current precarious socioeconomic context.

Furthermore, older women's livelihoods and identities are often shaped by gendered norms obliging them to prioritize familial relations. Traditional beliefs rooted in Buddhism and Confucianism promote filial piety or *Kwam Katanyu* in Thai, where younger family members are expected to care for the elders as an expression of gratitude (Fan 2007; Knodel, Teerawichitchainan, and Wiraporn 2018). A 2021 Ipsos survey found that over 90% of Thai people oppose placing elderly relatives in care homes, viewing it as irresponsible (Wuthithanakul

2021). However, this obligation to look after older family members at their own homes has been increasingly questioned, partly due to the recent anti-establishment political protests in the early 2020s, spearheaded by younger generations, which have challenged political authorities and traditional Thai values reflecting societal hierarchy, including *Kwam Katanyu* (Lertchoosakul 2023). Additionally, recent economic downturns following the pandemic have limited families' capacities to care for each other. Therefore, many older women may consider alternative care options, including retirement housing and privatized health services.

Given their central caregiving and familial roles, older women's health directly impacts their households (Archawanichkul and Boonmongkul 1996, 4). Being in the sandwich generation, "young-old" women in multigenerational families, comprising 37% of all Thai households in 2015, must juggle roles as caregivers of older and younger family members (UNFPA 2017). This phenomenon is a result of recent demographic shifts, including the rise in the proportion of the "older old" (aged over 80) from 0.8% to 3.6% in 2023 and delayed parenthood as the proportion of women having their first children at age 30 or older rose from 10.4% in 2001 to 14.5% in 2019 due to higher educational attainments and growing career opportunities (ESCAP 2023; Kaewbuadee and Pothisiri 2019, 57). Consequently, many of these "young-old" women have to simultaneously look after their children, younger grandchildren and older parents. Such care demands intensified during the pandemic lockdown, as reported by over 50% of women in Thailand across all age groups (UNDP 2022).

Beyond physical health, my research highlights the significance of mental resilience as integral to the "young-old" women's development of wellness and self-reliance as they experience multiple life transitions simultaneously, including career shifts, retirement, changes in familial and personal relationships, and evolving physical conditions (Radtke, Young, and van Mens-Verhulst 2016). It also explores how some participants drew upon Buddhism, a religion that has had a profound root in Thai society for centuries, to cultivate and strengthen their mental stability and resilience, especially amidst the pandemic. Research suggests that older women are among the most active participants in religious observances as they may have more spare time after retirement (Limanonda 1995, 80). Such activities also foster a sense of community and serve as compensation for women's relatively lower status in Buddhism, as they are not allowed to be ordained as monks in the same way as men in Thailand (Santisombat 2005, 128).

My research demonstrates the cultured, classed, gendered, and aged experiences of middle- and upper-class "young-old" Thai women, contributing new knowledge to gerontology and biomedical studies that view older people as a homogenous group. These previous approaches merely offer one-size-fits-all definitions of wellness to reinforce individuals to age a certain way. For example, Rowe and Kahn's (1997) definition of successful aging is having a "low probability" of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life" (433). Such a definition assumes that wellness in aging can be measured solely through scientific methods and biology, such as by examining individuals' medical records (Katz and Calasanti 2014, 28). My research, therefore, seeks to take a critical gerontological approach to challenge such deterministic definitions of aging and wellness, offering more multifaceted and deeper insights into the social and cultural contexts that shape them from the perspectives of "young-old" Thai women (King and Calasanti 2006).

Moreover, there is little research on older women's unique perceptions of health and wellness, let alone in a Global South context in feminist studies. Older women are often marginalized in feminist movements and advocacy (Segal 2013). More investment has also been allocated to social development projects targeting younger females, such as those promoting educational and employment opportunities, which are regarded as more economically productive than those focusing on older women (Wilson 2015, 818). Therefore, through an intersectional Global South feminist lens, my research centralizes the voices and personal narratives of "young-old" women, situating their understanding of wellness within broader sociocultural and economic contexts of a rapidly aging society in Thailand. By doing so, it contributes to the growing literature in feminist studies that is often dominated by perspectives of younger demographics of adult women, predominantly from the Global North.

Methodology

Participants and Recruitment

Participants were informed that they were recruited as part of a larger study on successful aging, which explored older women's perceptions and the sociocultural discourses surrounding "good ways to age" across various dimensions, including retirement, health, family, and leisure, among others. Most were recruited from my networks of families and acquaintances, and a few were recruited through *Young Happy*, a social enterprise I volunteered with that organises activities bringing together communities of older individuals. This sampling method was not aimed at generating a representative sample. It sought to capture the "situated knowledge" from the perspectives of women with a similar socioeconomic background to my family and myself and ensure some commonalities among participants (Haraway 1997). As a result, I can better represent their stories through my first-hand perspective as a college-educated upper-middle-class woman from Bangkok, the capital city of Thailand. Aside from those recruited through *Young Happy*, I had briefly met and interacted with most participants as they were friends and acquaintances of family members, but I had no close relationship with any. Such weak ties between us and my distance from their social and familial circles, alongside assurances of confidentiality and anonymity, made participants feel comfortable sharing information they might not have shared with close family members or friends, as they were less concerned about potential judgments and disclosure.

Nevertheless, it is essential to address our differences, including age gaps, educational backgrounds, and cultural experiences. Unlike the participants, I was in my early 30s and had been educated in UK universities since my undergraduate years, whereby I was influenced by predominantly left-leaning and feminist ideologies. Due to such cultural and education experiences alongside exposure to stereotypical representations of older people in the media, I inevitably presumed my participants' views to be relatively more right-leaning. Generational gaps and divergences in socio-political viewpoints emerged during the interviews, particularly regarding the extent to which older individuals or the public sector should bear responsibility for providing resources to ensure wellness.

All participants were biologically female (assigned female at birth) and identified as women. They were from either a middle- or upper-class background and lived in Bangkok and nearby provinces. Although they were not asked about the amount of their income and savings, it can be presumed from their occupational backgrounds that some could be well placed in the top 10% of the national income bracket, earning up to more than 100,000 THB (approximately 3,200 USD) monthly (Jenmana and Gethin 2019, 1). Some participants were still working or had retired from academia, governmental organisations, medical services, and financial institutions, where they were in higher positions and leadership roles. Some were entrepreneurs and freelancers. One was a housewife. All of them lived with at least one family member. Most were married with or without children, a few were divorced, and some were unmarried and/or single. My research intentionally focused on wealthier older women; these women are less accessible because they constitute the minority of the population and hence have been overlooked in previous research on Thai older adults, such as in Wongsala, Anbäcken and Rosendahl (2021).

Data Collection and Analysis

I obtained ethics approval from the Ethics Committee of City and St. George's, University of London, and participants were sent an informed consent form following the Committee's template (which was translated into Thai) to be signed electronically before data collection. Semi-structured online interviews were then conducted and recorded in Thai with sixteen women throughout the first two weeks of October 2021 via Zoom and LINE, to prevent the risks of COVID-19. I transcribed the interviews by listening and verbally repeating participants' responses into my laptop's microphone using the Microsoft Word voice typing feature to immerse myself in and empathize with their first-hand perspectives. Despite technical issues and limited access to non-verbal cues, online interviews offered unexpected advantages, including glimpses into participants' personal and residential spaces, which revealed their living conditions and practices related to wellness. For example, one participant pointed to her unused treadmill, functioning as a clothes airer, symbolizing, as she said, her "lack of physical activity."

Each interview typically lasted one to two hours and consisted of three parts: narrative, conceptual, and discursive (Kvale 2009). In the narrative part, participants shared their personal experiences, such as life stories, employment status, relationships, and living arrangements. The conceptual questions explored how they constructed meanings of aging, whether they had an ideal vision of aging, and whether their views had evolved over their lifetime, among other questions. The final discursive part examined how sociocultural and economic contexts shaped participants' experiences and perceptions, such as economic situations, media representations of older people, and political dynamics in Thailand.

While conducting the interviews, I avoided explicitly expressing my stance towards certain issues and challenging my participants' perspectives, particularly where the discrepancies between our generations and worldviews became apparent. As a result, they could express themselves without demonstrating desirability, such as by solely sharing views that could potentially match the researcher's. To further reduce the researcher's influence and strengthen the study's validity, I minimized direct probing by using broad questions like "What does a good aging life look like to you?" instead of close-ended ones, such as "Do you think a good aging life means being healthy?"

As a sole researcher, I analyzed data using thematic and discourse analytical approaches. Initially, I applied *inductive* thematic analysis to identify emerging patterns in participants' perceptions of successful aging to avoid imposing prescriptive definitions of the concept and using apriori themes (Clarke, Braun and Hayfield 2015). Such an approach sought to be *empathetic* with participants' life circumstances, emotions, and experiences (Gallagher and Zahavi 2020). To maintain closeness to the linguistic and cultural nuances of the data, I annotated the untranslated transcripts with words and phrases in Thai and translated them to English, such as "exercise" and "health insurance." Some of which served as initial codes. These were then organised in a Microsoft Excel spreadsheet alongside corresponding participant quotes. This process enabled me to track repetitions and divergences of ideas across the dataset. Codes were subsequently grouped into sub-themes, such as "maintenance of physical conditions" and "financial security" and broader themes, such as "self-reliance," until thematic saturation was reached.

Following thematic analysis, I conducted a critical discourse analysis. This analytical stage involved taking a *critical* approach by unpacking the sociocultural processes, policies, economic conditions, and societal power that may have shaped participants' experiences, perceptions, and practices pertaining to wellness and aging (Wodak 2004, 188). I supported my analysis with secondary sources, including government policies, national statistics, media representations, and literature on Thai cultural values, such as filial piety, to contextualise how language was used to construct the meanings of successful aging and strengthen analytical credibility. Throughout the analysis, I engaged in continuous reflexivity by addressing and noting how my socio-political stances, educational backgrounds, and emotional responses shaped the coding and interpretation process. For instance, I may have categorised participants' testimonies on their regular exercise routines as "self-discipline" due to my engagement with Foucauldian literature, although they may not have regarded such practice as such. Overall, the researcher's influences, such as unintended prompts, positionality, and relationships with participants, were reflexively addressed throughout data collection and analysis.

Findings and Analysis

Participants highlighted self-reliance as one of the most crucial components of successful aging.They defined and attempted to achieve self-reliance in several ways, including maintaining their physical health conditions to reduce care from family members and, in some cases, to provide care to them; enhancing their mental well-being; seeking non-familial care services; and adjusting their living spaces to accommodate solo living arrangements. According to them, being self-reliant means supporting oneself sustainably without becoming anyone's "burden" and maintaining stability in various aspects, including physical and mental conditions, financial security, and living arrangements.

Maintaining Physical Wellness for Themselves and Their Families

Almost all participants expressed that they would like to maintain their health and bodily conditions due to the internalization of beliefs that the aging body can become more vulnerable and deteriorate (Paulson and Willig 2008). Maintaining a physically strong and able body would allow them to carry out daily routines without the assistance of others, especially their family members:

> I want to be strong not only for myself but also for my children and grandchildren. When I am ill, they would need to look after me, and this is going to take up their time working because they would have to take me to the doctors, which is just too much for them. (SN, 66, former university professor)

Even though this participant was diagnosed with a later stage of lung cancer at the time of the interview, she still showed consideration for her family members when it came to care duties. Her testimony contests the traditional belief of filial piety or *Kwam Katanyu*, whereby younger family members need to look after the elders, and it reflects the precarious conditions of a neoliberal economy in which individuals are compelled to prioritize earning a living. Participants who were single and/or childless also placed a high value upon physical wellness because they did not have younger family members around them:

> Since I am single, I would not want to be anyone else's burden later. This means I should be taking care of myself. All of us [herself and her other two siblings who were 65 and 72 at the time] are single, which means we all have to take good care of ourselves, especially in terms of health. (MM, 69, former government officer)

As an unmarried and childless woman, MM realized she may be unable to find care support from younger family members. She also considered the wellness of her siblings when discussing the preservation of her physical health. Her testimony reflects the broader concerns that single and childless older people in Thailand may have regarding their care arrangements due to a lack of access to immediate and readily available familial care, especially in times of emergencies. Therefore, they would place even greater emphasis on self-discipline and self-care practices.

Furthermore, some participants were caretakers for their family members, making it essential for them to maintain and improve their health (Archawanichkul and Boonmongkul 1996). Over half of them described care as their duty or an integral part of their everyday routine. The pandemic also heightened concerns about personal and familial health and wellness, particularly among those caring for elderly relatives. Some expressed a strong responsibility to protect their parents from the virus and how the pandemic affected their livelihood:

> I would try not to go outside because I am scared I would bring the virus to the two elders [her parents] at home. Therefore, I would try to restrict my social life and limit myself from going

> outside by ordering delivery food or hurrying back home after going to the market. (PN, 64, freelance accounting consultant)

PN's quote further illustrates how she prioritized her parents' health over her own, expressing greater significant concern about potentially passing the virus to them rather than about its effects on her own body. These findings suggest that for "young-old" women like PN and other participants, caregiving is "framed as an ethic of selflessness and self-sacrifice" (Gilligan 2003, 157). They often discipline and restrict their lifestyles not only to maintain their health but also to safeguard that of their families.

Mental Wellness, Buddhism, and Self-reliance

Several participants discussed and defined mental wellness as the capacity and maturity to cope with life transitions and uncertainties (Hedelin and Strandmark 2001, 10). Such abilities were also interrelated with age and seniority, according to a few participants, as expressed in this quote from an interview with PV, a 60-year-old pharmaceutical company owner:

> When one gets older, they can learn more and more things from life. The more they learn, the more likely they can adapt and cope with what happens around them. (PV, 60, pharmaceutical company owner)

She further explained that as people grew older, they would have witnessed more things and would be more capable of emotionally coping with life changes and events. Mental resilience was also emphasized by participants as a coping mechanism during the peak of the pandemic (Vasara, Simola and Olakivi 2023). A few participants expressed concerns about COVID-19 and how they were learning to cope mentally at the time:

> [COVID-19] taught me that we must look after ourselves no matter what happens.... I used to be quite worried before, but since it is already happening, we must cope and live with it while protecting ourselves as best as possible. (MM, 69, former government officer)

These participants' quotes reflect the importance of emotional resilience as an older person, especially in times of crises and uncertainties. Their views resonate with neoliberal discourses, mainly in lifestyle and self-help media, which position the ability to "bounce back" as an ideal, and even essential, trait to navigate growing inequalities and austerity (Gill and Orgad 2018, 477).

Additionally, Buddhist teachings played crucial roles in participants' maintenance of mental wellness, including in their liberation from the pain of severe illnesses like cancer (such as SN) and management and control of temper (such as RS). Another participant demonstrated how the core teaching of Buddhism helped her manage to live with *Dukkha*, a Sanskrit term that can be translated as suffering, unsatisfactoriness, frustration, unhappiness, anguish, illness, or disease (Chabot 2018).

> I hold onto the teachings of Lord Buddha that everything comes and goes...everyone can face both happiness and Dukkha ... there are two sides to everything. We should not just look at one side and hold on to it. We must tell [ourselves] that [although] today we are happy, the next [day] we may be facing Dukkha. We must be able to live with it so that we do not feel restless.... (PP, 63, housewife)

Her testimony here demonstrates that older people, including herself, have utilized Buddhism to "acknowledge and learn to accept that all things are uncertain," avoid feeling anxious, and be at peace with the present through practices such as mindfulness and meditation (Chabot 2018; Wongsala, Anbäcken and Rosendahl 2021, 8).

There were no mentions of any form of support from others, including family members and professional services, besides practices relating to Buddhism and religious beliefs. Such a finding reflects the influences of contemporary neoliberal values of emotional self-reliance and Buddhist teachings promoting self-sufficiency and a reliance on oneself (Wibunsilaprot and Thitapanyo 2020). The lack of mentions of professional mental health support could manifest the stigmatization of mental health issues in Thai culture, hindering people from receiving professional mental support (Pitakchinnapong and Rhein 2019).

Similarly to their physical health, some participants perceived mental wellness and stability as qualities they should develop for their own sake and the benefit of their families. One spoke about how she needed to provide mental support as a senior in her family when her younger brother passed away:

> I must remain strong and be their mental support because I am a senior [in the family]. I cannot just keep on weeping. That was wrong because there was no use, and I would not get anything in return. People will die at a certain point in time. That is all. (RS, 65, fish vendor)

The participant here associated seniority with mental maturity. From her perspective, resilience cannot be developed solely for personal gains but also through and for networks of family members, communities, and caregivers in the collectivist Thai cultural context (Soonthornchaiya 2020).

Furthermore, mental and physical status are strongly interconnected, according to some participants. Some perceived a positive mindset as a prerequisite for a "good aging life":

> The mind leads the body. (RS)

This participant's reflection resonates with a crucial debate about the relationship and separation between the mind and the body proposed in Cartesian dualism (Duncan 2000). It also reinstates the neoliberal rhetoric whereby individuals can manage and regulate their bodily conditions through their mental capacities and resilience, thereby underscoring the importance of emotional wellness (Gill and Orgad 2018).

Preparing Private Resources to Maintain Wellness

Almost all participants discussed the necessity of preparing and accumulating various resources, such as finances and care arrangements, to maintain and enhance their wellness. Care was commonly highlighted by participants as one of the most crucial resources. Nonetheless, none of the participants explicitly expressed that it is an obligation for younger family members to provide long-term care for them. For instance, PT, a 61-year-old part-time pediatrician, shared her intention to explore care facilities for professional support in the future. At the time of the interview, she lived with her husband, their 23-year-old son, who was a medical student, and older relatives:

> This [retirement housing] will be a trend in the future.... I must understand that he [her son] has his work priorities and won't have time to take care [of me].... Our age gap is quite big.... When I get older, he has to work very hard.... I need to start planning because when I get much older than this and can't look after myself as much as I can now, I need to have [an appropriate] place to live. (PT, 61, pediatrician)

PT further elaborated that the availability of such care centers could proliferate in the future. She also emphasized her preference for such centers as they are likely equipped with trained professionals and better facilities than in one's own home, and other older adults who could potentially be her companions.

PT stated that she cared for her son since he was younger, while pursuing her career up until the time of the interview. She would bring him food while he stayed at his university dormitory and give him rides to college. While PT did not explicitly mention her husband's role, her testimony suggests that caregiving responsibilities are primarily assigned to women, including herself, in line with prevailing Thai gender norms. Yet, she did not expect her son to look after her to repay for her care and express gratitude, despite the deep-rooted filial piety culture.

Alongside care homes and facilities, several participants expressed a desire to adapt their living spaces to accommodate solitary living in anticipation of potential immobility. NJ and PT said they may redesign their residences by adjusting them into one-floor homes with no stairs to minimize physical movements and risks. Notably, these individuals stated this while still being physically capable, demonstrating the importance they had attributed to preparing for the foreseeable future. Their perspectives also reflect a shifting trend within Thai society, where children and younger family members may not co-reside with their parents and elders in the future, nor feel obliged to look after them. Therefore, older adults, including my participants, may need to seek alternative care solutions and living arrangements beyond their familial settings to look after their wellbeing.

Arguably, the very same participants who expressed a lack of expectation for care from their family members believed filial piety was a moral obligation for themselves and therefore continued to care for their parents. Through their experiences caring for them, some may have learned about the potential implications of dependency in their later years of life. For instance, this participant felt compelled to prepare for a self-reliant lifestyle due to her role in caring for her late mother, who fell severely ill and passed away:

> My mother died ... nine years ago. This made me realize that I need to take care of [my] health, and it is not certain whether I will become bedridden [like her mother] in the future. I need to save a sum of money to care for myself later ... when I am in a condition that needs dependency. (NJ, 60, senior government officer)

NJ's testimony represents the necessity to accumulate financial resources to pay for medical expenses in case of emergencies and accidents, especially because she did not have any children or younger relatives living with her. Other participants, including KW, a 63-year-old cosmetic clinic owner, mentioned that she needed to save her money to invest in health insurance premiums. It is worth noting that health insurance is becoming privatized, as stated in the latest government policies, whereby all companies and private sector organisations are obliged to sell insurance policies for people to prepare for aging (OIC n.d.).

These participants perceived that the accumulation of financial resources is a personal responsibility, which reflects the government's advice for Thai citizens to manage their finances by investing in bonds, tracking their expenditures and income, and reducing debts due to limited welfare resources (DOP 2020). It is also worth noting that most participants possessed a greater capacity than the average Thai person to afford professional care services and renovate living spaces. The average cost of living at a privately owned elderly care home is approximately 192,000 to 1,350,000 THB (equivalent to about 6,200 to 440,000 USD) per resident annually, which is not affordable for the majority of Thai people, who earn an average of 240,000 THB annually (equivalent to 7,700 USD) (Bangkok Asset Intergroup n.d.; NESDC 2022). Such insights further highlight disparities between older adults in contemporary Thailand, where only 5% of the senior population can afford professional care and domestic help (TGRI 2021). Nevertheless, regardless of their socioeconomic status, most participants still expressed concerns over their financial and care resources, further exacerbated by the pandemic outbreak, shifts in traditional familial values and relations, and the scarcity of public welfare.

Discussion and Conclusion

This article has examined how the maintenance and enhancement of wellness among "young-old" women in Thailand are deeply intertwined with, and significantly motivated by, self-reliance. Participants' frames of reference and understandings of self-reliance and wellness were very much focused on the ease of "burden" on individuals in their families. My research has generated novel insights into the distinctiveness of the Thai cultural context, whereby multigenerational households are prevalent, and elderly care responsibility is usually perceived as belonging to families due to traditional beliefs (Knodel, Teerawichitchainan, and Wiraporn 2018). Older women thus face the imperative to maintain physical health to reduce reliance on limited public welfare and private care resources provided by family members simultaneously.

Furthermore, some participants sought to strengthen their physical and mental conditions to become independent and self-regulating (i.e. neoliberal) subjects while serving as the backbone of their families, actively providing care and support to loved ones. As primary care providers, some felt obliged to look after their bodily conditions, such as by avoiding contracting and transmitting the COVID-19 virus to more vulnerable family members. Some also saw themselves as more mentally matured as they became older, hence becoming the emotional support for family members during life transitions and crises. My research has, therefore, contributed novel insights into care relationships, living arrangements, and familial priorities of older women, which are distinctive from their younger counterparts, as demonstrated in existing feminist scholarly work on neoliberalism, middle-aged women's careers, and care responsibilities, such as Rottenberg (2022). It has illustrated their unique positions and perspectives of being both a care provider and receiver in a contemporary neoliberal society, where self-reliance is not only valued but has become imperative for the maintenance of their wellbeing and their families' simultaneously.

My research has further demonstrated the complex interplay between Buddhism and the modern neoliberal culture in promoting emotional self-reliance. Several participants consistently highlighted the significant roles of Buddhist teachings, emphasizing one's ability to navigate uncertainties and life transitions, particularly during the pandemic outbreak (Wibunsilaprot and Thitapanyo 2020). It has furthered knowledge in feminist and gerontological literature, such as Shimoni (2023), which often neglects the roles of spirituality and religious beliefs in shaping older individuals' sense of self-reliance and independence. By doing so, it has contributed to broader discussions on wellness and aging by demonstrating the interplay between socioeconomic and spiritual factors that shape individuals' mental status.

My research has highlighted a paradox of care in Thai society, an underexplored dynamic in existing literature on older adults. On the one hand, as expectations for children and younger family members to care for aging parents appear to be diminishing, "young-old" women, including my participants, are seeking to maintain their wellness through private care and financial resources such as personal savings, health insurance, and privatized care facilities. This shift reflects the erosion of filial piety and traditional age-based hierarchies, driven by recent socio-political movements and growing socioeconomic precarity in Thailand (Arunmas 2023; Lertchoosakul 2023). On the other hand, filial piety remains culturally significant, as reflected in participants' continued caregiving roles toward their aging parents.

My study has generated distinctive insights about relatively wealthier groups of older women, who could afford independent living arrangements to avoid dependence on family members for care. Potentially, different views could have been found had this research been conducted with those in the lower income brackets, who may need heavier reliance on familial care. Therefore, it is crucial to note that my research findings are not entirely generalisable nor applicable to all older individuals. Nonetheless, they unveil the social disparities and distinctions between older adults of varying socioeconomic backgrounds and identities.

Additionally, my research has captured the unique meanings of wellness and women's aging amidst the spread of COVID-19, which has rarely been accounted for in existing literature. The pandemic significantly heightened the urgency for participants to maintain wellness and accumulate their means to do so, despite their economic status. Financial resources and insurance were considered necessities for some to manage emergencies and critical situations, such as immobility and illnesses. Some also saw saving up as an individual responsibility and seldom discussed pensions and public welfare. My study offers valuable insights into a Global South context like Thailand, where welfare has not only been privatized and diminished but has been almost non-existent as a fundamental right for all citizens. Instead, it primarily functions as immediate aid for selected vulnerable groups (Jensantikul 2022, 22).

The findings overall suggest that aging is regarded as less about collective responsibility and more about individual risks due to the withdrawal, or rather the absence, of state provision amidst neoliberal global capitalism and political economic crises (Neilson 2006, 156). Older women, including my participants, must maintain their mental and physical wellness to reduce dependence on family members and look after their elders simultaneously with their means and resources. Thus, my research raises a crucial question of whether *older women can be entirely self-reliant as they age in a neoliberal capitalist economy, especially during economic crises and societal disruptions, while striving to maintain their wellness and look after others.* It can be inferred that, for these women, the promotion of wellness remains "an act of communion" (hooks 2018, 215). Participants' understanding of wellness and self-reliance is shaped by a balance between independence and interdependence between themselves and their family members, communities, and societies. Therefore, my research advocates for physical and mental health interventions targeting older adults that should not exclusively promote privatized solutions and individual responsibility, even for those from more affluent backgrounds. Such interventions should account for more intersectional perspectives and experiences of aging, thereby addressing the multiplicity of social identities, including age, sexuality, socioeconomic status, and gender. They should acknowledge the roles and wellness of family members across different age groups co-residing with and/or providing care for older adults.

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"Where is the *Sudheni Didi?*": Community Perspectives and Revisiting Nepal's Maternal Health Policies

by Sunisha Neupane

Abstract: This article examines Nepal's maternal health policies in the context of a remote community in western Nepal. There has been a substantial decline in maternal mortality and an increase in institutional deliveries, in Nepal, but, along with these achievements, inequities in maternal health continue. Drawing on immersive participatory research conducted in 2015 in two villages in Baglung district, the study integrates observation, fieldnotes, focus group discussions, participatory workshops and interviews with women, health workers and national maternal health experts. Findings show that distance, terrain, limited health post hours, and unreliable transport make access to institutional services practically challenging in remote Nepal. Female Community Health Volunteers (FCHVs) occupy an in-between position, understanding women's lived experiences while doing their best to follow protocols and mandates. Community members express the need for home-based support when facilities cannot be reached. The disappearance of the *sudheni* reflects a broader policy shift that privileges service availability and biomedical definitions of skilled care. The article argues that maternal health policy must move beyond institutional targets toward context-responsive approaches that centre women's lived experiences and make maternity care accessible to remote populations.

Keywords: maternal health; maternal mortality ratio; community; lived experiences; maternity care; *sudheni*

Résumé : Cet article analyse les politiques de santé maternelle au Népal dans le contexte d'une communauté éloignée de l'ouest du pays. Au Népal, la mortalité maternelle a considérablement diminué et les accouchements en établissement ont augmenté; cependant, malgré ces progrès, des inégalités en santé maternelle subsistent. Fondée sur une recherche participative immersive menée en 2015 dans deux villages du district de Baglung, l'étude combine observations, notes de terrain, discussions de groupe, ateliers participatifs et entretiens auprès de femmes, de professionnels de la santé et d'experts nationaux en santé maternelle. Les résultats montrent que la distance, la topographie, les horaires restreints des postes sanitaires et le manque de fiabilité des transports compliquent pratiquement l'accès aux services en établissement dans les régions éloignées du Népal. Les femmes bénévoles pour la santé communautaire occupent une position intermédiaire, comprenant les expériences vécues par les femmes tout en s'efforçant de respecter les protocoles et les mandats. Les communautés ont à de nombreuses reprises fait valoir le besoin d'un soutien à domicile lorsque l'accès aux établissements est limité. La disparition de la *sudheni* témoigne d'un virage politique plus large qui favorise la disponibilité des services et une conception biomédicale des soins qualifiés. L'article soutient que les politiques de santé maternelle doivent dépasser les objectifs institutionnels pour adopter des approches adaptées au contexte, centrées sur les expériences vécues par les femmes et facilitant l'accès aux soins de maternité aux populations éloignées.

Mots clés : santé maternelle; taux de mortalité maternelle; communauté; expériences vécues; soins de maternité; *sudheni*

Author: Sunisha Neupane is a PhD in Medical Anthropology and Development Studies at the Institute of Development Studies, University of Sussex. Her research examines health equity, maternal health, care practices, and the politics of birthing in remote Nepal, drawing on long-term ethnographic and participatory fieldwork.

Prologue

In 2015, I conducted a study on the maternal health needs of women in a remote village in western Nepal. My initial research question was: why are women not utilizing the services provided by the state? It seemed simple. I had been reading academics such as Paulo Freire, Farzam Arbab, and Robert Chambers and was influenced by their community-based approaches; I saw this study as an opportunity to live alongside the community members, ask questions, listen, and engage with their perspectives. I applied immersive participatory action research (PAR) methodology, designed with flexibility, allowing the research question to evolve through engagement with the community. My aim was to identify barriers to service uptake and, in collaboration with community members, develop an action component which is integral to a PAR methodology. I envisioned returning to implement what women themselves identified as necessary to access services. However, the question turned out to be far more complex than I had originally anticipated, and no clear actionable steps emerged. Having grown up in Nepal, I believed I understood the country and its problems well enough. Yet, being in the field, I realized I had arrived with assumptions, including that the issue was straightforward and would lead to a clear set of solutions. The experience transformed my understanding of maternal health in remote areas and my approach to research. This paper reflects that transformation, not through the answers I found, but through the questions posed by the participants. Although the data were collected a decade ago, this study offers a rare longitudinal perspective when read alongside more recent trends. It provides critical insight into the structural and socio-cultural conditions that shaped maternal care access at a key moment of policy transition, many of which persist today, making the findings both timely and relevant.

Introduction

To bring about justice and collective prosperity, we must start with one of the most vulnerable groups: young mothers. The global reduction in maternal mortality ratio (MMR) is remarkable: a 42% decrease from 1990 to 2020 (Berhan and Abeba 2024). MMR has steadily declined globally for the last 40 years, yet it is not zero. Should we rely on this hopeful trend and wait for MMR to eventually reach zero, or should we examine whether structural barriers to improved maternal health are hidden beneath the aggregated data? I take the latter approach. Immersed in a remote community in Nepal, I probed the social reality of pregnant women. What this approach uncovered was a non-negligible disparity that the average data trend does not capture but is reflected in the lived experiences of pregnant mothers in remote areas. Of all the learning from this research, one question stood out most, encapsulating my findings: "Where is the *sudheni didi*?"[1] Traditionally, *sudheni* (traditional midwives) assisted women during childbirth.

For decades, improving maternal health has been a priority for governments and international development agencies globally, including in Nepal. Notably, Nepal has significantly reduced MMR (Figure 1). Saving mothers is unequivocally vital and the reduction represents an important public health achievement. However, statistics on MMR, taken alone, risk producing an oversimplified narrative of success. Much remains to be done to ensure that marginalized women's maternity experiences are not left hidden behind the numbers. MMR continues to vary across social groups, and many women still face challenges accessing health services (see Table 1 for disparities) (Chaurasiya et al. 2019). While Figure 2 shows an increase in births with Skilled Birth Attendants (SBA), it can be inferred that the rest of the births still occur at home without assistance. Moreover, although MMR is a critical indicator, it only reflects mortality rates and fails to capture the quality, accessibility, or lived experiences of maternity care (Devkota et al. 2020; Engel et al. 2013; Glenton et al. 2010; MoH 2017; MoHP 2011; Suvedi et al. 2009).

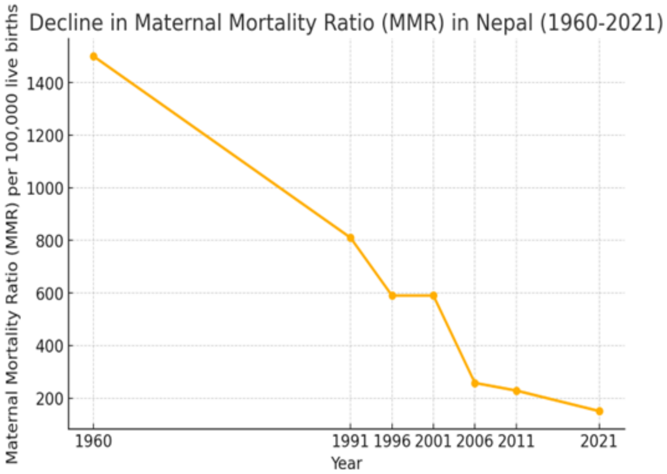

Figure 1Nepal MMR decline

Caste/ethnicity	MMR
Muslim	318
Terai/Madhesi/other	307
Dalit	273
Janjati	207
Bahun/Chhetri	182
Newari	105

Table 1: Disaggregated MMR per 100,000 live births (Suvedi et al., 2009)

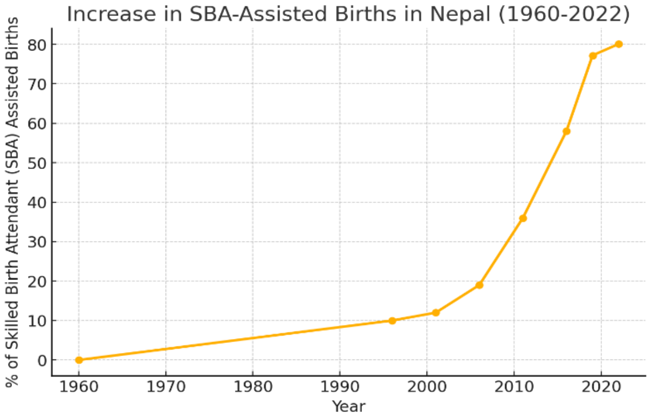

Figure 2 Births attended by SBA

In this paper I explore the policy shifts that have contributed to Nepal's reduction in MMR. I then draw on insights from my immersive fieldwork, centering the needs of women and local healthcare providers in remote Nepal, and examining their perspectives on maternal health. Reducing MMR is crucial, and my intention is not to dismiss this need or undermine the initiatives that have contributed to MMR reduction. Rather, through this study I seek to complement the MMR metric by exploring the lived reality of maternal health in remote settings.

Policy Context

Nepal's maternal health policies have prioritised saving mothers and promoting safe delivery, and rightly so. Over time, the country has progressively developed maternal health programmes with key milestones shaping service provision and availability for safe delivery. Nepal's first national health survey (1965–66) revealed an MMR exceeding 1500 per 100,000 live births (Thapa 2014). Before the 1950s, home births were common and no national programs existed for maternal health. The Maternal and Child Health and Family Planning (MCH-FP) project (1963–65) marked the first state-led intervention, spearheaded by the World Health Organization's (WHO) first MCH advisor to Nepal (international appointment), a public health nurse (international appointment), and Dr. Rita Thapa (national appointment). About her appointment Dr. Rita Thapa said: "The 1964 project was tricky as there was an absence of skilled or any health workers, which crippled the MCH-FP expansion beyond Kathmandu Valley."

In response to lack of health workers, in 1968, Nepal introduced Health Aides as a community-based health care providers program to extend institutional MCH-FP services, notably preceding the 1978 Alma-Ata Declaration, which underscored the importance of community-based healthcare. By 1975, the Integrated Community Health Project trained Health Aides, who were later formalized as Village Health Workers (VHWs). Following the eradication of smallpox, vaccinators were further trained as VHWs, adding to the rural healthcare workforce. These efforts set the foundation for the Female Community Health Volunteer (FCHV) program, launched by the Ministry of Health and Population in 1988, modelled after community-based health workers from Nepal's successful malaria eradication campaign (Thapa 2014). The FCHV program recruited and trained local volunteers to provide essential health services, offering a cost-effective solution to workforce shortages.

Meanwhile, in 1987, *sudhenis* were formally integrated into Nepal's healthcare system, under the Safe Motherhood Initiative termed as traditional birth attendants (TBAs) (Brunson and Tamrakar 2018; MacDonald 2017; Shehata 2015). They combined traditional knowledge with biomedical practices, such as the use of clean blades and sterile sheets to improve sanitation and safety during home births.

Safe Motherhood Gains Attention

By the 1990s, maternal health gained policy traction, reflecting global shifts in maternal and reproductive health agendas. While the Long-Term Health Plan (1975–1990) integrated maternal health into Nepal's primary healthcare system, the National Health Policy (1991) gave maternal and child health a standalone focus. However, institutional birth rates remained low, and in response, Nepal developed the National Reproductive Health Strategy (1998), laying the foundation for the Safe Motherhood Plan.

Expansion and Incentivization

The National Safe Motherhood Plan (2002–2017), revised in 2005, aimed to create a safer environment for pregnancy and childbirth. The Maternal Incentive Scheme (2005) and National Free Delivery Policy (2009) introduced financial incentives for antenatal care (ANC) visits and institutional births, while the SBA Policy (2006) promoted deliveries at birthing centers. Under this plan, Auxiliary Nursing Midwives (ANMs) at health posts and staff nurses at district hospitals were trained to assist deliveries, with referrals to district or provincial hospitals for complications. The Nepal Health Sector Strategy (2015–2020) prioritized healthcare quality and equitable access, while the Right to Safe Motherhood and Reproductive Health Act (2018) legally ensured access to maternal care. The National Safe Abortion Policy (2003) strengthened reproductive rights and aimed to reduce unsafe abortions. Building on these efforts, the Nepal Safe Motherhood and Newborn Health Road Map (2018–2030) took a comprehensive approach by strengthening birth preparedness and community-level interventions, expanding ultrasound services in rural areas, providing financial incentives through the *Aama Surakshya* program, improving reproductive health morbidity management, and enhancing emergency referral systems for high-risk cases.

Along with these policies, Dr. Thapa credits Nepal's declining MMR to insistence on integrating MCH with family planning, despite "population control" orientated donor agencies pushing to separate family planning as a standalone initiative. While these policies have undoubtedly contributed to reducing MMR and seem appropriate in theory, they do not fully capture how these policy shifts are experienced by women and frontline health workers in remote communities. My 2015 fieldwork aimed to explore how these policies translate into reality.

Methods

The project was approved by the research ethics committee at the International Development Research Centre and the Nepal Health Research Council in 2015. Fieldwork took place from April to November 2015 in two Village Development Committees (VDCs) of Baglung district where 66% of births were reported to occur at home (MoHP 2011). Under new classifications since 2017, these VDCs are part of Nisikhola Gaunpalika in Province 4. The region, characterized by mountainous terrain and poor road access, comprises *Bahun, Chhetri, Thakuri, Magar,* and *Dalit*[2] communities. Both VDCs had health posts with birthing centres, staffed by Health Assistants (HAs), ANMs, and FCHVs. Health posts serve as primary healthcare and birthing centres. ANMs undergo 18 months of training after high school and manage normal deliveries, referring complications to higher-level facilities. I integrated participatory research principles throughout all stages of design and data collection.

Data Collection

I hired research assistants (RAs) from the community following the ethical guidelines. They were actively involved in the study throughout the fieldwork. Before data collection, two RAs and I refined interview guides and mapped neighbourhoods. Pregnant women and mothers of infants were identified and invited through word-of-mouth referrals, including by their husbands, mothers-in-law, FCHVs, and Health Assistants (HAs). The RAs played a central role in identifying and inviting participants and also in organizing and leading meetings. Jagat, the male RA, led focus group discussions (FGDs) with men, while Kavita, an ANM, conducted semi-structured interviews and FGDs with women. The RAs were trained in note-taking and submitted detailed accounts for analysis. All interviews and group discussions were conducted in Nepali.

In total, we conducted 20 interviews and 30 FGDs across nine villages (each with a population of approximately 600). FGDs were used to capture collective narratives and social dynamics, while individual interviews provided deeper insight into personal experiences. All recruited participants were invited to attend FGDs held in their respective villages. To keep group sizes manageable (12–15 participants), multiple FGDs were sometimes organized in the same village. If a participant remained silent or was unable to express themselves freely during an FGD, this was noted by the RAs or myself, and I followed up with a one-on-one interview. We also conducted individual interviews with all identified pregnant women. Participatory workshops were held in each VDC, drawing around 70 participants per event. These were larger, open-invitation meetings where all community members could attend to discuss maternal health issues. Local political leaders also joined and supported facilitation.

Individual interviews took place in participants' homes. FGDs were held in local schools, and participatory workshops were conducted in community centers. Interviews explored individual experiences with pregnancy and childbirth, particularly among pregnant women. Focus group discussions examined shared perceptions and social dynamics around maternal health. Participatory workshops engaged a broader range of community members to collectively identify maternal health needs and priorities. Beyond formal data collection, residing in the village enabled immersive engagement, including observation, field notes, and informal conversations with women about their daily lives. I also conducted interviews with maternal health experts in Kathmandu. Even though fieldwork was shorter than initially planned because of the 2015 earthquake, thematic saturation was achieved for the domains explored in this paper.

All interviews and FGDs were audio-recorded with informed consent. The data were transcribed in Nepali and translated into English, with close attention to preserving tone, meaning, and contextual nuance. Initial coding was done manually using the original Nepali transcripts, with support from the RAs, who were familiar with the language and the local context. A manual and inductive thematic analysis was conducted without the use of qualitative data analysis software. Responses were coded into emerging themes such as barriers to maternity care, perceptions of health services, the role of traditional birth attendants, and community-identified solutions. To uphold the participatory nature of the study, no pre-existing frameworks were imposed during coding; rather, categories were grounded in participants' own narratives and priorities.

Although participants did not directly engage in coding, RAs based in the community were involved in early analysis discussions to enhance contextual accuracy and interpretation. Rigour and trustworthiness were supported through prolonged engagement in the field, triangulation across interviews, FGDs, participatory workshops, and fieldnotes, and regular debriefing with the RAs. Themes were refined through iterative review, drawing on data from multiple sources to confirm patterns and identify inconsistencies.

As an educated Nepali woman, fluent in the language and culture but not immersed in rural life, I occupied a position that was both familiar and slightly distanced. Through daily reflexivity and journalling, I reflected on my positionality, motivation, and their influence on the research. Over time, the fieldwork fostered relationships of trust and acceptance.

Findings: Community Perspectives

This section presents findings from interviews, FDGs, and participatory workshops with women, FCHVs, and healthcare providers. Four major themes emerged: (1) physical and systemic barriers to institutional delivery, (2) the continuing prevalence of home births and the limits of biomedical policy approaches, (3) the role and limitations of FCHVs, and (4) the remembered value of the discontinued *sudheni* (traditional birth attendant) practice. A recurring sub-theme was the emotional and logistical burden placed on women, particularly those from remote and marginalized caste (*dalit*). While shared experiences cut across groups, perspectives varied by role, for example, between women, FCHVs, and HAs, and these are explored below.

Kavita[3] and I hiked uphill for two hours for a FDG in a *dalit* community. Nine women had gathered, including two young girls. I was surprised to see them, as we had specifically invited pregnant women and mothers of infants. It turned out that they were seventeen years and pregnant.

Sangita said it was her ninth month. She seemed uncomfortable. Kavita, noticing her unease, asked several times, "*Baini, thik chau*?" ("Sister, are you okay?") She remained quiet. After Kavita was insistent, Sangita said she was feeling discomfort. As an ANM, Kavita immediately told her that labour might be starting and she should go down to the health post. Sangita looked at us silently.

I asked if she could walk, after all, it would be hours down and up. Sangita replied, "I cannot go, it will be difficult to come up". A few days later, we got news that she gave birth to a baby girl at home. Kavita sighed, "It is like this for now, let us hope things will change for women." We could only hope that by Sangita's daughter's time, things would be different.

Distance, terrain, and the walk to the health post were recurring concerns in discussions among all groups: women, husbands, and healthcare providers. For some hilltop communities, the nearest health post was a five-hour walk, making access during labour difficult and often leaving women at home to give birth without assistance. Below is a conversation with a FCHV *didi,* Sita and Anita, a 38-year-old *dalit* woman living three hours uphill from the health post.

"There is always uncertainty … will I survive, will I die? What will happen? The body feels weak, there is no strength, and I feel afraid." Anita

I ask her, "How many times have you been to the health post?"

"I haven't gone. I can't go it is difficult."

Sita *didi* intervenes: "You have to go though, walk slowly and try to go."

Anita replies, "It is exhausting during pregnancy, then I have to walk back too."

"Where will you give birth?" I ask.

"At home. All my children were born at home," says Anita

Again, Sita *didi* intervenes to tell me, "I tell her to go to the health post, but she says, 'How will I go? Who will take me?' I tell her to walk slowly, step by step. When she says she is feeling unwell, I insist that she must go." Sita *didi* is making sure I know that she does her job well.

I ask Anita, "Do you feel like you should go?"

Anita says, "Of course, I feel I need to go. But labour can be quick, then I might have to give birth on the way. If labour lasts a long time, then maybe we can make it to the health post. It would be easier if a *sudheni* were in the village like before to help. Where did that program go?"

Sita *didi* adds, "She is right, I know of cases where women are on the way to the health post and end up giving birth on the trail. The problem of access becomes even greater when someone needs to be carried in the dark."

Since there is financial incentive, the expectation is that all women somehow make sure that they get to the health post to access services. I ask: "Is there an ambulance?"

"Yes, there is an ambulance. But it serves three VDCs it is not always available when we need it. We cannot rely on it." Sita *didi.*

FCHVs often shared a dual perspective, understanding women's concerns while also defending their own roles as part of the health system, highlighting their liminal position between the community and the health system. In another instance, another FCHV, Mina *didi* said, "There are many situations where women are not able to go to the health post, especially at night, and also when the local health post is closed or when there is no health workers present. This happened very recently, I got a call and the daughter-in-law was in pain. I called the ANM, her husband picked up the phone, and she wasn't available. I tried taking the pregnant woman to the health post, but we couldn't make it there on time, so she gave birth on the way." Along these lines, Binita, a young mother, participating in a focus group discussion once said: "Often women's labour is unpredictable, and they deliver where they are, while working in the fields sometimes or in the trail."

During a discussion with the healthcare staff, Rita *didi* (FCHV) said: "Additionally, all these issues you hear, many women face these challenges alone, as their husbands are away as migrant workers." The HA, Dirga sir, said: "It is true that the health post opens from 10 AM to 4 PM, so that also adds to the challenge." Bhakta sir, also an HA, added: "There is nowhere to stay near the health post even if we advise women to travel a few days in advance."

An additional issue raised by the women and FCHVs were lack of postnatal care (PNC) visits. Bhakta sir also admitted that, although ANC happens, PNC remained almost nonexistent. He attributed this to both accessibility challenges and "lack of awareness" among women:

> PNC is … yes, not common. Women do not come after giving birth as it is harder. FCHVs are not trained to perform ANC or PNC. But we [trained personnel] do not do home visits. It is not within our job protocol. It is also difficult for women to come to the health post, especially for the communities that are far. But the women are also not aware of the risks.
>
> You know sometimes I have no choice but to induce fear so that they don't miss checkups. I have to tell them about tragic incidents that I have seen in pregnancy so that people in the community realize the seriousness of this matter. Even though we use negative examples, the result is positive [increased use of health services such as ANC and delivery].

This form of strategic fear was viewed effective from the male HA perspective; however, it was not echoed by FCHVs or community members and appears to function as an informal, individual-level strategy within the health system. I asked Bhakta sir what he thinks is a solution that is safe but also takes into account the women's concerns and challenges. He replied:

> What could be done is to appoint someone from the health post for home visits to perform ANC and PNC and provide regular checkups. But delivery at home is not possible, we cannot travel will all necessary equipment.

Bhakta Sir suggests a home-based care model similar to what women participants discussed during discussions. While the government mandates and offers financial incentives for completing four ANC visits and institutional births, reaching facilities remains a challenge, especially at night. If husbands are away as migrant workers, there is no one to carry the women. HAs noted that women are usually brought to the health post only if a complication is perceived; otherwise, they give birth at home. Crucially, it is family members and FCHVs, who end up deciding whether a pregnancy is normal or requires medical attention. HAs tended to emphasize protocol, resource limitations, and logistical concerns more than community members or FCHVs, who focused more on lived experience and practical challenges in receiving maternity care. Having examined the community perspectives on accessing maternity care, the following section presents proposals and solutions put forward by FCHVs and community members during discussions and workshops, offering locally envisioned strategies for improving assisted births.

An individual expressed during a participatory workshop: "This is an important topic that needs to be discussed regularly in the community. You should come with a program to improve maternal health in this area." The FCHVs, women and the community members, repeatedly brought up the *sudheni* practice and asked if it is possible to revive the community-based birth assistance model:

> If FCHVs were trained to supervise childbirth at home during emergencies, it would be very helpful for women but not sure how we will do it. Maybe something like *sudheni* before. These days, we don't have *sudheni.* Mohana *didi* (FCHV).
>
> The thing is if there was a trained person in the village, she could supervise easy cases, and we could

> take complicated cases to the health post. Gita (participant).

In the two VDCs where I worked, I met only two *sudheni didi*, both over the age of 65, with no one to inherit their knowledge. Former *sudheni* Rukamaya *didi,* now an FCHV, shared that despite mandates for institutional births, she is still called upon, reflecting the ongoing need for her traditional knowledge for home birth:

> I am often called to help with births in my village and also in neighboring villages. I am the only *sudheni* in this area. Sometimes I get called all the way from Bhalkot, which is far. Although I am told to bring all the women to the health post for delivery I have to go and help when it is necessary and when the women cannot be carried. I am often not sure about whether I should go help or not but I have to go.

Despite the efforts to encourage institutional deliveries, home births continue to be a reality for many women in remote Nepal. MoH (2017) shows 41% of births still occur at home; one in ten is unassisted. Geographic disparities persist, with 69% of urban women delivering in health facilities compared to just 44% in rural areas. In this study area, 25% of births were estimated to have occurred without any assistance (MoHP 2022). This raises a critical question: who helps women in remote areas when they cannot reach a health center? The gap between policy and practice remains evident, as the government mandates institutional deliveries yet health posts do not accommodate the unpredictability of childbirth.

Findings: Opportunities for Home-based Care?

A recurring discussion in the community was whether FCHVs could take on expanded roles. The community looks to them for greater support because they are the only community-level providers linked to the state healthcare system. While they play a crucial role in increasing healthcare service utilization by fostering community participation, raising awareness, and sharing information on maternal health, they are not a substitute for *sudheni*. FCHVs are not trained or authorized to assist with deliveries; their responsibilities remain limited to health education, family planning, and vaccination. Unlike ANMs/SBAs, they do not undergo biomedical training. Moreover, interviews with the maternal health experts in Kathmandu confirmed the state's commitment to biomedical safety in childbirth, with no plans to reintroduce home-based care. However, as this study shows, gaps in this approach leave women in remote areas vulnerable, often falling through the cracks.

When asked about their role, Devi didi said: "We are already doing our best and a lot. We cannot do anything more." On the same topic, Dirga sir, HA noted:

> I think it could be possible to build FCHVs' capacity and provide them with quality training for ANC and PNC. But the problem is that it requires an ANM course and education. People who reach that level of education do not want to work voluntarily. So, there's a risk of training educated women to assist at community level, only for them to leave for other opportunities. And it's their right to do so.

Rukamaya *didi,* who traditionally was a *sudheni* and later received training, described how she transitioned into her current role:

> I became an FCHV eighteen years ago. Before that, I was a sudheni and also attended a training by the government, where I learnt about clean plastic, clean blade, clean thread, which we also knew but we don't always have new plastic. The program is not there anymore. I was already helping with deliveries, so after that program ended, I was asked to become an FCHV. … But the sudheni training only happened once. Do you know what happened to the program?

She continues to attend deliveries in the village due to her prior midwife training:

> I have considerable experience delivering so I am still called when labour starts. I can tell whether the baby is upright or upside down inside the mother's womb. I insert three fingers with gloves into the vagina to check the baby's position. I am usually called to assist.

She believes that a better solution would be to allow deliveries at home but with assistance:

> I think it would be more convenient if women could give assisted birth at home. I try my best, but my education is limited. I cannot inject medicines or do other procedures, and I am told not to help with deliveries so I worry if it is okay to help. When possible, we take pregnant women to the health post, but when that's not an option, I still end up supervising the delivery.

She also recalled a case where transportation challenges had tragic consequences:

> I tried calling the health workers at Jyaukhola health post, but they were all at a training program in Burtibang. The head of the health post was in Baglung. If we could have taken the mother promptly to Burtibang [closest hospital], maybe the baby would have survived. The mother needed a cesarean. But this year, she gave birth to a healthy daughter in Palpa [urban town]. That night, when she went into labour, there was no bus service, so we couldn't get her to Burtibang in time.

Her continued practice, despite the absence of formal support or authorization, highlights the practical maternity care expertise available within the community.. The question of whether FCHVs could be trained for more maternal health responsibilities remains complex. Expanding their role could help women in remote areas have a supervised delivery. But formal medical training requires years of education, which volunteers may not be willing or able to undertake without proper remuneration. The risk of trained health care providers leaving for better opportunities further complicates the issue. As the HA pointed out, ensuring sustainability in such programs requires balancing capacity-building with workforce retention strategies to serve remote communities.

While FCHVs and healthcare workers acknowledge that institutional deliveries are available, they also emphasize that access remains a challenge. The geographical remoteness of villages means that even when health posts exist a few hours walk away, they remain inaccessible for pregnant women experiencing labour. Terrain and transportation barriers are not incidental obstacles but rather systemic issues contributing to social injustice that need to be addressed in Nepal's remote healthcare infrastructure. These barriers are not just logistical; they are produced and maintained by long-standing underinvestment in rural healthcare (Farmer 2004). The failure to expand maternal care services beyond health posts and into communities disproportionately affects women in the remote areas. *Dalit* women, who commonly live in the hilltops in this area, and low-income families, who are more likely to give birth at home because of financial and geographic constraints, are less likely to go to an urban area or to the closest hospital (Devkota et al. 2020).

As mentioned by the participants above, even when women plan to deliver at a health post, the limited operating hours (10 am–4 pm) is a barrier. Health posts in remote villages function on a restricted schedule, leaving women with few options if they go into labour at night. It is common to call an ANM who will then come to the health post, but all of this takes logistical effort during a time that is critical and needs quick reaction. But even then, the ANM may not get to the health post on time. The government's initiative to provide ambulances in rural areas has not translated into fully functional practice either, as mentioned by the participants. The study found that while an ambulance exists, its availability is unreliable because of limited resources and competing demands across multiple villages. From a political economy of health perspective (Baer et al. 2013), this reflects a symbolic policy intervention rather than a functional solution. This disconnect highlights the limits of global health metrics applied unilaterally without consideration of context or making provisions for equitable solutions. Maternal health policies often measure success through service availability (e.g., number of health posts, ambulances provided) rather than service accessibility and effectiveness.

These findings highlight challenges to maternal healthcare access in rural Nepal, despite policy efforts to encourage institutional delivery. While health posts provide critical services, geographical inaccessibility, unreliable transport, and limited availability of healthcare personnel restrict effectiveness. Local health workers, such as *sudheni,* were phased out based on biomedical standards rather than community needs, leaving a critical gap in remote maternal health needs. Women continue to give birth at home due to the logistical challenges they face rather than choice. FCHVs express a strong desire for additional training, particularly in emergency delivery care, suggesting a potential role for community-based birth attendants akin to the discontinued *sudheni* practice. The lack of PNC visits also underscores a critical gap in maternal health services. Even after the implementation of National Safe Motherhood plans, postpartum care remains largely unavailable, leaving many women without essential follow-up care. This aligns with broader global evidence indicating that PNC often receives less attention compared to ANC and institutional delivery initiatives.

The need for maternity waiting homes was also discussed during FGDs as a practical solution, yet such infrastructure remains absent in many remote areas. The FCHV program plays a crucial role in bridging the gap between communities and the formal healthcare system, yet it does not provide home-based care for pregnant women. As a result, when a woman goes into labour and is unable to reach the health post, she is left without trained assistance. From Berry's (2008) perspective, this reflects a structural failure to recognize alternative models of skilled care that could work within the constraints of rural Nepal. Berry (2008) and Qadeer (2005) critique the biomedicalization of maternity care, arguing that when health systems prioritize institutional deliveries without ensuring equitable access, they contribute to systemic injustices. Berry (2008) highlights how global maternal health policies often define "skilled" care in strictly biomedical terms, sidelining community-based support systems that women in remote areas rely on. This exclusion leaves women in rural areas with limited or no options, reinforcing disparities rather than reducing them. This lack of accessible care is not just a gap in service delivery, but injustice embedded in the way maternal health policies are designed and implemented. Systemic neglect failing to account for lived experiences and local realities therefore further marginalizes those without access to institutional care (Qadeer 2005).

It is not the *sudheni* themselves that the community said they wanted back but rather the possibility of home-based care supported by someone knowledgeable in birthing. Given the challenging terrain and the distances to the nearest health post, which is neither easily accessible nor open 24 hours, they wonder why an alternative, community-based option could not be provided again. The conclusion of my fieldwork raised a pressing question: what happened to the *sudheni* practice? In the next section I trace the policy changes and historical shifts that led to shifts from *sudheni* to TBAs, followed by biomedically trained SBAs, then finally to ANMs. Although this issue was not the original entry point of my research, it emerged as a key theme through my fieldwork, making it essential to discuss it now.

Discussion: Understanding the S*udheni* Question

Historically, *sudheni* with their traditional knowledge played a vital role as caregivers in their communities, providing home-based care. They are particularly desired by the people living in remote mountainous regions where formal healthcare has been scarce. After integrating into the health system in 1987, they continued assisting with births, using state-provided birthing kits to ensure sterilization. However, following a policy shift influenced by the WHO recommendation to promote institutional deliveries, Nepal discouraged *sudheni* practice and discontinued their training in 1997, replacing their role with SBAs who were biomedically trained. The policy analysis by Shehata (2015) notes that government surveys found TBAs ineffective in reducing MMR, leading to a WHO-influenced shift toward SBAs and evidence-based care. This transition, however, is under explored and did not account for the lived experiences and challenges of women in remote Nepal.

The discontinuation of *sudheni* was not an isolated decision but part of a broader shift in global maternal health policies which impacted many countries such as Morocco, Tanzania, Zambia, and Nepal (Allen 2004; Cheelo et al. 2016; Obermeyer 2000). The Safe Motherhood Initiative 1987 marked the first global effort to reduce maternal mortality through health system upgrades, increased healthcare personnel, family planning, and the training of existing traditional midwives such as *sudheni* under the title TBA (Mahler 1987; MacDonald 2017). Training TBAs was initially seen as a progressive step in acknowledging traditional knowledge within national programs (MacDonald 2017; Pigg 1997). However, this approach was later deemed ineffective in reducing maternal mortality (Allen 2004; Jordan 1989; MacDonald 2017; Pigg 1997; Starrs 1997). Following a 1996 review, the TBA training program was discontinued and home-births were either banned or discouraged, shifting the focus to increasing the number of SBAs (Bergström and Goodburn 2001; Cheelo et al. 2016; Starrs 1997).

WHO's introduction of SBAs in 1996 reinforced a biomedical model of maternity care, defining *skilled* in ways that excluded traditional birth attendants. WHO's SBA framework prioritized clinical competence but failed to integrate the relational and community-based aspects of maternal care that women valued (Berry 2008). This shift was not necessarily based on rigorous evaluation of TBAs' effectiveness in specific contexts, nor did it incorporate the perspectives of the women they served (Jordan 1989; MacDonald 2017). Conversations with women in this study also suggest that their experiences were not considered in this policy shift.

The Millennium Development Goals then focused on increasing institutional births, providing financial incentives for obstetric care, free caesareans and promoting family planning which all contributed to reducing MMR (Seltzer 2002; Vogel et al. 2015; Dumont et al. 2001; Jaffré 2012). While important in reducing MMR, these efforts overlooked understanding the challenges faced by remote areas.

Well-intentioned Policies and Unintended Inequities

The findings from this study show that across the different groups of participants, women emphasized the challenges of accessing services; FCHVs underscored their commitment despite limited training; and HAs framed the problem through institutional limitations, revealing layered and complex perspectives on maternal healthcare in remote Nepal. The findings also suggest that in this area, caste shapes maternal health access, due to *dalit* communities living higher up in the hills complicating access to the health posts.

While some of the villages in this study have, by 2025, acquired health posts closer to them, many other remote villages in Nepal have not. In Nepal, 78.1% of the population lives in rural areas, making home births a continuing reality. Despite the country's progress in reducing maternal mortality, these ongoing challenges underscore the need for a deeper understanding of the inequitable opportunities for safe motherhood faced by remote communities.

This study shows a fundamental gap remains in ensuring a triangle of essential needs: timely and easy access to birthing centres, access to SBAs who can recognize complications early, and equitable access to complete ANC/PNC. These components are interdependent, requiring careful coordination and time-sensitive responses. However, no single policy effectively addresses all three aspects in a way that is practical for women in remote areas.

During an interview for this research, a maternal health expert in Kathmandu highlighted a critical concern in maternal health policymaking: who makes decisions at the national level. Despite policies being designed to serve women, decision-making bodies remain overwhelmingly male-dominated. The lack of women's representation in policy formulation raises question about whose realities are being considered and who shapes maternal health priorities. The lack of diverse perspectives, including the absence of varied caste and ethnic representation, reinforces top-down approaches that overlook the lived experiences of pregnant women, especially in remote and marginalized communities.

From my discussions and observations, women are not particularly seeking the return of *sudheni* themselves or advocating for all traditional practices, nor are they rejecting biomedical services. Neither am I advocating for a return to unsafe home births. Rather, the women want their challenges and realities to be acknowledged in a way that leads to a feasible and safe solution. They feel forgotten as policies continue to assume that institutional births are universally accessible. This study highlights how national policy guidelines expect women to comply without accounting for the structural barriers that hinder access, failing to recognize that the geographical challenges faced by women in remote areas differ significantly from those in regions where institutional birth policies are more feasible (Devkota et al. 2020; Ghimire et al. 2019). The lack of road infrastructure and maintenance, inadequate ambulance services, and limited staff hours at health posts, reflect systemic neglect of a relatively hidden population rather than logistical difficulties alone (Farmer 2004; Qadeer 2005). These systemic barriers are not accidental but rather the product of long-standing underinvestment and policy decisions that exclude understanding the barriers faced by people living in remote areas.

Nepal's health system continues to depend on foreign aid, with approximately 50% of the health budget reliant on international donors (Karkee and Morgan 2020; Chaurasiya et al. 2019; Sharma et al. 2018). External funding influences health financing and also shapes maternal-health policy priorities, sometimes aligning them more with global frameworks than with locally identified needs (Bhandari and Dangal 2014; Sharma et al. 2016; 2018).

The title of this paper asks, "Where is the *sudheni didi*?" The answer lies in how national policy since 1996 has been impinged upon by foreign aid pressures and global health protocols which, in remote geographical areas in Nepal, are not always easy to implement. To continue ignoring this reality is inequitable to women living in remote areas. Allowing home births to occur without assistance, failing to sustain a workforce, for example, by incentivizing work in remote areas, neglecting to build a home-based care system, and not ensuring sufficient staff for assisted deliveries for all, is injustice and, in Farmer's (2004) terms, a form of structural violence.

"Where is the *sudheni didi?*" A few are still alive but invisible within the maternal healthcare system. Others have passed away without their traditional knowledge being passed on. The shift toward biomedical care was swift and did not allow space for intergenerational transmission of traditional birthing knowledge, effectively severing a long-standing community-based support system for pregnant women in remote areas. According to a maternal health expert interviewed in Kathmandu, as the state moves further toward biomedical models, there has been limited room for discussion about integrating traditional knowledge and skills alongside national health system. The erasure of *sudheni* also reflects a wider trend of sidelining Indigenous and local care models, in favour of western biomedical frameworks (Olson 2013; Berry 2008). Yet, as the findings here suggest, many women in remote Nepal still long for aspects of home-based care, not out of resistance to biomedical safety but because in the current system they do not receive the relational care they need, while it is still difficult to access institutional services in remote Nepal. The question, then, is not only where has the *sudheni* gone but also whether there is space to reimagine maternity care in ways that value biomedical safety, community-based needs, and traditional knowledge.

Conclusion

Using the case of *sudheni*, this study highlights the critical need for contextually grounded understandings of women's lived experiences. Without a transformative approach to maternal health that centres the perspectives and challenges of women in remote regions, Nepal risks overlooking existing maternal health inequities, despite national progress. Policies must go beyond institutional mandates to recognize that accessibility is not simply about the number or presence of health posts but about whether women can actually reach and utilize services. Without context-responsive approaches, sustaining the maternal health achievements of the Millennium Development Goals and attaining the Sustainable Development Goals of universal access to maternal healthcare will remain a challenge.

Limitations

While this study provides valuable insights, several changes have occurred since 2015, including the construction of a hospital in the area expected to be completed by 2026. A significant limitation of this study is that ANMs were not interviewed in-depth. Although they participated in community-level participatory workshops, their perspectives on their roles and experiences are not captured in this paper. Also, the paper does not incorporate perspectives from policymakers or development partners, whose insights could provide additional context regarding decision-making processes that led to the exclusion of *sudheni*. This study is limited in geographic scope, focusing on a few villages in Baglung, western Nepal. While the findings highlight broader structural barriers faced by women in remote Nepal, maternal health challenges may vary based on region, caste, ethnicity, and local healthcare infrastructure, necessitating further context-specific research.

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Acronyms

ANC	Antenatal Care
ANM	Auxiliary Nursing Midwife
DoHS	Department of Health Services
FAO	Food and Agriculture Organization of the United Nations
FCHV	Female Community Health Volunteer
FGD	Focus Group Discussion
HA	Health Assistant
MCH	Maternal and Child Health
MMR	Maternal Mortality Rate
MoH	Ministry of Health

MoHP	Ministry of Health and Population
PHC	Primary Health Centre
PNC	Postnatal care
PR	Participatory Research
RA	Research Assistant
SBA	Skilled Birth Attendant
SMI	Safe Motherhood Initiative
TBA	Traditional Birth Attendant
VDC	Village Development Committee

Endnotes

1. *Didi* is a Nepali kinship term meaning elder sister. It is commonly used as a respectful form of address for women slightly older than oneself and does not imply a biological relationship.

2. Within the caste hierarchy, *dalit* refers to groups historically considered as belonging to the "lowest" caste. The classification reflects entrenched social structures that have led to systemic discrimination and exclusion. I use the term here to acknowledge these realities, and the continued spatial and social separation, such as the presence of *dalit bastis* (neighbourhood).

3. Anonymity note: All personal identifiers, including names of individuals, have been anonymized.

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How do Indigenous People in Kjipuktuk Conceptualize Poverty? A Qualitative Study Exploring the Relationship of Impoverishment to Health

by Madeline Rae and Margaret Robinson

Abstract: This pilot study examines Indigenous conceptualizations of poverty in Kjipuktuk, Mi'kma'ki (Halifax, Nova Scotia) to lay groundwork for a holistic model of Indigenous poverty that can link with holistic models of Indigenous health already in use. Using community-based methods and Mi'kmaw cultural practices, the researchers conducted sharing circles and interviews with 12 Indigenous participants who had experienced or were still living in poverty. Results strongly supported the distinctiveness of Indigenous experiences of poverty and identified starting points for a holistic poverty model.

Keywords: Indigenous poverty; holism; Mi'kmaw culture; colonialism; community-based research

Résumé : Cette étude pilote porte sur les conceptions autochtones de la pauvreté à Kjipuktuk, Mi'kma'ki (Halifax, Nouvelle-Écosse), en vue d'élaborer un modèle holistique de la pauvreté autochtone pouvant s'articuler avec les modèles holistiques de la santé autochtone déjà utilisés. À l'aide de méthodes communautaires et de pratiques culturelles micmaques, les chercheurs ont mené des cercles de partage et des entretiens auprès de 12 participant·e·s autochtones ayant vécu ou vivant encore dans la pauvreté. Les résultats corroborent de manière marquée la singularité des expériences autochtones de la pauvreté et dégagent des pistes pour l'élaboration d'un modèle holistique de la pauvreté.

Mots clés : pauvreté autochtone; holisme; culture micmaque; colonialisme; recherche communautaire

Authors:

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Margaret Robinson (she/her) is a Two-Spirit citizen of Lennox Island First Nation who grew up in rural poverty in the Eskikewa'kik district of Mi'kma'ki, which is governed by Peace and Friendship Treaties. Robinson earned a PhD from the University of Toronto and now works as an Associate Professor at Dalhousie University, where she holds the Tier 2 Canada Research Chair in Reconciliation, Gender, and Identity. She uses Indigenous and community-based research methods to understand how culture and identity support health and well-being.

Introduction

In Canada, census data indicates that while Indigenous poverty is declining, Indigenous people remain more likely to experience poverty (Statistics Canada 2025). In 2021, the poverty rate for First Nations living off-reserve was 14.1%, nearly double the rate for non-Indigenous people at 7.9% (Statistics Canada 2022). Research in Canada also consistently links poverty among Indigenous people to adverse health outcomes (DeCastro et al. 2011; Native Women's Association of Canada 2023; White, Wingert and Beavon 2007). For example, Indigenous communities experience higher rates of chronic diseases, mental health issues, and lower life expectancy compared to settlers, and these health disparities are often rooted in poverty-related factors such as food insecurity, inadequate access to healthcare, and substandard living conditions (Hahmann and Kumar 2022; Tjepkema, Bushnik, and Bougie 2019).

Researchers often measure poverty by comparing household or per capita income against thresholds set by settler governments. This highlights income disparities but fails to engage Indigenous understandings of wealth and want. In this pilot study, we aimed to determine the feasibility of developing a holistic model of poverty that could link with holistic models of health used in Indigenous health research. A holistic approach to poverty research has been espoused by The Native Women's Association of Canada (2017, 4; 2022, 2) and by researchers supported by Status of Women Canada (Kenny et al. 2004, 5), both of whom emphasize that poverty also involves a lack of access to resources, opportunities, and cultural connections. The Native Women's Association of Canada proposes that "poverty is social disconnection, which is why cultural identity and social inclusion are absolutely necessary to poverty reduction" (NWAC 2017). A holistic approach acknowledges the importance of cultural and community ties, which are integral to Indigenous well-being. In this study, we aimed to check whether a holistic framing of poverty resonated with Indigenous people living in Kjipuktuk and, if it did, we hoped to identify starting points for future holistic models of Indigenous poverty.

Indigenous poverty rates are high across North America, primarily due to lasting impacts of settler land theft and the destruction of traditional economies (e.g., fishing, hunting, farming; see DeCastro et al. 2011). Colonial governments intentionally disrupt Indigenous land ownership, possession, and governance, including appropriating land for settler occupation, forcibly relocating Indigenous peoples, and establishing reserves, destabilizing Indigenous economies, and establishing a pattern of widespread multigenerational poverty (Centers for Disease Control and Prevention 2015). The Native Women's Association of Canada states that "the colonial structure has been responsible for destabilizing health in Indigenous communities, especially through the displacement and forced relocations of Indigenous people to remote and/or rural communities" (2023, 1). Land dispossession, and the imposition of foreign governance systems and economic models, continue to affect Indigenous people today.

Indigenous women, girls, and Two-Spirit peoples are more likely to experience gender-based violence and violent crimes than cisgendered Indigenous men (Davidson, Mantler, and Jackson 2024). Poverty increases vulnerability to violence by reducing autonomy and service access. Indigenous women's economic power is further shaped by over-incarceration and motherhood. In Canada, Indigenous women represent 5% of the female population yet make up 39% of the female prison population (NWAC, 2017, 7), with many spending their prime earning years incarcerated. Indigenous women are also three times more likely than settler women to become young mothers, increasing their likelihood of experiencing "severe impacts of poverty such as mental health deterioration, and living in overcrowded housing" (NWAC 2017, 7).

Our pilot study aimed to better understand Indigenous experiences of poverty and to consider non-fiscal ways to measure poverty. Our research question was "How do Indigenous people in Mi'kma'ki conceptualize poverty?" To ground this work in the experience of people currently living in poverty, we used the case study of urban Indigenous people living in Kjipuktuk, home to over 16,000 Indigenous people (Statistics Canada 2022).

Methods

This study used a community-based approach that integrates Mi'kmaw practices. Our methods were informed in part by Dr. Lynn F. Lavallée's (2009) work on Sharing Circles and Anishnaabe Symbol-Based Reflection, which offers critical insight into balancing Indigenous research methods and Western research principles in qualitative inquiry. We adopted Lavallée's use of sharing circles instead of focus groups and were intrigued by her use of symbol-based reflection in qualitative thematic coding (2009, 1-97), which we hoped would help to root our analysis in the words of study participants.

Recruitment

A total of 12 participants were recruited; 10 attended one of two sharing circles and 2 were unable to attend a circle but gave individual interviews instead. Participants were recruited via convenience and snowball sampling. Flyers were posted in central Halifax Regional Municipality (e.g., Gottingen St., Barrington St., Spring Garden Rd., etc.), and distributed to organizations serving Indigenous people (e.g., Mi'kmaw Native Friendship Centre). Flyers incorporated the Mi'kmaw pictographic system known as Gomgwejui'gaqan ("suckerfish writing"), including images for "I honour you," "I respect," and "I thank you." To reach Indigenous people who may not access Indigenous services, and to make local agencies aware of our study, recruitment materials were also distributed to organizations that provide resources and support to people experiencing poverty. Organizations included: Direction 180, Venus Envy, the Salvation Army, YMCA, Halifax North End Memorial Library, Halifax Central Library, Dalhousie University, Halifax Sexual Health Centre, and Nova Scotia Mental Health and Addictions.

To express interest in the study, people were directed to make contact with Rae, the research coordinator, by email, voicemail on the study cellphone, word of mouth, or by leaving a handwritten, confidential letter for pick up at a local shelter or service agency. This flexibility in recruitment was needed because many people living in poverty lack a computer, phone, or fixed address. Most participants emailed the research coordinator, with a few communicating through staff at a local agency. A few participants called the study phone directly, leaving a voicemail. One scheduled their in-person interview through handwritten letters given to the Salvation Army. While we welcomed anyone who identified as Indigenous and had experienced poverty while living in Mi'kma'ki, the majority of people who responded to our recruitment call were women (see Table 1).

Screening

People who expressed interest in our study were asked three screening questions. The first of these was "Do you identify as an Indigenous person?" Since denial of Indigenous identity is a tactic of colonial regulation, we defined "Indigenous" as a person whose ancestors have lived in Mi'kma'ki since time immemorial, or whose Indigenous territory was elsewhere. We asked if participants were First Nations, Métis, Inuit, a person of Indigenous ancestry, a person with multiple Indigenous ancestries, or not sure of their ancestry. We invited people who did not identify with these categories to self-describe their Indigeneity.

Our second screening question was "Do you have personal experience with poverty?" This aimed to ensure study data were rooted in the lived experience of poverty. Our third screening question was "Did your experience of poverty occur while you were living in the unceded territory of Mi'kma'ki and/or within the Canadian provinces of New Brunswick, Nova Scotia, Prince Edward Island, or Newfoundland and Labrador?" This question aimed to ensure we were gathering data about experiences in Mi'kma'ki, since poverty experiences may be regionally specific.

To summarize participants' social locations (Table 1), we asked eligible participants five optional demographic questions: 1) year of birth; 2) highest level of education completed; 3) gender identity; 4) sexual orientation; and 5) time they experience poverty (e.g., "All my life," "age 60 and over," et al.).

Participants were provided information about the researchers, the study plan, their rights as participants, and how to contact the researchers and/or the Dalhousie Research Ethics Board with questions or concerns (REB #2022-6091). Where preferred, this information was also shared verbally by Rae, the research coordinator. Participants signed consent forms permitting us to record the sharing circle or interview, contact them to confirm transcript accuracy, and quote them in study publications, under a name of their choosing. Some participants could not be reached again. In these cases, participant data shaped our thematic analysis and was incorporated into findings and discussion, but direct quotes are not used. This was done to honour the consent of participants who gave their time to sharing circles or interviews but may have been prevented from participating further due to circumstances.

Consultation with Elder Ann Labillois

Before data collection, Rae met with Elder Ann Labillois, the Mi'kmaw Elder-in-Residence at Dalhousie University, for advice on how to approach the study and organize the sharing circles in a Mi'kmaw way. Elder Labillois accepted a tobacco tie and agreed to consult on the project. Over lunch, Elder Labillois shared with Rae that each sharing circle should begin and end with ceremony. She requested that Rae provide stones with words of encouragement on them (e.g., "love," "patience," "community") and permit each participant to select one to hold during the circles and keep afterwards if they wished. Elder Labillois also gave recommendations to support cultural and general safety during the circles. Elder Labillois was consulted again after data collection for her opinions and recommendations on the creation and dissemination of a zine based on study findings.

Data Collection

Sharing circles were led by Elder Labillois and Dr. Robinson. At the time of the study, the COVID-19 pandemic was of concern to many in the region, so the first circle was held online in May of 2023; a second, in-person talking circle was held at the Halifax North Memorial Public Library on Gottingen Street in July of 2023. We hoped an in-person circle could reach individuals who did not have a computer and/or private space to participate virtually. The Halifax North Memorial Public Library was chosen as the in-person location for its accessibility for people with mobility challenges and its long-standing role as a welcoming space. The North Branch Library is located in downtown Halifax, close to the Mi'kmaw Friendship Centre and other service agencies. Participants in the in-person circle were provided with pizza, coffee, tea, soda, and water. A spirit plate was prepared and set outside and leftovers were available to take home.

Our sharing circles resembled focus groups in that they were time-limited (2 hours), used broad questions to guide speakers, and were audio recorded. One sharing circle was held on an online platform. Traditionally, ceremonial talking circles in Mi'kma'ki are held in person (although the pandemic led some Elders to conduct ceremonies online), continue as long as they need to, and are not recorded or photographed. By incorporating elements of Mi'kmaw talking circles, we hoped data collection would support equal power dynamics, prioritize storytelling, personal experiences, and healing, have an unhurried pace, and be culturally relevant for participants. Sharing circles began with an introduction from Dr. Robinson (in-person) and/or Rae (online), in which each briefly shared their motivations for the study. Once participants had a clear sense of who was in the room (real or virtual), Elder Labillois led the group in ceremony. Once ceremony was complete, we began recording. The virtual sharing circle was held on Microsoft Teams, which records visual and audio simultaneously. In-person sharing circle and interviews were recorded using hand-held devices, with data stored according to protocols approved by Dalhousie University.

We asked participants: 1) What is poverty?; 2) What types of poverty are there?; 3) How do you know if someone is in poverty?; 4) What types of impoverishment have you survived?; 5) Does poverty look different for Indigenous people than for others?; 6) What does "having enough" look like where you are?; and 7) What strategies have worked for you for getting by? The first four questions aimed to consider poverty holistically by inviting discussion that might frame poverty in multiple ways. Questions 4 and 7 reflected our concern with the deficit-focused nature of our study and attempted to affirm participants as active agents in their own lives. With Question 5 we hoped to gain insight into how colonialism, intersecting with other systems of oppression, shape experiences of poverty for Indigenous people. With Question 6 we hoped to elicit a vision of sufficiency that could be compared or contrasted with Mi'kmaw values such as Netukulimk (responsible relations with the natural world, often expressed through protocols for hunting, fishing, or gathering).

We held individual interviews to collect data from participants who were unable to attend a sharing circle. Participants had the option of being interviewed by Rae, a white cis-woman with experience working with Indigenous community members living in poverty and who had been their contact with the study to date, or Dr. Robinson, a Two-Spirit Mi'kmaw woman with lived experience of poverty. This choice aimed to centre participant safety and comfort, as some participants may have preferred an interviewer with shared experiences and/or cultural identity, and others may prefer someone they are unlikely to re-encounter in daily life. Elder Labillois made herself available to interview participants prior to and following their interviews, though none of the participants decided to meet with her.

Participants received $100 CAD as an honorarium for their time. In addition, up to $20 was available to participants to cover travel (e.g., bus fare, gas money), and up to $100 to cover childcare costs, with no receipts required. Honoraria were distributed by e-transfer immediately following the virtual circle and in cash before in-person circles or interviews. Participants were not required to answer the research questions or to attend the entire circle/interview to be compensated but only one participant in the in-person circle left early.

Data Analysis

Thematic coding was done in Microsoft Excel by the research coordinator. Our process was influenced by Anishnaabe symbol-based reflection, which Lavallée describes as a participatory action arts-based approach to qualitative research (Lavallée 2009, 30) and which honours the belief that "research cannot possibly be completely objective" since everything is interconnected (Lavallée 2009, 23). Our study incorporated teachings from the Anishnaabe symbol-based reflection by analyzing one study question at a time to reduce negativity or positivity bias. Quotes were treated as data points rather than answers to our questions such that stories and experiences remained complex and contextualized. Finally, stories describing methods for getting by were incorporated into a distributable zine to honour reciprocity and highlight participant skills.

Results

Following screening, we asked five optional demographic questions; responses are summarized in Table 1.

Themes

A number of themes emerged during data analysis. Study questions were categorized as themes, with sub-themes identified from participant answers. Sub-themes were created based on these answers if *more than one* participant offered the same, or a similar, response. Following thematic breakdown by question, the research coordinator observed if there were any overarching themes among question responses. Theme 2 *(Are there different kinds of poverty?)* and theme 6 *(Does poverty look different for Indigenous people?)* were the only study questions/main themes with 100% affirmative responses from participants.

What is poverty?

Our first question aimed to draw out participants' own definitions of poverty, and there were three themes in participant responses. At least three participants stated that poverty exists because of systematic failure, and not because of the failure of those experiencing poverty. As participant CTRG said:

> Because a lot of people, for them poverty is a judgment of character, when it's not. I think poverty is really a failure of the system. People that have been in poverty are some of the hardest working people that I've ever met. And if they were just given a chance by the system to work that hard in a place that might give better results, or better opportunity, then they would have a really wonderful life. But again, the system has failed them. So I guess it's almost a combination of what is poverty, and what poverty is not. And it's not a judgment of character. (CTRG, May 17th 2023)

This quote highlights the impact of neoliberalism, which suggests that poverty results from individual failings rather than numerous complex systematic failures on the part of government and other institutions of power. Further, framing poverty as systematic requires acknowledging the roles of imperialism and colonization. This theme aligns with our assertion that poverty and health impacts of poverty must be responded to holistically, taking modes of oppression such as racism, necropolitics, ableism, white supremacy, imperialism, capitalism, and neoliberalism into account.

A second theme was that at least three participants defined the experience of poverty as being in "survival mode," defined by participants as living 24 hours at a time, without consistent and safe shelter, unsure where you will get your next meal. As participant CM explained:

> I think there's the extremes we think of, but nowadays in life, there's a wide range. Because I think just surviving is poverty too. You may have your bills paid, but you have nothing extra at the end of the month to do anything with your life. You don't get to live, you're just surviving, and that's poverty too. (CM, July 12, 2023)

A third trend was that at least two participants defined poverty as a "state of mind," indicating poverty is about how a person interprets their situation. This theme suggests that poverty is not always defined by socio-economic-status. As T said, "Poverty? They always try to say it's money wise, but what I believe is it's an interpretation of a person's world" (Nov, 2023).

Are there different kinds of poverty?

All participant responses agreed that there are different kinds of poverty. Participants defined poverty in multiple ways but each definition framed poverty as a lack of something essential for a full and balanced life, whether that lack is financial, spiritual, or physical. Participants described poverty as generational (i.e. inherited from parents, passed to children), individual (i.e. not shared with others and/or unrelated to the influence of outside actors), or situational (i.e. dependent on circumstances or events). This is demonstrated by two quotes from participants:

> A few like other types of poverty, or at least ways that we can define them. For me, there are systemic, generational, individual, and situational types of poverty. (CRTG, May 17 2023)

> I believe that there are levels of poverty too that exist. In those levels of poverty, it's very—it can be individualized, personal to me, intergenerational poverty, community poverty, the area in which you live is impoverished.... (YP, July 12, 2023)

How would you know if someone is in poverty?

In response to this question, two or more participants indicated that unless you take the time to get to know someone's specific situation, you cannot infer that they are living in poverty by simply looking at them. As participant JLG said:

> When I can tell someone is living on the street and has mental health issues, I know our system doesn't support them, and if I see them in the same spot day or night, it's pretty obvious they don't have a place to live, but other than that, that's a hard question. (JLG, July 12, 2023)

A second and related theme, touched upon by MB in the quote above, suggests that the impacts of shame and social stigma drive people to hide their poverty conditions. As participant MB explained:

> I don't think you always do know [someone is in poverty], unless people tell you. I think people have a way of hiding it well. And if you're not particularly close to somebody, you don't know what they're struggling with. So, they may have nice clothes on, but maybe they don't have enough to eat. (MB, May 17 2023)

And CM agreed that poverty was sometimes intentionally camouflaged:

> So as for telling if someone is in poverty, I think it's hard, because I think blending is a big piece of it. A lot of people don't want you to know, they don't want the stigma around it. (CM, July 12 2023)

This social stigma can have terrifying implications, especially in the form of Child Protection Services. As demonstrated by the quotes below, Child Protection Services was described as making negative assumptions about Indigenous parental care, which participants framed as a barrier to providing for their children in times of poverty.

> We had welfare coming to our door, because my brother used to chew on his sleeves, they'd say, "You're starving your kids," my mum would say, "Look in the cupboard!" And she'd have the cupboards full of food, and they didn't know what to say. (CS, July 12, 2023)

> And also fear of, if something good did come into my life, that it would be taken away. Constant fear that child protective services would be involved in our life and learning how to keep things a secret. (YP, July 12 2023)

What types of impoverishment have you survived?

When asked about forms of impoverishment they had survived, two participants recalled embarrassment when accessing resources, as T described:

> I can think back to a time where we were in town and mom went into the welfare office and she told us to come, and my brother was mortified. Mortified, he goes "I can't let nobody see me coming in here, they're going to think we're poor." (T., May 17 2023)

Multiple participants expressed that they did not realize they were living in poverty until circumstances allowed them to compare themselves to settlers, either by moving into the city, or attending a camp or school with children who had access to more resources. Participant MB said:

> But then when I started going to school and comparing myself to other people, seeing all of the middle class houses they lived in, it made me realize that—for me I'm still often thinking of poverty as realizing you don't have the things that other people have, and having people talk about stuff as if it's normal to have these things, when none of that is the case for you, and that was the case for me. (MB, May 17 2923)

> My family grew up on $12,000 a year from welfare, and sometimes I see these celebrities with a Rolex watch. I saw one that was like $37,000 and I was like "that man is wearing three years of my family's income on his wrist!" It's hard for that to not make you feel crazy. (CRTG, May 17 2023)

Multiple responses spoke to efforts to shield children from realizing that their caregivers are experiencing economic/financial poverty, which offers insight into why participants didn't realize they were in poverty as children themselves. As MB explained:

> I didn't really understand the severity of the situation until my mom came home with a box of food, and I didn't realize she didn't buy it at the grocery store. I started looking through this and I was like, we don't need any of this, why would you buy this? And it wasn't until years later I realized it was because she went to the food bank—she didn't buy it at the grocery store. (MB, May 17 2023)

Despite this tactic of shielding children, some participants had noticed the impacts of poverty-related stress on their caregivers, whether or not they attributed it to financial poverty at the time. Fears related to poverty were exacerbated by government intervention, as one participant described:

> Poverty is a fearful situation regardless of who you are, but I find there is a huge added fear of child welfare involvement for Indigenous people who are in poverty than for someone else in poverty. (Anon, July 12, 2023)

At least two participants stated that poverty is generational, with both lack and strategies for managing lack passed down from relatives and/or caregivers. As DJ said, "We camouflage it, we hide it, and I'm very good at doing that. I learned that very well from my mom" (DJ, May 17 2023). Multiple participants expressed that living in poverty results in higher stress and fear.

What strategies for getting by have worked for you?

Answers to our question about survival strategies spoke to the importance of food security. Participants described ways to meal prep, save leftovers, extend the shelf-life of food, where to go to access food resources, and the importance of being attentive for opportunities. As MB described, "Stocking up when I see that something's on sale at the grocery store, being mindful of what we're gonna eat" (MB May 17 2023). Several participants suggested that traditional ways of living and building community mitigate or reduce the impacts of poverty and reported accessing communal or interpersonal food resources, as DJ describes below.

> I love anything that's off the land. I love moose meat! My friend came up from Newfoundland and she knows I love moose meat. She and her partner gave me a bottle of moose meat. I can't wait to have that moose meat. Sharing meals, you know, with our community members, our collective kitchen with MCDC [Mi'kmaw Child Development Centre] you know, reclaiming our roots. That's a big thing for me too as well, is focusing on those items that we have off the land. And that is the way our people did it back then. We didn't have grocery stores! (DJ, May 17 2023)

At least four participants described asking the community/friends/family for aid or accessing helping resources offered by local governments or organizations. One participant reports that as a child they shoplifted from local stores with a friend:

> We'd go into the store, buy something, I'd tap the lady on the shoulder, she'd turn, and he'd grab the money. First place we did it was the Capitol store up here on Gottingen Street. We looked at each other and said 'oh God!' It kept food in my mouth, shoes, food in my grandmother's house, so I didn't see it as being anything wrong. And I did that for years. (Anon, July 12 2023)

Participants also stressed gratitude, in terms of feeling and expressing thanks for good things, which they connected to Indigenous cultural and spiritual ways of knowing, being, and ascribing/defining value. As DJ and CRTG explained:

> You know, even though there's other stressors going on in my life, I take that time to be grateful for the true blessings in my life. I think having those values that my mom gave me: be appreciative of the things that I have in life. And also not to be materialistic, don't focus on material. You can't carry that to your grave, you know. (DJ, May 17 2023)

> It's just gratitude and forgiveness for myself. I start thinking a lot about where I wanna be, where I should be, or I want to be at this place in my career, I should be at this place in university, in my classes.... And then I sit down and I think: I'm exactly where you need to be right now, because the fact that I'm even here in university, I'm getting a degree—that speaks volumes for itself. (CRTG, May 17 2023)

Multiple participants endorsed thrift store shopping and strict budgeting as ways to make ends meet. Participants voiced an eagerness to share the methods that help them to make ends meet and to share local resources they have used. With participant permission, we collected these strategies and resources into a zine, *Making Ends Meet*, which was publicly distributed in digital and hard copy as well as distributed to local Indigenous and non-Indigenous community-based organizations and resource centers in Halifax Regional Muncipality. Participants whose data was used in the zine were asked to review the suggestions and quotes credited to them and to sign a consent form allowing us to publish the zine.

Does poverty look different for Indigenous people than for others?

All participants agreed that poverty looks different for Indigenous people than it does for settlers. Multiple participants linked their answer to the role of colonization, as shown below.

> Considering our people were forced to live on reserves, that has a huge impact on poverty. (MB, May 17 2023)

> And I feel like… poverty is different for Indigenous people because I agree there's a sense of community. (JLG, July 12 2023)

> I think poverty for Indigenous people does look different, but I don't have a whole lot of experience being in an Indigenous community, I grew up in Halifax, so I didn't grow up on reserve…. We were poor, but I also had access to a lot of things—a lot of things other Indigenous children probably didn't get. (YP, July 12, 2023)

Participants also highlighted the control exerted over Indigenous families by settler governments, which makes Indigenous people in poverty more vulnerable. As one participant said:

> Child welfare is very quick to jump in and take Indigenous kids and place them somewhere else, even just for the littlest things, not just poverty. Just because this home may look like what we'd deem as a poverty situation, it doesn't mean that they're actually not getting their basic needs or are actually unhappy or need to be taken from their family, that their family isn't taking care of them. It's a sin, be-

> cause so many kids get displaced when really all that family needed was some help. I also think it's different if you're on reserve or off reserve. (Anon, July 12, 2023)

What does "having enough" look like where you live? What would it mean to have enough?

Our final question invited participants to imagine what it would mean to have enough, and four themes emerged. The first of these stressed financial security.

> There's a lot of aspects to this for me, and one of the big things I think for me is financial fulfillment, and other aspects of fulfillment, I think there is the coexistence with them. (CRTG, May 17 2023)

A second theme in participant answers was that having enough means being able to shift out of "survival mode" and ask for more. Participants varied by what "more" they wanted, with one participant framing it as developing higher ambitions. Participants distinguished "having enough" from having an excess of consumerist goods or money, with "having enough" defined very minimally, as shown in these quotes from JLG and YP:

> Having enough looks like I can feed myself. I can turn the lights on, I have a roof over my head, I get to sleep in a bed. That's enough—more than enough for me. (JLG, July 12 2023)

> Having enough for me, like having bills paid, having a place to sleep, being able to open up the cupboards or the fridge and say to my daughter "pick whatever you want." (YP, July 12 2023)

Across both focus groups and individual interviews, participants indicated that "having enough" usually involved connecting with Indigenous community, land, and water. Participants indicated that "having enough" would mean no longer living in "survival mode." Participants clarified that "having enough" is not synonymous with excess. Love and community were among the most repeated responses to the question of what "having enough" looks like, supporting the assertion of this special issue of *Atlantis Journal* that "healing is an act of communion."

Discussion

This pilot study provides valuable insights into how Indigenous people in Kjipuktuk conceptualize poverty, highlighting the limitations of solely relying on fiscal measures. Participants' experiences underscore the significance of a holistic approach that incorporates cultural connection, access to resources, and social inclusion, aligning with the perspectives of organizations like the Native Women's Association of Canada. The study's findings suggest that poverty, as experienced by Indigenous individuals, is deeply intertwined with historical and ongoing colonialism, land dispossession, and systemic discrimination.

Participants agreed that the experience of poverty is distinct for Indigenous peoples, primarily due to the role of colonization. While the research team aimed to prioritize women and gender-non-conforming participants in recruitment, we did not ultimately reject any potential participants who identified as cis-gendered men. This likely reflects the reality that Indigenous women, girls, and Two-Spirit people are likely to experience poverty in their lifetime (Kia et al. 2020). Participants highlighted gendered impacts of poverty, such as those pertained to raising children, feeding a family, sourcing and cleaning clothing, and keeping house, as well as gendered responses to such impacts. Because our aim was to test the feasibility of a holistic model of poverty in Mi'kma'ki, the research questions did not pursue issues of gender in greater depth, but future studies should consider making gendered experiences of poverty a focus of data collection. This approach should consider the multifaceted nature of poverty and how gender shapes poverty's impact on health, access to services, and vulnerability to violence.

We found that the sharing circle methodology, guided by Mi'kmaw cultural practices and Elder Ann Labillois, did facilitate a culturally safer space for participants to share their experiences. This research emphasizes the importance of centering Indigenous voices and perspectives in poverty research and policy development. Future research should explore the development of culturally relevant poverty indicators and interventions that address the root causes of Indigenous poverty, while also promoting cultural resilience and well-being.

Limitations

Given that our sample population included individuals who are currently experiencing poverty, recruitment and follow-ups proved difficult. Rae communicated via handwritten letters, phone calls, emails, and in-person, but many individuals who could have contributed valuable data were likely unable to participate due to their circumstances. Since participating in research is not a highly paid activity, study data may be skewed to represent participants who no longer live in poverty, and experiences of poverty decades ago may differ from experiences of poverty in the present day. While gender was discussed tangentially by participants, gender-specific study questions may have offered more insight into the impact of gender on Indigenous experiences of poverty in Mi'kma'ki. Finally, experiences of poverty likely vary by location, and interpretations of such experiences may vary by Indigenous nation.

Future research should be led by Indigenous communities, engage more Indigenous nations, take up questions of gender directly, and expand accommodations to include more participants actively living in poverty. Questions about gender and sexual orientation, along with other intersectional identities, should be incorporated to allow for a more nuanced understanding of Indigenous experiences of impoverishment.

Conclusion

This pilot study suggests that a holistic model of poverty does resonate with Indigenous people who have experienced poverty in Mi'kma'ki. Participants indicated that poverty is determined by the absence of factors that support a well-rounded, balanced life. While many participants described poverty as living in "survival mode," indicating a lack of money, food, and/or shelter, many also described poverty as a lack of spirituality and connection with land. These responses suggest that poverty, like health, can be understood holistically.

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Appendix

Table 1. Demographic Characteristics of Participants

Age Group	Participants
Born in 1960s (ages 64-54)	3
Born in 1990s (ages 34-24)	3
Born in 1970s (ages 54-44)	2
Born in 1980s (ages 44-34)	2
No answer	2
Gender Identity	Participants
Women	7
Men	3
No answer	2
Sexual orientation	Participants
2SLGBTQIA*+	4
Straight or Heterosexual	4
No answer	4
Education Level	Participants
High school	3
Vocational or technical college	2
Some college or university	2
Undergraduate degree or equivalent	3
Master’s degree or equivalent	1

Doctorate degree or equivalent	0
No answer	1
Time of Life Experiencing Poverty	Participants
All my life	4
Age 60+	0
Age 40-59; Middle age	1
Age 20-39 Early adulthood	3
Age 13-19; Secondary school	2
Childhood: Age 6-12	3
Early Childhood: Up to age 5	2
No answer	1
Notes: Within sections, some answered in multiple categories.	

Table 2. *Thematic Breakdown*

Study Question	Themes
1. What is poverty?	1.1 Poverty is a systemic and/or a policy failure 1.2 Poverty is survival mode 1.3 Poverty is a state of mind
2. Are there different kinds of poverty?	2.1 Consensus is yes
3. How do you know if someone is in poverty?	3.1 Not always possible to tell 3.2 Hiding poverty due to shame & stigma

4. What types of impoverishment have you survived?	4.1 Embarrassment accessing food banks 4.2 Not realizing until compared to others 4.3 Shielding children 4.4 Hiding poverty from others 4.5 Poverty is generational 4.6 Poverty brings stress & fear
5. What strategies for getting by have worked for you?	5.1 Food Security 5.2 Returning to the land, culture, and community 5.3 Asking for help/community support 5.4 Gratitude 5.5 Thrifting 5.6 Budgeting
6. Does poverty look different for Indigenous people than for others?	6.1 Consensus is yes
7. What does 'having enough' look like where you live? What would it mean to have enough?	7.1 Financial security 7.2 Community and love 7.3 Not being in survival mode

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When You Know Better You Do Better: Creating Cultural Safety for Black Patients

by Olivia Riley-States and Renee Crossman

Abstract: Background: Western healthcare is inundated with processes that don't meet the cultural needs of racialized populations or consider non-medical aspects of health and healing. Social structures and power imbalances make it difficult to change these processes. The health experiences of Black people are affected by mistrust, racial microaggressions, and discrimination. To foster health and healing, we must consider the harm done when care is not culturally responsive. Methods: To address the lack of culturally safe healthcare, we completed a quality improvement project to develop an educational workshop about cultural safety with Black patients. The workshop was created using the theoretical lens of relational inquiry and included a literature review, environmental scan, and consultations. The workshop is designed to challenge providers to be self-reflective of their biases while developing an understanding of the health needs of Black patients, especially the African Nova Scotian (ANS) population. Results: The session has been delivered and evaluation feedback indicated positive experiences with some change in knowledge. Participants engaged in difficult discussions about bias and discrimination in their workplaces and themselves. Conclusion: Cultural safety education can positively impact healthcare providers' attitudes. Healthcare is multifaceted for Black people; healthcare providers must understand the intersection of anti-Black racism and health. Rebuilding trust with the Black community, acknowledging harm, and increasing representation in healthcare are necessary to address health disparities for Black people. Healing the relationship between ANS communities and the healthcare system requires critical reflection and targeted actions. Cultural safety education can initiate change.

Keywords: cultural safety; Black patients; African Nova Scotian; education; healthcare

Résumé : Contexte : Les soins de santé occidentaux sont saturés de processus qui ne répondent pas aux besoins culturels des populations racialisées ou qui ne tiennent pas compte des aspects non médicaux de la santé et de la guérison. Les structures sociales et les rapports de pouvoir inégaux compliquent le changement de ces processus. La méfiance, les microagressions raciales et la discrimination ont une incidence sur l'expérience des personnes noires dans le système de la santé. Pour favoriser la santé et la guérison, il faut tenir compte des préjudices causés lorsque les soins ne sont pas culturellement adaptés. Méthodes : Pour remédier au manque de sécurité culturelle dans les soins de santé, nous avons mené un projet d'amélioration de la qualité visant à mettre en place un atelier éducatif sur la sécurité culturelle auprès des patient·e·s noirs. L'atelier s'appuyait sur le cadre théorique de l'enquête relationnelle et comprenait une analyse documentaire, une analyse de l'environnement et des consultations. Il avait pour objectif d'encourager les prestataires de soins à réfléchir à leurs propres préjugés, tout en approfondissant leur compréhension des besoins en santé des patient·e·s noirs, en particulier de la population afro-néo-écossaise. Résultats : La séance a été offerte et les rétroactions découlant de l'évaluation ont fait état d'expériences positives et d'une certaine amélioration des connaissances. Les participant·e·s ont pris part à des discussions difficiles sur les préjugés et la discrimination, tant dans leur milieu de travail qu'à titre personnel. Conclusion : La sensibilisation à la sécurité culturelle peut avoir des retombées positives sur l'attitude des prestataires de soins de santé. Les soins de santé sont multidimensionnels pour les personnes noires; les prestataires de soins de santé doivent comprendre l'intersection entre le racisme envers les personnes noires et la santé. Rebâtir la confiance avec la communauté noire, reconnaître les torts causés et accroître la représentation dans le système de santé sont essentiels pour réduire les inégalités dans le domaine de la santé chez les personnes noires. Pour restaurer la relation entre les communautés afro-néo-écossaises et le système de santé, une réflexion critique et des mesures ciblées sont nécessaires. La sensibilisation à la sécurité culturelle peut amorcer un changement.

Mots clés : sécurité culturelle; patientes noirs; education; Afro-Néo-Écossaises; soins de santé

Authors:

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Creating Cultural Safety for Black Patients: Introduction

Health equity has become a focus of healthcare leaders, but what does it mean to be healthy? Health and healing are often viewed from a biomedical lens focusing on evidence-based care and medicine, reflecting a Eurocentric perspective. Western medicine is inundated with practices, procedures, and care goals that don't meet the cultural needs of racialized populations or consider essential, non-medical aspects of health and healing. Power imbalances are inherent in healthcare settings and care-based relationships. Social structures and systemic racism make it challenging to change this perspective. Unfortunately, inequities for racialized people are also evident in healthcare leadership. Healthcare leaders must critically analyze the healthcare system and the ongoing harm that Black people experience when accessing it. To meet the needs of the Black population, it is essential to understand their experiences within the healthcare system and the social factors that impact health. The health experience of Black people includes historical and current mistrust of the healthcare system and healthcare providers, as well as other interconnected social systems. Black people also face racial discrimination and microaggressions in the greater community and healthcare environments (Cénat et al. 2022a; PHAC 2020). To foster health and healing, we must acknowledge the harm we cause racialized populations when the available healthcare is not culturally safe or responsive. Continued negative experiences in healthcare can cause mental and physical health symptoms. The PHAC (2020) found that Black women reported their mental health as excellent or very good less frequently than their White counterparts.

Olivia Riley-States who is African Nova Scotian (ANS), has had negative experiences as a healthcare provider and consumer. These experiences created a desire to analyze the healthcare experiences of others in Canada and explore opportunities to improve the health experiences of African Nova Scotians, people of African and/or Caribbean descent, and others who identify as Black, including those of mixed race. Dr. Renee Crossman is an assistant professor who supervised the project, completed as part of the degree requirements for a Master of Science in Nursing. Healthcare leaders can improve health equity and create changes throughout the health system by engaging in professional development and opportunities to learn how to create culturally safe spaces. Informal and formal leaders can also advocate for changes and act as role models. Change does not often come from a place of comfort. To truly create equity in healthcare, we must acknowledge the power imbalances and social structures that drive our practices and be willing to move beyond the Eurocentric views of health and healing. When we consider healing as an act of communion, we must partner with ANS patients and communities to co-create opportunities for wellness in spaces that reflect their perspectives and experiences.

In this paper, we describe the findings of the literature review, environmental scan, and consultations. The findings include healthcare experiences of Black patients and healthcare providers, including mistrust, racial discrimination and microaggressions, and their mental health impacts. We discuss the need for representation of Black people in healthcare and culturally relevant care, such as Afrocentric practice. Finally, we describe and discuss the development of a workshop to address the adverse health experiences and improve cultural safety in a health system that serves women, children, and their families.

Theoretical Lens

Throughout this project, we were guided by relational inquiry (Doane and Varcoe 2021). Relational inquiry includes hermeneutic phenomenology, pragmatism, and a critical lens. Hermeneutic phenomenology is about lived experiences and is essential to cultural safety (Doane and Varcoe 2021). Additionally, pragmatism means that knowledge is only as good as it is relevant (Doane and Varoe 2021). Therefore, healthcare providers must engage in inquiry as action to determine how culture and lived experiences impact the care encounters of individual patients and families, as well as the Black community as a whole (Doane and Varcoe 2021). We included the application to practice and a locally relevant context to ensure the relevance of the educational workshop. Finally, our critical lens guided our ability to begin to understand and unpack the hierarchies, social structures, and power systems that continue to impact Black patients accessing healthcare and Black healthcare staff.

Methodology

We began by engaging in casual and informal discussions with colleagues to explore the healthcare experiences of Black people locally in Nova Scotia. We learned that Black colleagues had experienced and witnessed microaggressions and discrimination and some lacked trust in the healthcare system despite their roles as healthcare providers. White colleagues also witnessed treatment of Black patients that was different from that of their White counterparts. Based on these discussions, we created a proposal to develop an educational workshop to increase cultural safety for Black patients in the local health system. Due to the limited scope and time frame of the project, the intended population was limited to the Mental Health and Addictions (MHA) program. To develop the background for this workshop, we conducted a literature review, consulted with local key stakeholders, and performed an environmental scan of health institutions in Atlantic Canada to determine if related resources were in use. This was a quality improvement project and, therefore, did not require ethical review board approval. However, we maintained the confidentiality of the consultations and, before completion, received approval from the research department and the director of the MHA program. Additionally, prior to consultations, the project was explained and verbal consent to proceed was obtained.

Literature Review

We searched four databases: Google Scholar, CINAHL, PsychInfo, and Pubmed. The quantitative studies were critically appraised using the PHAC (2014) Critical Appraisal toolkit. Qualitative studies were analyzed using the Critical Appraisal Skills Programme (CASP) checklist (CASP 2017). Twenty-three articles were reviewed. We included North American articles that described the health experiences of Black patients or the impacts of those experiences. From the articles selected, we extracted themes. To explore the use of cultural safety training and modes of delivery, we included articles from several countries that described the implementation or experiences of healthcare providers who participated in education related to cultural safety or cultural competence with any population.

Consultations and Environmental Scan

We consulted with local stakeholders in NS. Throughout this paper, we will refer to the individuals who participated in the consultations as "consultees." The consultees were healthcare staff, both Black and White individuals in the health system and one Black community member. It was essential to consult both Black and White participants to ensure the perspective of Black people was heard while also ensuring the learning needs of the White healthcare providers were met. The consultations consisted of one-hour semi-structured interviews. Finally, we completed an environmental scan of health institutions in Atlantic Canada. We reviewed websites and emailed healthcare network contacts to inquire about educational resources available to healthcare workers on cultural safety and working with Black patients. We thematically analyzed the data from the environmental scan and consultations based on Braun and Clarke (2006). This included six steps: familiarizing ourselves with the data, generating codes, creating themes, reviewing themes, determining the significance of the themes, and reporting the findings (Braun and Clarke 2006).

Findings of the Literature Review, Consultations, and Scan

As we aim to increase cultural safety, we must first understand the underpinnings of the concept and, secondly, acknowledge the factors that influence Black experiences in health. Cultural safety is described as a combination of cultural awareness, sensitivity, and competence (Yaphe, Richer, and Martin 2019). Often, the word *competence* is associated with completion, increasing the perception that providers must know everything about a culture (Lekas, Pahl, and Fuller Lewis 2020). However, cultural competence is grounded in continuous learning, reflection, and understanding of the implications of sociocultural factors (Garneau and Pepin 2015; Kaihlanen, Hietapakka, and Heponiemi 2019). Similarly, cultural humility refers to lifelong learning encompassing openness, acceptance of patients' own expertise, and self-reflection in caring for people from different cultures (Lekas, Pahl, and Fuller Lewis 2020; Prasad et al. 2016)

Historical experiments like Tuskegee, the use of Henrietta Lacks' cells, and current experiences of discrimination foster a lack of trust in the healthcare system for Black people (Cénat et al. 2022a; CDC 2022 Wolinetz et al. 2020). During the 40-year Tuskegee experiment, researchers studied the natural course of syphilis by denying treatment to Black participants and idly standing by while they suffered the horrific outcomes of the disease left untreated (CDC 2022). Commonly known as HeLa cells, Henrietta Lacks' cancer cells were used for years of profitable research without her or her family's knowledge, consent, or compensation, contributing to developments in polio, cancer, and other medical treatments (Wolinetz et al. 2020). Cultural safety is generally applied to working with Indigenous populations despite the importance of applying the principles to all diverse people (Browne et al. 2021; Kaihlenan et al. 2019; Pimental et al. 2022; Yaphe, Richer, and Martin 2019). In 2015, the Truth and Reconciliation Commission of Canada (TRC) called for education to address systemic racism and bias in healthcare, solidifying previous work (TRC 2015). Nonetheless, we found a paucity of literature about education for cultural safety with Black patients. To create culturally safe spaces, healthcare providers must understand the impact of culture on behaviour and show empathy and respect (Prasad et al. 2016). Cultural safety is not a new concept, though there has been a recent increase in uptake in healthcare settings (Browne et al. 2021; Kaihlenan et al. 2019; Pimental et al. 2022; Yaphe, Richer, and Martin 2019). Cultural safety training has been shown to increase awareness of culturally specific issues and barriers to care, increase knowledge and ability to incorporate cultural safety into daily practice, and improve patient interactions (Browne et al. 2021; Kaihlenan et al. 2019; Pimental et al. 2022; Yaphe, Richer, and Martin 2019). Cultural training has been generally well-received, however, some resistance from the dominant race (White) has been found (Browne, Varcoe, and Ward 2021; Erb and Loppie 2023; Micheal et al. 2021). In some studies, at times, White participants have felt attacked during discussions about White privilege and have made racist, harmful comments toward facilitators (Erb and Loppie 2023; Micheal et al. 2021). Facilitators have experienced burnout due to the challenging nature of course delivery and a lack of support from leadership (Erb and Loppie 2023).

For Black patients in Canada, healthcare experiences challenge relationships with health systems and contribute to health disparities such as increased rates of diabetes and lower self-rated mental health than their White counterparts (PHAC 2020). In the following sections, we discuss three contributing factors to these health disparities, including historical and current mistrust, racial discrimination, and racial microaggressions. We also discuss how these factors impact mental health and help-seeking behaviour. Further, we articulate the critical necessity of including Afrocentric practices, the need for increased representation in healthcare, and the challenges in achieving diversity in the healthcare workforce.

Historical and Current Mistrust

Black patients have been subjected to unethical treatment in the health system through experiences such as the Tuskegee experiment (Alsan and Wanamaker 2018; CDC 2022). During this experiment (1932-1972), Black patients were not treated for syphilis even though, during the study, penicillin became the first line of treatment (CDC 2022). Schwei et al. (2014) found that 47% of African American patients reported high institutional trust compared to 61% of White participants when other variables were controlled (OR: 1.93; 95% CI, 1.16–3.23). Black consultees in this study also described a lack of trust in the healthcare system and providers. White consultees described a lack of effort from healthcare providers to develop a trusting relationship with their Black patients and families, resulting in less collaboration in care. Similarly, Boulware et al. (2003) found that Black participants were more likely to be concerned about privacy breaches and harmful experiments being done without patients' knowledge (p=.01). Black patients were less likely to trust both their healthcare providers and health institutions (Boulware et al. 2003; Schwei et al. 2014; Webb Hooper et al. 2019). A lack of trust can increase health disparities; Waldron et al. (2023) found that trust was a barrier to Black patients' help-seeking behaviours for mental illness. All of the White participants in the consultations described a general desire to improve relationships with Black patients and families and the greater Black community. Similarly, Black consultees were open to rebuilding relationships with the healthcare system.

Racial Discrimination

Racial discrimination is inadequately justified differential treatment based on race and disadvantages a racial group (Cénat et al. 2022). Racial discrimination is associated with symptoms of mental illness such as depression, anxiety, and sleep issues, as well as decreased overall mental health (Cénat et al. 2022a; Cénat et al. 2022b; Chan, Pullen Sansfaçon, and Saewyc 2023; Moody et al. 2022; Nguyen et al. 2023). Cénat et al. (2022a) found that 53.1% of Black Canadians aged 15-40 experienced racial discrimination in healthcare, with at least four out of ten participants experiencing racial discrimination every day. Examples include being treated as if they were not intelligent, not being respected, and being threatened (Cénat et al. 2022a). Sacks (2018) found that Black women dressed well when attending healthcare appointments to avoid discrimination and attempted to personally connect with healthcare providers to avoid the race-based assumption that they were unintelligent. There is a social system that maintains the power imbalance in care encounters, which results in Black patients struggling to humanize themselves to avoid discrimination (Sacks 2018). Chan, Pullen Sansfaçon, and Saewyc (2023) found that 35% of Black, Indigenous, and People of Colour (BIPOC) participants experienced racial discrimination compared to 2.1% of White participants.

In NS specifically, Black people are impacted by environmental racism. Environmental racism includes placing toxic waste facilities near Black communities and allowing pollutants in Black communities (MacDonald 2020; Waldron 2018). Examples include the historic Black community of Lincolnville, which has increased cancer rates and is located next to a waste facility; in a 2002 study, 28.5% of Black people in NS lived within 5 km of a waste facility (Waldron 2018). In NS, Black nurses described what was referred to as the "Black tax" or the added weight of being a Black nurse that results from the physical and emotional distress of navigating the racial hierarchies of nursing and healthcare (Jefferies et al. 2022). Black nurses have found it challenging to integrate into nursing due to organizational policies and institutional ideologies that decrease entry into nursing practice (Jefferies et al. 2022). Despite making efforts to improve the health disparities for Black patients, we are still a long way from achieving health equity.

Racial Microaggressions

Racial microaggressions are subtle verbal, behavioural, or environmental indignities (Nadal et al. 2014). Sometimes, microaggressions are subconscious; however, they may also be intentional (Nadal et al. 2014). Examples from the consultations include Black patients and their families who were treated differently from their White counterparts, despite a similar clinical presentation; care teams made less effort to build relationships and support family involvement in care; and Black patients were discharged earlier and more unwell than White patients with similar disease processes. White healthcare providers stated they had difficulty addressing these concerns because it was sometimes challenging to name and prove, even though they said that a difference was evident to them. Strikingly, Cénat et al. (2022a) found that 49.8% of their study participants were made to feel that their accomplishments were due to preferential treatment based on race, while Williams et al. (2020) found that their study participants experienced hostility due to assumptions of unfair advantages.

Impacts of Historical and Current Mistrust, Racial Discrimination, and Microaggressions

Racial microaggressions and discrimination are negatively associated with mental health symptoms for Black patients, including anxiety, depressive symptoms and sleep problems (Cénat et al. 2022a; Cénat et al. 2022b; Chan, Pullen Sansfaçon, and Saewyc 2023; Moody et al. 2023; Nguyen et al. 2023; Waldron et al. 2023; Washington and Randall 2023). Black patients have vigorously prepared for health appointments due to anxiety about racial discrimination (Washington and Randall 2023). Nguyen et al. (2023) also found that racial discrimination was associated with 12-month and lifetime anxiety levels. Higher levels of everyday discrimination have been associated with increased psychosomatic symptoms (Cénat et al. 2022b). Similarly, higher levels of racial discrimination have been associated with increased depressive symptoms and sleep problems (Hart et al. 2021; Lavner et al. 2022). For BIPOC youth, racial discrimination has been associated with missed physical healthcare needs and previous 12-month suicide attempts (Chan, Pullen Sansfaçon, and Saewyc 2023). Cénat et al. (2022b) found an association between higher levels of experienced racial discrimination and increased psychosomatic symptoms, with headaches being the most prevalent. Mays et al. (2017) found that for Black patients, discrimination was associated with early treatment termination (AOR=13.38, $p<0.05$), with race being the most common reason for discrimination in healthcare. Experiences of racism also indirectly affect provider trust (Pugh et al. 2021). Provider trust mediates the relationship between racism and medication adherence, demonstrating the importance of building trusting relationships with patients and their families (Pugh et al. 2021).

Representation and Afrocentric Practices

Black care providers are hard to find, and Black patients have difficulty finding culturally competent care providers (Waldron 2020; Waldron et al. 2023). Consultees described a lack of diversity in the healthcare workforce; unfortunately, race-based data on the nursing workforce in Canada is not collected (Canadian Nurses Association n.d.). Consultees reported that healthcare providers did not try to build trust and rapport with Black patients and their families. During the consultation process, healthcare providers expressed a desire to learn more about the experiences of Black patients to improve their ability to meet care needs. Healthcare providers expressed a lack of interactions with Black patients because they are not seeking care as often as others, often waiting until their condition becomes an emergency. Every healthcare professional noted differences in the care provided to Black patients that were "difficult to name." The consultees also described experiencing or witnessing racial microaggressions that they were unsure how to address in practice. Organizations have made efforts to increase representation through designated positions; however, it can be a challenging environment for Black care providers when they are the only Black employees in a care area. Black employees have also experienced racial discrimination when their colleagues feel they did not earn their position; instead, they were given the position because of their race (Cenat et al. 2022a). Although these positions are intended to increase representation, they have the potential to cause further harm. Organizations should intentionally support Black employees and build awareness that they possess the same qualifications as others in the same or similar positions. Organizations should also have strong policies against racial discrimination that outline a clear path for reporting and managing discrimination. Finally, it is essential to ensure that all employees have received education about cultural safety, such as the educational resource we have developed which is discussed in the next section.

Black patients should have access to care that is culturally relevant. Consultees reported that healthcare providers did not make the same effort to collaborate with Black patients and their families as they did with their White counterparts. The health care that Black consultees received did not meet their needs culturally or the needs of Black families that healthcare professional consultees work with. Consultees reported that care practices were based on the views of White people and, therefore, did not relate to the cultural values of Black patients. Afrocentric practices are culturally relevant models of care grounded in Black people's culture, lived experience, and history (Hatcher et al. 2017). The Seven Principles or Nguzo Saba that guide Afrocentricity are from various African cultures and include unity, self-determination, collective work and responsibility, cooperative economics, purpose, creativity, and faith (Hatcher et al. 2017). As all Black people are not the same, Afrocentric practices may vary. Although the principles are common in Afrocentric practice, healthcare providers must ensure they do not stereotype Black patients or assume they are all the same. Cultural humility requires ongoing learning and openness to the values and beliefs of others (Prasad et al. 2017). As healthcare leaders, we must maintain this openness and use inquiry as action to ensure we do not perpetuate the feeling for Black patients that they need to act a certain way to be viewed individually and with humanity. Healthcare leaders must be actively anti-racist, recognizing that racism is built into the health system. The burden of dismantling these systems should not be on the equity-deserving group. All patients and families should be engaged in the care process and planning and determine how the principles relate to their lived experience and expectations for care.

White Resistance

Discussions about White privilege can be challenging for some White people, often those who feel they have faced many hardships and had a difficult life that they do not feel was privileged (Browne, Varcoe, and Ward 2021). In an interview with Guardian News (2020), sociologist Robin DiAngelo describes White fragility as defensiveness or hurt feelings that White people develop when their racial views are challenged, including those around White privilege. The behaviours associated with White fragility make it difficult to address and challenge racial biases, even if they are subconscious, because people become fearful of the response (DiAngelo 2011; Guardian News 2020). An example is a White healthcare provider treating a Black patient with less respect than a White patient. The Black patient and other healthcare providers may notice this difference, but they are afraid to say something out of fear that the White healthcare provider will become defensive. Therefore, the disrespect continues with this patient and is accepted. When the next Black patient arrives for care, this behaviour continues. This is how White fragility works to uphold racism (DiAngelo 2011; Guardian News 2020). Together, the findings of the literature review, environmental scan, and consultations formed the foundation of the educational workshop.

Educational Workshop Development

Creating culturally safe environments requires healthcare providers to acknowledge and address the negative experiences Black patients continue to face in health settings. The adverse sequelae from these experiences are not in the past. Mistrust and negative health outcomes are not only historical; they paint a picture of the current healthcare arena for Black patients. Healthcare providers must be intentional about developing an awareness of the experiences that Black patients and their families face outside of healthcare and while accessing services. Critical reflection is essential to cultural humility (Prasad et al. 2016). To address this need, we developed a workshop in cultural safety with Black patients intended for use in the MHA program in a pediatric health system. The workshop draws on the results of the previously described literature review, environmental scan, and consultations. The outline for the eight-module workshop includes an introduction to the course and the following:

1. African Nova Scotian People: A brief history of ANS people, environmental racism, and the history of Africville.
2. The Health Experiences of Black Patients: An overview of the negative experiences Black people have accessing healthcare, including racial discrimination, microaggressions, and historical and current mistrust in the healthcare system.
3. Cultural Safety and Black Patients: An overview of the concepts of cultural safety and how to apply them.
4. Relationship Building and the Black Community: Strategies to build relationships with Black individuals, families, and communities.
5. The Importance of Representation and Afrocentric Practices: An overview of the representation of Black people in healthcare, the principles of Afrocentric practice, and how to apply these principles.
6. Applying Knowledge to Practice through Case Discussions: The unit also discusses White fragility and how it works to uphold racism.
7. Community Resources: Contact information for Black health resources.

While the workshop is intended to increase cultural safety for all Black patients, the intended delivery is in NS; therefore, we have focused on the ANS population. The purpose of the workshop is to increase the knowledge of healthcare providers about the experiences of Black patients and their families and how to create culturally safe and relevant spaces.

Drawing on the principles of Knowles' Adult Learning Theory and Rogers' Diffusion of Innovation Theory, the educational workshop had to be relevant to the potential adopters or participants (Collins 2004; Dearing and Cox 2018). To meet this requirement, we included healthcare staff who were potential adopters in the consultation process to ensure they were engaged and the content met their learning needs. According to Knowles' theory, adult learners need problem-based learning, the opportunity to draw on past experiences, and to understand how the information will help them (Collins 2004). Similarly, drawing on Rogers' theory, potential adopters must understand the relevance of a new innovation and how it will be better than their current practice (Dearing and Cox 2018). Therefore, case studies that explore microaggressions, racial discrimination, and historical mistrust in practice are included to provide an opportunity for participants to apply their knowledge to real situations combining their prior knowledge and what they have learned in the course to a real scenario that has the potential to occur in their care area (Collins 2004; Dearing and Cox 2018).

Results of the Education Workshop

Olivia Riley-States has co-facilitated the educational workshop developed through the quality improvement initiative (as described above) for various groups of healthcare professionals in a healthcare system that services women, children, and their families. Participants included healthcare professionals, such as physicians, social workers, psychologists, administrative staff, youth care workers, clinical managers, directors, and genetic counsellors. Olivia Riley-States has also facilitated sessions for nursing students. Sessions varied in time from 90 to 180 minutes and covered all eight modules. The sessions included case-based learning, developed specifically for each group and incorporating relevant examples from their practice settings and contexts. Pre and post-tests were completed using an online platform. The results showed some change in knowledge, with an increase in correctly answered multiple-choice questions. Examples of the questions include defining environmental racism and the number of historic ANS communities. The post-session evaluations showed that participants felt the sessions were valuable and that their practices would change based on what they learned. Discussions during sessions revealed that many participants were unaware of the experiences that Black people, especially African Nova Scotians, had faced in the past and continue to face today. Participants were also able to discuss bias within the healthcare system and ways to challenge the system to better serve patients rather than forcing patients to fit within Eurocentric systems. Some participants did have difficulty acknowledging topics such as environmental racism, citing resource-scarce White communities or making comparisons to White experiences. The facilitators worked through this, grounding the discussions in the theoretical perspective of relational inquiry, using inquiry as action to better understand the perspectives of the participants while also maintaining a critical lens of the power imbalances that allow White people to lack understanding of the challenges that Black people face.

Olivia Riley-States continues to facilitate this education to healthcare providers and nursing students in NS. Feedback/data collected is used to improve session content and delivery. The long-term goal is to ensure that cultural safety with ANS patients becomes mandatory for healthcare providers in NS. Olivia Riley-States aims to partner the education department at IWK Health to expand the delivery of the education workshop and collect data through focus groups and interviews, exploring the experiences and changes in attitudes of healthcare workers who have attended a session. Unfortunately, due to a lack of representation of ANS people within the health system, there are barriers to ensuring the content is delivered in-person by an individual with lived experience and, therefore, alternative modes of delivery, such as online, will be explored.

Implications for Healthcare Leadership

The province of NS released the Health Equity Framework in 2023, providing guidance to healthcare systems to increase health equity. Key themes include patient experience, policies, and practices (Department of Health and Wellness 2023). The government of NS and the health systems within it have recognized the disparities in healthcare outcomes, access, and experience. This knowledge has not necessarily reached all healthcare professionals working with the system. It is imperative for healthcare workers to increase their knowledge of the experiences of Black people to provide care that is safe and culturally relevant. Culturally safe spaces can have an immense impact on patient experience.

Unfortunately, not all healthcare providers are culturally competent (Waldron et al. 2023). Healthcare leadership has a responsibility to advocate for educational opportunities to address the lack of cultural safety for Black patients in NS healthcare settings. The Nova Scotia Health Equity Framework underscores the need to advance training in cultural humility and competence, both of which are addressed in this educational session as components of cultural safety (Government of Nova Scotia, 2023). Healthcare educational institutions and professional licensing bodies also are accountable to ensure that entry-level competencies for healthcare providers in NS include the knowledge required to provide care that does not cause harm to African Nova Scotians. Healthcare providers can lead quality improvement initiatives and initiate change on a systems level. Influential leadership will be required to change attitudes and increase awareness of Black patients' health experiences.

Another implication for healthcare leadership is the need to challenge any resistance to discussions about White privilege and the need to dismantle systems that uphold it. Avoiding discussions about race to maintain the comfort of the dominant race and avoid conflict works to uphold racism by not addressing it (DiAngelo 2011). Using a critical lens allows us to recognize the privilege that healthcare providers of all races hold, although particularly White, and the power imbalance in care relationships. The need to maintain White comfort also creates a barrier to cultural safety for Black patients. There is an assumption that White comfort comes before cultural safety for Black patients, which is evident in the avoidance of race discussions. Healthcare leaders should demonstrate self-awareness and address unacceptable or unethical behaviour, including racism. Healthcare leaders must also analyze their role in upholding hierarchical colonial systems where Black people are not often in leadership or management roles (Beard, Julion, and Waite 2020). Deliberate and intentional action is needed to dismantle hiring systems that only hire White people into leadership positions (Beard, Julion and Waite 2020). Attention must be given to the environments in which healthcare providers are hired to ensure retention of Black providers (Beard, Julion and Waite 2020). Black healthcare providers, such as nurses, must navigate the nursing profession while managing the additional pressure of working within racial hierarchies in nursing and healthcare (Jefferies et al. 2019). It is essential to acknowledge and address these factors as increasing representation in healthcare professions helps to diversify practices and perspectives; seeing a person that looks like them can also increase comfort for racialized patients.

Conclusion

There is growing interest in health equity, and healthcare leaders can improve the quality of care Black patients receive by creating culturally safe healthcare environments. It is imperative to ensure that healthcare systems in Nova Scotia address the harm they cause racialized communities. Health intersects with many other factors, including racial and cultural identity. Healthcare leaders must consider the effects of anti-Black racism throughout all systems and structures in NS and Canada that impact health. Black people face discrimination, microaggressions, and overt expressions of racism in the workplace and hiring processes (PHAC 2020). These factors impact income, which can affect access to healthy foods or transportation. All of the social determinants of health are interconnected and strongly influenced by anti-Black racism. Anti-Black Racism is a determinant of health (PHAC 2020).

The workshop we have developed provides foundational knowledge about Black patients in NS, their health experiences, and how to provide culturally safe care. Black patients' lived experiences and history impact the way they receive care. Factors such as mistrust, experiences of racial discrimination and microaggressions, and a lack of access to Black care providers and culturally relevant healthcare have a negative impact on mental health and decrease help-seeking. We developed an educational resource for a health system that serves women, children, and their families through the lens of relational inquiry, which combines hermeneutic phenomenology, critical reflection, and pragmatism. Healthcare leaders should engage in education that increases their cultural humility and should act as role models for others. Healthcare leaders can actively work toward dismantling systems that uphold racism to reduce health inequities. We are at a critical juncture in health care provision to Black patients. Enhancing this care through increased understanding and application of cultural safety with Black patients is essential. The time is now.

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Tracing the Importance of Mother Blame

by Irene Shankar

Abstract: During a health crisis, vaccines can curb the spread of diseases and provide much-needed immunity for all those deemed at risk. To reach herd immunity and successfully curb disease spread, a significant portion of the population needs to get vaccinated. Thus, it is vital to consider the conditions under which people will accept or refuse vaccinations. Using a case study from the 2009 H1N1 pandemic, this paper examines how historical cases of iatrogenesis, medical intervention on women's bodies, societal practices of blaming mothers for children's ill health, and the provincial government's record on healthcare funding and support worked together to inform women's vaccination decisions. The findings, based on 19 qualitative semi-structured interviews, indicate that during the 2009 H1N1 pandemic, pregnant women were concerned about making the wrong decisions due to societal mothering blame and gendered responsibility within the field of medicine. Their decision to get vaccinated was made in consideration of medical surveillance and scrutiny of pregnant bodies and their feelings of (dis)trust in the provincial government. The research findings allow for a more complex understanding of health decisions by situating women's vaccination decisions within a larger historical and sociopolitical context. Moreover, the findings indicate that trust cannot be readily invoked in moments of crisis but requires a sustained and ongoing dedication to examining issues of gender inequity within medical practices and governmental policies.

Keywords: vaccination decisions; H1N1; trust; surveillance; risk; responsibility; mothering blame; gender

Résumé : Lors d'une crise sanitaire, les vaccins peuvent freiner la propagation des maladies et conférer une immunité essentielle à toutes les personnes considérées comme à risque. Pour atteindre l'immunité collective et réussir à freiner la propagation des maladies, une part importante de la population doit être vaccinée. Il est donc essentiel de prendre en compte les facteurs qui amènent les gens à accepter ou à refuser la vaccination. À partir d'une étude de cas menée lors de la pandémie de grippe H1N1 de 2009, cet article examine comment des cas historiques d'iatrogénèse, des interventions médicales sur le corps des femmes, les pratiques sociales consistant à culpabiliser les mères pour la mauvaise santé des enfants, ainsi que le bilan du gouvernement provincial en matière de financement et de soutien aux soins de santé ont conjointement orienté les décisions des femmes en matière de vaccination. Les résultats, fondés sur 19 entretiens qualitatifs semi-structurés, indiquent que pendant la pandémie de grippe H1N1 de 2009, les femmes enceintes craignaient de prendre les mauvaises décisions en raison de la culpabilisation sociale des mères et de la responsabilité liée au genre au sein de la profession médicale. Leur décision de se faire vacciner a été prise en tenant compte de la surveillance et du regard médical portés sur les corps des femmes enceintes et de leur sentiment de confiance ou de méfiance à l'égard du gouvernement provincial. Les résultats de l'étude offrent une compréhension plus approfondie des décisions en matière de santé en replaçant les décisions des femmes en matière de vaccination dans un contexte historique et sociopolitique élargi. De plus, les résultats indiquent que la confiance ne s'établit pas facilement en période de crise, mais qu'elle nécessite un effort constant et continu pour examiner les enjeux de l'inégalité entre les hommes et les femmes dans les pratiques médicales et les politiques gouvernementales.

Mots clés : décisions relatives à la vaccination; H1N1; confiance; surveillance; risque; responsabilité; culpabilisation des mères; genre

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Introduction

All health decisions, including vaccination decisions, are made in a larger sociopolitical and historical context (Blume 2006). Misinformation, mistrust in medicine and/or government officials, public skepticism of medical discoveries due to past cases of iatrogenesis, and lack of sufficient understanding of scientific studies, vaccination testing, and approval processes impact how the public responds and/or adheres to medical advice (Kitta 2012; Lupton 2007). Moreover, our understandings of medicine, health, and governance, along with gendered roles and expectations, determine whether we follow or refute health advice (Blume 2006; Lupton 1997). For example, early inoculation attempts by Edward Jenner were met with fear of contamination, along with apprehension about Jenner's vaccination being "rushed" (Kitta 2012). The discourse of "rushed" vaccinations, which has persisted over time, speaks to the public's fear of vaccines being produced without sufficient scientific rigour, leading to a lack of knowledge about their potential side effects.

Accordingly, this paper examines how women who were pregnant during the 2009 Human Swine Influenza (H1N1) pandemic made their vaccination decisions. Within most heterosexual households, vaccination decisions are made by women (Matoff-Stepp et al. 2014; McCarroll et al. 2016). Thus, I consider how discourses of fear and perceptions of risk, along with their varying levels of trust in medicine and local government, impacted their vaccination decisions during the H1N1 pandemic. By situating individual health decisions in a larger context of gendered responsibility and mothering blame, and the participants' experiences of neoliberal governing practices, this paper examines how trust in medicine and government impacts vaccine uptake. The neoliberal mandate seeks to reduce the role of government in maintaining or enhancing population health. This individualized focus ignores the much-needed social determinants of the health framework and serves to justify the ongoing reduction in healthcare funding and services (Chappell and Penning 2009). As a resource-dependent economy, Alberta (the province in which this study was completed) has historically dealt with low oil prices through significant cuts in education and healthcare spending instead of tax increases, a trend that it has continued to present day. It is within these budget cuts and the resulting public outrage that the study participants found themselves making decisions regarding the H1N1 vaccination. Thus, I consider this larger sociopolitical context (such as health care decisions and other social welfare practices being implemented by the provincial government) that facilitate the enactment of trust, such as concrete and demonstrable commitment to public health and well-being by health and government officials, commitments that are contrary to prevailing neoliberal mandates of governing bodies (Armstrong 1995; Lupton 1997; Raphael 2016).

Background

Immunizations are often referred to as the heart of modern medicine and are responsible for saving two to three million lives worldwide each year (WHO 2016). A high immunization rate creates herd immunity for the wider community by preventing outbreaks, which protects vulnerable groups. Without immunization, as demonstrated during the COVID-19 pandemic, communicable disease resulted in widespread death and devastation (Bandini et al. 2023). To curb the spread of contagious diseases, a widespread uptake of the vaccination is needed, along with an equitable and accessible distribution system of vaccines. Structural barriers, such as a lack of health care services and infrastructure, transportation, and adequate storage, result in vaccine inaccessibility for marginalized communities.

Despite the accessibility of COVID-19 vaccines in Canada, the vaccination rates for children remained low. For instance, as of August 2022, 82.03% of Canada's total population had completed the primary series of vaccination and 85.24% of Canadians had received at least one vaccine (PHAC 2022). During the same period, only 55% of children between the ages of 5 to 11 had received at least one dose and 42.44% had completed the primary series. This may be due to parental hesitancy to vaccinate their children. Humble et al.'s (2021) study shows that when the COVID-19 vaccine became available in Canada in 2021, only 27% of parents reported willingness to get their child vaccinated.

A similar low uptake of vaccines was evident during the 2009 H1N1 pandemic in Canada, with only approximately 41% of Canadians opting for the H1N1 vaccination (Gilmour and Hofman 2010). H1N1 is a respiratory illness with similar symptoms to the flu. By April 2009, approximately 18,449 deaths in 214 countries were attributed to H1N1 (WHO 2009 as cited in Brien et al. 2012). Canada had two waves of the H1N1 pandemic: the first wave took place from April to July 2009, and the second wave occurred from October to December 2009, resulting in around 428 deaths in total (IPAC 2014). Upon Health Canada's approval of the H1N1 vaccine, Canadian Federal Health Minister at the time, Leona Aglukkaq, declared the adjuvanted vaccines as safe and effective for use and "encourage[d] all Canadians to get vaccinated, since there is simply no better way of fighting the H1N1 virus" (CBC 2009a). Children, the elderly, people with compromised immune systems, and pregnant women were understood to be particularly at risk for the H1N1 virus and were strongly urged to get vaccinated. However, only about 37 percent of Albertans and 41 percent of Canadians were vaccinated in 2009 (Gilmour and Hofman 2010). Specifically, within the province of Alberta, the overall vaccination rate remained at 36%, with 53% for children aged 6 months to 4 years and 35% for pregnant women (Government of Alberta 2010). With approximately 47% uptake in the United States and Canada, most pregnant women in North America did not get vaccinated despite the public messages that warned pregnant women that they and their fetuses were at risk of contracting H1N1.

Vaccination rates, in general, tend to be low among pregnant women (Cox et al. 2023). There was a similar low uptake of vaccines during the COVID-19 pandemic. Despite the increased rate of hospitalization, the vaccination rate for COVID-19 among this group remained low, with only 25% of pregnant women in the United States and approximately 60% of pregnant women in Alberta and 68% in Ontario, Canada, being vaccinated in 2021 (Centre for Health Informatics 2021). These statistics implore us to ask why some pregnant women, despite being cautioned of the risk, do not get vaccinated. Importantly, how do women, who tend to be the primary vaccination decision-makers in heterosexual households (Kitta 2012; McKenzie, Tomkinson, and Attwel 2024), make vaccination decisions for themselves and their families?

Methods

The COVID-19 pandemic motivated me to revisit the data set for the H1N1 vaccine collected in 2011. Using the 2009 H1N1 pandemic as a case study, I examined the socio-political considerations that inform pregnant women's vaccination decisions. Despite being told that they were at high risk for succumbing to H1N1 and with health officials urging them to get the adjuvanted H1N1 vaccination, the overall vaccination adherence rates for pregnant women during the 2009 pandemic remained low, with an immunization rate of approximately 47.2% for pregnant women in Canada (Gilmour and Hofman 2010). In Alberta, where this study was conducted, only 35% of pregnant women received the H1N1 vaccine (Government of Alberta 2010). Accordingly, using purposive sampling to select participants due to their expertise and knowledge of a particular issue (Campbell et al. 2020), I interviewed 19 women who were pregnant during the 2009 H1N1 pandemic to understand how they made their vaccination decisions during the pandemic.

This study received ethics approval from the Mount Royal University's Human Research Ethics Board and was funded by Mount Royal University's Internal Research Grant. The primary participants for this study were recruited in 2011 from daycare centres, preschools, and an undergraduate university. The secondary interviews were completed using a snowball sampling technique, where the primary participants were asked for suggestions for other women to interview in the Calgary and Edmonton areas. All the participants were pregnant during the 2009 H1N1 pandemic. The participants ranged in age from 29 to 43 years, and all held post-secondary degrees. Among the 19 participants, 12 were vaccinated during the pandemic, while the remaining 7 had declined H1N1 immunization. Except for two participants who were adamantly anti-vaccination, all participants identified themselves as pro-vaccine and had immunized their children. Due to the aims and focus of this paper, data from the two women who identified as anti-vaccinators were not used in these findings. The quotes used in this paper are identified using a pseudonym and contain their vaccination decision and occupation. All identifying information has been removed from the data.

The data for this study was collected through semi-structured interviews in which the researcher relied upon a set of predetermined open-ended questions but was open to asking about other areas identified by the participant. Within the interviews, particular attention was paid to their overall experiences during the H1N1 pandemic; their understandings and perceptions of childhood immunization; the process through which decisions for children's vaccination were made within their household; the participants' relationship to the field of medicine; their apprehensions, and fears during the pandemic; and where they sought assistance with and information for their vaccination decisions. Each interview took approximately 1 to 1.5 hours to complete and took place at the location of participants' choosing, such as their homes, workplaces, or coffee shops. The interviews were recorded and professionally transcribed.

Participants spoke strongly about the state of health care and education within Alberta, the history of medicine, specifically how women and their concerns have been treated and/or ignored within the field of medicine, and gendered caregiving responsibilities. They placed their vaccination decisions firmly within their sociopolitical context. The transcribed interviews were coded using NVivo software and analyzed through a Critical Discourse Analysis (CDA) framework. Discourse is a general domain of statements which includes all texts, statements, representations, and meanings that exist about a particular subject and/or object (Mills 2004). In other words, discourse encompasses knowledge, representations, and/or understandings about a particular concept. CDA framework allows for the examination of the larger socio-political and historical context (such as provincial funding for healthcare, education, and other social welfare resources and services) within which vaccination decisions were made by those deemed to be at risk, with attention to the issue of gender inequality and enaction of power.

The first level of coding involved close reading of the transcripts and identification of broad patterns within the data. This was followed by a second level of coding of emergent themes and the relationship among them. Throughout coding and analysis, I paid particular attention to how participants understood and constructed notions of risk, responsibility, surveillance, and governance. The results highlight participants' struggles with gendered responsibility, refutation of medical dominance, distrust of political governance, and their understanding of risk. Following the qualitative research framework, this qualitative case study demonstrates the nuances and complexities of vaccination decisions for a specific group of women in Alberta in 2009. As such, the results are not generalizable to other groups. However, the overarching themes of this study have been contextualized through an in-depth literature review of vaccination hesitancy and decision-making. Together, these qualitative findings and incorporated research demonstrate the impact of the larger sociopolitical context on vaccination decisions. These findings have been grouped into three interrelated sections below.

Results: Fear and Trust

The results show that during the 2009 H1N1 pandemic, highly educated and well-informed women were reluctant to get vaccinated due to their concern about mothering blame and their lack of trust in medicine and the governing party. Within this ever-present culture of mothering blame, these participants reported feeling overwhelmed and stressed about making the “right” decision during their pregnancy, without adequate resources and information. To reiterate, all the participants included in this paper are highly educated women who think of themselves as pro-vaccination, making the findings particularly informative about how vaccination decisions are made during a health crisis.

Fear

During the 2009 H1N1 pandemic, health officials deemed pregnant women to be at high risk of contracting and getting ill or dying from H1N1 and thus, strongly urged pregnant women to get vaccinated (Alphonso 2009; Tucker Edmonds et al. 2011). The participants of this study, all of whom were pregnant during the pandemic, were counselled by their doctors to get vaccinated. While medical professionals were urging vaccination in the best interest of the public, the participants felt scared and panicked.

> It was really scary, and people were going to die … you should go get your immunizations…. (Joliot, stay at home parent, vaccinated)

> I did it [get the vaccination] out of fear … it was scary, I mean at work it was a scary place to be and … we were panicked because it was literally like pandemonium. (Gertrude, nurse, vaccinated)

> I don’t like to be feared into something, like for me it needs to be more educating than fear to get me to do it…and fear is powerful, it would force me … I don’t know if that is their intention, but that is what happened both times: people get panicked. (Ada, stay-at-home parent, not vaccinated)

Some of the participants reported being scared and were vaccinated out of fear. Others, like Ada, became angry and resisted the vaccination in refutation of the discourse of fear, which they felt was being intentionally mobilized to secure vaccine compliance. Interestingly, while all the participants believed the health messages that said they were at an increased risk of getting ill and/or dying from H1N1, their responses varied. This is consistent with Tucker Edmond et. al.’s study (2011), which found that 51.8% of pregnant women believed that they had an increased risk of encountering severe effects of the H1N1 virus without the vaccine. However, as noted earlier, this understanding of being at increased risk did not translate into adherence to vaccination advice. While the participants were concerned about contracting H1N1, in some cases their fear of the virus was eclipsed by their fear of the vaccine. Instead, the participants wanted information about vaccination safety.

> There was no good information presented to us at all. We were basically, I think, pressured into it by people—and as in “people,” I say the news, the, you know, medical directors, or even my management team being like, “Do this. Do this. Do this. Do this. Do this. Do this. Do this” … they wouldn’t even give it to you when you asked because I think they … maybe they didn’t have time, or else maybe it just didn’t exist. So, one word to sum it up was a lot of pressure into it. (Gertrude, nurse, vaccinated)

> There was no information about whether the vaccine, at least early on—there was no information on whether the vaccine was safe for pregnant women…. (Jocelyn, lawyer, vaccinated)

> It had never been tested on pregnant people. And they didn’t really know, I mean. They tell you it’s safe, but you don’t [know], right? You just don’t really know. So that was my concern. (Lera, legal assistant, vaccinated)

The participants reported that they felt responsible for making urgent health decisions for themselves and their children during a global pandemic without adequate information about the vaccine. In particular, all of the participants asked doctors and other health officials for information on drug trials and any potential side effects of the vaccination. Quite revealing is the participants' fear about the potential side effects of the vaccine on the fetus.

> I mean, these are the children I am talking about; I am not just dealing with myself like this is the health of my children, so I wanted to make sure I was getting information which I would feel good about. (Mae, photographer, not vaccinated)

The vaccination decision was not only burdensome due to the lack of information about vaccination trials and side effects, but participants felt an added responsibility to make the right decision for their unborn children's health. All the participants spoke with their doctors and also independently researched whether the vaccine was safe for pregnant women and their fetuses, specifically.

> When I was contacted by Occupational Health and Safety … I said, "Well, what studies have been done? How many pregnant women have been immunized with this vaccine?" and she was like, "Oh, well it is safe," and I said, "How safe? Give me the numbers. Like, give me the statistics" because that is what I want to know and the study she cited something … was like 400 people that were in the study and I said, "That is all … if you want people to get immunized then you need to be able to present them with real statistics…. (Shirley, nurse, not vaccinated)

> [Public health officials] need to be sensitive to the needs of pregnant women, which is not a blanket assurance of safety, especially when you [referring to public health officials] cannot back that assurance with data, to help women understand how to make informed choices about whether or not to vaccinate. (Marie, teacher, vaccinated)

Instead of being referred to scientific studies and data to address participants' concerns regarding vaccination safety, many of the participants were provided with a blanket statement of safety. Without addressing the specific questions about vaccine trials, medical professionals kept reinstating that the vaccines were safe for pregnant women and their fetuses, which participants found to be dismissive of their concerns. Blanket safety assurance was perceived as a lack of care or willingness to engage with the patient's specific fear. As explained by Gertrude above, these women were being told what to do but were not being given the information they needed to make their vaccination decisions. In the absence of empirical information, they were told to trust their medical professionals and governments, who had their best interests at heart. As seen below, some participants trusted their medical professionals while others found the blanket assurance of safety, along with the discourse of trust, to be dismissive of their fears, infantilizing, and patriarchal.

Trust

During a health crisis, the public needs to be able to trust that the health advice and protocols being offered are in their best interest. As seen in the current COVID-19 pandemic, distrust of health and government officials contributes to vaccine hesitancy and lack of adherence to recommended health measures (Liu, Zhao and Wan 2021). The participants of this study spoke at length about the role of trust in facilitating their vaccination decisions. For some participants, it was their trust in their doctor that led them to get vaccinated.

> I think I really trusted my doctor, and she was pretty clear about "yeah, I think this is something worth doing," and … I think it was general public awareness, having a conversation with a doctor that I really, really trusted and…also wanting to do the right thing for the baby…. (Rita, program officer, vaccinated)

Other participants felt apprehensive that they were being asked to trust medical professionals and the government in the absence of facts and other empirical evidence. These participants also spoke about their ongoing distrust of medicine and the government, which made them more apprehensive about adhering to the health advice. Below, I discuss their precarious trust in medicine, followed by their distrust of governance.

Refutation of Trust in Paternalistic Medicine

Personal perception of health, illness, diseases, and the field of medicine can determine whether someone will act upon or refute various health promotion messages disseminated during health pandemics (Blume 2006; Lupton 1997). Accordingly, some of the participants were skeptical of vaccination advice being offered because they had a history of their pain and ailments being dismissed by their medical professionals and being denied a medical diagnosis for their health concerns. To maintain participants' confidentiality, I will not discuss their highly specific and personal medical experiences. However, there are historical and contemporary examples along with research on how women's health concerns have been dismissed by medical professionals (Cleghorn 2021; Comen 2024). For example, historically, menstrual pain has been deemed to be exaggerated or indicative of a woman's "unhealthy lifestyle" (Lupton 2007,149). Women in pain continue to be dismissed by medical professionals, particularly poor, racially minoritized, older, and/or disabled women (Comen 2024; Mukherjee, Reis and Heller 2003; Quintner 2020). The participants situated their personal experiences within the lingering patriarchal practices of the medical field that facilitate the ongoing erasure and/or under-research of women's pain and ailments while simultaneously increasing medicalization and surveillance over their bodies (Cleghorn 2021; Comen 2024).

In Western societies, women's bodies and lives are heavily medicalized. For instance, from menstruation to menopause, women are often expected to refer to medical advice and products to manage their bodies (Lupton 2007; Chappell and Penning 2009). Medicalized surveillance and dominance are heightened during pregnancy, with women being told what to eat, how and how much to exercise, and even how to sleep (Lupton 2007). Participants in this study, such as Marie and Rosalinda, spoke at length about the prevailing paternalism within medicine, which infantilizes pregnant women and renders them powerless over their bodies.

> I think within health care, there is a bit of a problem of paternalism, too, right? This idea that, um, health-related knowledge is privileged information that only doctors and nurses have, and that as a member of the public, I can't have. That somehow, being involved in my own healthcare decisions either makes me rebellious, or annoying or … you know what I mean? I think that whole paternalism within the health care system is a problem…. (Marie, teacher, vaccinated)
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> I wouldn't say I rejected the medical approach to birth, but I certainly felt … it takes a woman's power away from her when a doctor says, "Well, you have to do this, and this and this," and again the whole cycle of intervention, like if you get induced then you are more likely to … the contractions are more likely to get the best of you and you are more likely to need an epidural. If you get an epidural, you can't walk around, and you are more likely to have other complications which lead to a C-section, where they have more control, and it is more about the doctor's experience and the doctor being able to control what is happening, and it is less about honouring a woman's own ability and power in that respect. (Rosalinda, professor, vaccinated).

The ever-increasing medical surveillance of and intervention on pregnant women's bodies (Lupton 2007) shaped participants' responses to H1N1 medical directives, whereby vaccination advice during the pandemic was interpreted as further control and dominance over their pregnant bodies. For these participants, the medical advice to get vaccinated without the offer of information about vaccine safety for pregnant women was seen as another manifestation of patriarchal practices within medicine, requiring their complete and uncritical compliance with medical professionals.

> I don't know, it [H1N1 vaccination advice] is similar to the whole "don't eat fish" and "don't do this, this and this," like women have been birthing babies for centuries, you know? In plague conditions, flu, and stuff, you know? (Lise, professor, not vaccinated)

> I don't just take their [doctors'] word for it [vaccination] either. I suppose this started when I was pregnant because I was so concerned about how the medical model treats pregnant women, like in terms of pregnancy as an illness or a disease, and you have to be hospitalized. If everything is totally healthy and normal, I think it really takes the agency away from the woman by putting her in a position where all those decisions are made for her. (Marie, teacher, vaccinated)

While the H1N1 vaccinations had been demonstrated to be safe for pregnant women, the information about vaccine trials and safety was not shared with the participants while they struggled to make their vaccination decisions even when they had explicitly asked for this information. During the 2009 H1N1 pandemic, the blanket assurance of safety without the provision of detailed evidence of vaccine safety was taken up by the participants as a retrenchment of doctors' medical authority, whereby the doctor is presented as the experts who "know the best" and pregnant women are not allowed to question medical professional's authority or advocate for their own medical need. As seen above, the copious amount of advice being issued to pregnant women due to the prevailing hyper-surveillance of pregnant women within biomedicine (such as advice on what to eat during pregnancy) led to some participants being skeptical of medical advice being issued during the pandemic. Exhausted by the medical gaze, whereby their every decision and action are heavily scrutinized for their potential impact on the fetus, this study's participants found themselves pushing back against yet another narrative of risk and responsibility.

> It's not that I think vaccines are unsafe. I just think they need to be tried and studied, and all this came out so quickly, you know?... I remember specifically like where I lined up and what the building looked like and all that kind of stuf f… I kept the paperwork, like who keeps their flu shot paper? But I kept it because obviously, I was like "If there is something wrong with this baby, I've got this paperwork!" [laughter]. (Lera, legal assistant, vaccinated)

> And you know, to be perfectly honest, I did sort of think in my head, you know, if the baby has some sort of problem developmentally or … you know? And it's like, "Where did this come from?" I was definitely going to raise the red flag and say, like, "I had this vaccination because I felt like I was working in an environment where I was really, really high risk. Maybe you guys need to have a look at this the next time, right? But luckily everything was fine and [name of the child] is great, and there was no issue, but it was always in the back of your head…." (Gertrude, nurse, vaccinated)

Moreover, participants found themselves in the difficult position of having to make a health decision during a global pandemic without access to the empirical evidence (such as data from immunization trials) to provide assurance that the vaccination would not negatively impact their fetus. Their fears regarding vaccination need to be contextualized within historical iatrogenic health interventions on pregnant women, such as thalidomide, a drug given to pregnant women for nausea, which resulted in severe fetal damage (Bradby 2009). Not only were the participants worried about potential negative reactions from the vaccine, but they were also worried about being held responsible for making the decision that could potentially harm their fetus. They were worried that they would be blamed for getting vaccinated. Their fear of being blamed is due to the prevalence of mothering blame, whereby women are held responsible for their children's ill health. The participants were unsure which decision (whether to get vaccinated or not) would be most effective in mitigating any potential risk to their fetus. Along those lines, their risk of being labelled as bad mothers was contingent upon them making the "right decision," a decision they felt unequipped to make. It is not surprising that Leah gathered evidence (her vaccination record) that would allow her to refute the label of "bad mother" in case her fetus experienced a vaccination-induced iatrogenic disorder.

Refutation of Trust in Governance

These interviews were conducted during the 43-year reign of the Conservative provincial government in Alberta, during which the government has made significant funding cuts to public spending, including the provincial health care system. The participants were perplexed that they were being asked to trust the same government which was making decisions detrimental to the population's health.

> Also, we know in Canada, and our province specifically when you have such a high percentage of people who can't get a family doctor, you know like health care is obviously being mismanaged at a governmental level in this province, and then you have scandal after scandal in health care, uh … you know? So, all of those things seem to fit with all this other stuff that seems—well is—completely inappropriate in terms of leadership. (Marie, teacher, vaccinated)

The H1N1 pandemic took place while Canadians were struggling with doctor shortages and the implications of significant cuts to healthcare spending. In response to the reduction of government spending, the United Nurses of Alberta President, Heather Smith, warned that the incoming cuts would be akin to the "destruction of the 1990s" as "the last thing Albertans want now is longer waits in Emergency rooms and another huge shortage of staff and beds" (United Nurses of Alberta 2009). Faced with health directions from government officials during the pandemic, the participants were wary of trusting a government that they felt had reduced their access to health care.

> Well, I guess I don't trust the Alberta government that much … Almost all my hospital experiences have been horrible, come to think of it! I broke my collarbone when I was in my twenties, really badly, and it took three hours to even get seen and … it was horrible. And then I remember they finally took an X-ray and then they started freaking out saying I needed surgery, then … anyways, in the end, they didn't do anything—which was fine—but, like, now it has like, healed all crooked and whatever … I don't know, I have had so many bad experiences I could go forever, but yeah, I just don't really trust them that much. I mean, we are all human; they are educated and they know a lot, but I don't necessarily think that they are always right. (Ada, stay at home mom, not Vaccinated)

Within this larger sociopolitical context, some participants, like Ada, had "many bad experiences" that led to their distrust of the provincial government in charge of the healthcare services and influenced their vaccination decision during the 2009 H1N1 pandemic. For others, like Gertrude, the slow uptake of information from the front-line staff and being perplexed by decisions made by the administrators, despite being a healthcare worker herself, led to her distrust of governing bodies.

> Yeah, and sort of just from watching, like, you know, the guys at sort of the top of the pyramid in health care, the medical directors, the health boards, all that kind of stuff, honestly, how long it takes the information from the ground floor to work its way up to them guys take a really long time! And to be quite honest, I feel like they have no understanding at all of even what they are talking about… (Gertrude, nurse, vaccinated).

Discussion

Discourses of risk and responsibility are often utilized within public health messages designed to inform the public about health risks and how to avoid such dangers through responsible management of risk (Petersen and Lupton 2000). Within such a narrative, individual risks and health effects are presented as the consequences of a person's choices and, as such, the sole responsibility of the decision-maker (Petersen and Lupton 2000). This individualized focus and "the emphasis on risk factors which are within the control of the individual contributes to the confirmation of [the] active citizen, the self who can be, and indeed ought to be, in control of his or herself" (Nettleton 1997, 215). However, as seen in this case study, the reiteration of risk can also become an obstacle to meaningful responses in situations when fear is the only thing that is being offered. The participants found themselves fearful of the pandemic but without the information on vaccine safety and any potential side effects that they needed to make the "right" decision. The continual and individualized focus on risk led them to dismiss health directives as an overt attempt by medical professionals to control their bodies.

Moreover, instead of a meaningful discussion of vaccine safety, the participants' request for information was met with a blanket reassurance, which many women found dismissive and infantilizing. This dismissiveness was seen as another manifestation of the authority and control that medical institutions exercise over pregnant women. Participants' questions regarding vaccine safety are understandable. Without clear information from medical professionals, many of the participants reported doing their own research, which might have lead to unreliable and incorrect information. For instance, a review of 722 anti-vaccination sites found that every single website claimed that vaccines cause harm and vaccination policies are profit-driven (Wolfe, Sharp, and Lipsky 2002 as cited in Kitta 2012, 5-6).

Despite the lack of information, the participants felt an intense responsibility to make the right decision. Women tend to be the primary decision-makers for their family's health, including decisions on vaccinations (Matoff-Stepp et al. 2014; McCarroll et al. 2016). In this study, participants struggled with their vaccination decisions due to their fear of making the wrong decision, which may harm the fetus. This pressure to make the "right" decision is located within a larger context of gendered responsibility, whereby mothers are held responsible for the health of their children (Lupton 2007; Singh 2004). Within this punitive discourse of mothering blame, women are held responsible for the well-being of their children, to the omission of social determinants of health factors such as accessible healthcare, affordable food, safe housing, and quality education (Marya and Patel 2021). The findings from this qualitative study, while not generalizable, are an important reminder that there can be dire and unforeseen implications of holding women solely responsible for their children's health and well-being. During a health crisis, such as the COVID-19 pandemic, this individualized and gendered discourse of mothering blame could lead to pregnant women's hesitancy to get vaccinated for fear of making the "wrong" decision. These findings remind us that there remains an urgent need for medical health professionals and governing bodies to actively dismantle mothering blame and gendered responsibility within medical discourse.

Similarly, the medical surveillance of pregnant women also has far-reaching consequences. The participants of this study, already under medical surveillance as pregnant women, interpreted the calls for vaccination as another mode of control by medical professionals. In this case study, the heightened medical surveillance during pregnancy remained a source of frustration for many women, contributing to their disregard and skepticism of medical advice to get vaccinated during a global health crisis.

Some participants refused to get vaccinated during the 2009 H1N1 pandemic because of their underlying distrust of the medical field and the provincial government. As discussed earlier, participants reported an ongoing discomfort with the unquestioned medical authority of doctors and other patriarchal practices within the field of medicine. There is a long history of doctors being dismissive of women's health concerns and engaging in infantilizing discourse toward patients who identify as women to reassert their medical authority. For instance, women complaining about pain that cannot be easily discerned through medical technology are often dismissed as mentally unwell (Cleghorn 2021; Mukherjee, Reis and Heller 2003; Quintner 2020). Thus, the participants' concerns in this case study need to be contextualized within the ongoing practice of women's health being ignored within the field of medicine. The field of medicine must not only identify and eliminate the patriarchal practices embedded within medical practices, there also needs to be active consideration of and reflection on the ways women's experiences of being dismissed and infantilized continue to shape their subsequent medical care and response to public health messages.

Trust is an important factor in vaccination uptake (Liu, Zhao and Wan 2021; Sturgis Brunton-Smith and Jackson 2021). This qualitative case study provides a more nuanced understanding of how trust (or lack of it) is created over time and requires a sustained commitment to public health and well-being. In this case study, the Alberta government's record of drastic cuts in health spending and the participants' prior compromised medical treatment led to their lingering distrust of the provincial government. As a result, the participants of this case study were unwilling to trust that the government had their best interests at heart. A similar trend was evident in the COVID-19 pandemic, whereby those with reduced trust in the government had lower vaccination rates and more refusal of pandemic health measures (such as physical distancing, quarantine guidelines, and mask mandates) (Leblang, Smith and Wesselbaum 2024; Viskupič, Wiltse and Meyer 2022). This case study demonstrates that trust requires a sustained and demonstrable commitment to population health and well-being and cannot be invoked in moments of crisis.

Collectively, these participants' experiences indicate that health decisions are seldom made solely based on the health advice being provided. Rather, people's willingness to adhere to medical directive(s) is dependent on a larger sociopolitical context. For many of the participants, their trust (or lack of it) in the government shaped their willingness to abide by the health directives. A significant finding of this study is that the participants' trust, or lack thereof, did not stem from a single instance but was shaped over a lifetime of experiences. In other words, how health care is managed and whether it is adequately resourced shapes individuals' trust in a given political party and overall healthcare policies and practices.

Unfortunately, instead of considering the larger sociopolitical historical context within which women make their health decisions, public health messages continue to prioritize an individualized and gendered discourse of risk and responsibility. The gendered discourses of risk and responsibility facilitate a shift in responsibility for the child and maternal health to women – a strategy that has not only proven to be ineffective but also will continue to dissuade women from trusting medical and government officials in moments of crisis.

Conclusions

In this 2009 H1N1 pandemic case study, the participants, who were pregnant at the time and deemed to be at high risk of illness from the virus, reported being fearful due to risk-centred public health messages. The various risks presented by the disease heightened the participants' fear and, in some cases, led to an outright refusal to get vaccinated. As seen in the overwhelming loss of life and social upheaval caused during the COVID-19 pandemic, there are significant risks to population health and overall well-being during a pandemic. Accordingly, warnings about potential dangers are warranted, as such information can help keep people safe through increased vaccine uptake (Hilverda and Vollmann 2022). Emergency health planning can be strengthened by studies that show how people deemed to be at high risk respond to health messages.

During the COVID-19 pandemic, the vaccine adherence rates among pregnant women remained low (Galanis et al. 2022). In consideration of these statistics, health officials and researchers must examine the larger sociopolitical conditions under which such health decisions are made. In this qualitative case study, pregnant women's decision regarding the H1N1 vaccination was shaped by their experiences of medical surveillance, dismissiveness of their concerns, and their ongoing distrust of the local provincial government. While the findings from this qualitative study cannot be generalized, there are some important findings to consider for increasing vaccine adherence during future health crises.

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The Cruelty of the Curative

by Alanna Veitch and Jen Rinaldi

Abstract: In this paper, we take up Lauren Berlant's (2011) theoretical framing of *cruel optimism* to ground our critique of normalizing scripts around disability, recovery, and healing which shape conceptualizations of health. We argue that these scripts do little to account for the multitude of disability experiences that meet and cycle through intersections of race, gender, class, culture, sexuality, and personhood. This work first requires engaging with mainstream perspectives on recovery and healing which undergird Western rehabilitative practices, and a turn toward Black and Indigenous conceptualizations of health and healing as practices grounded in community and social justice. We situate our review and discussion within a North American and Canadian context. Next, we describe the arts-informed counter-narrative methodology we utilize to share glimpses into our digitized disability stories. Our stories comprise moments of disruption, vulnerability, and isolation, enabling us to transform silence into language and action, and to reflect on the intricate dance between disability, health, and illness we are bound up in and continue cycling through. We show how our counter-narratives, when brought together, challenge the "getting better" meta-narrative. We target notions of getting better because, like the cruel promise of recovery, they idealize a return to "normal" and dismiss histories that bear on the present in felt and embodied ways. Rather than "getting better," bound up in fantastical promises, we find the authenticity of our own failures and vulnerabilities generative, indecipherable, and enduring.

Keywords: counter-narrative; cruel optimism; digital storytelling; affect; healing

Résumé : Dans cet article, nous nous appuyons sur le cadre théorique de l'*optimisme cruel* proposé par Lauren Berlant (2011) pour fonder notre critique des discours normatifs sur le handicap, le rétablissement et la guérison, lesquels influencent les conceptions de la santé. Nous soutenons que ces récits ne tiennent pas compte des expériences du handicap, qui se situent et évoluent à l'intersection de la race, du genre, de la classe, de la culture, de la sexualité et de l'identité personnelle. Ce travail nécessite d'abord de remettre en question les perspectives dominantes sur le rétablissement et la guérison qui sous-tendent les pratiques de réadaptation occidentales, puis de se tourner vers les conceptions noires et autochtones de la santé et de la guérison, ancrées dans la communauté et la justice sociale. Notre étude et notre discussion s'inscrivent dans un contexte nord-américain et canadien. Nous décrivons ensuite la méthodologie de contre-discours fondé sur les arts que nous utilisons pour offrir des aperçus de nos récits de handicap numérisés. Nos récits comportent des moments de perturbation, de vulnérabilité et d'isolement, nous permettant de transformer le silence en langage et en action, et de réfléchir à la dynamique complexe entre handicap, santé et maladie, dans laquelle nous sommes pris et que nous continuons de vivre. Nous montrons comment la mise en commun de nos contre-discours permet de contester la métanarration du « aller mieux ». Nous nous intéressons aux notions d'« aller mieux » parce que, comme la promesse cruelle du rétablissement, elles idéalisent un retour à la « normale » et minimisent les histoires qui influent sur le présent de manière vécue et ressentie. Plutôt que d'« aller mieux », notion imprégnée de promesses fantastiques, nous considérons l'authenticité de nos échecs et vulnérabilités comme génératrice, indéchiffrable et persistante.

Mots clés : contre-récit; optimisme cruel; récit numérique; affect; guérison

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Introduction

> [T]he *affective structure* of an optimistic attachment involves a sustaining inclination to return to the scene of fantasy that enables you to expect that *this* time, nearness to *this* thing will help you or a world to become different in just the right way. But…optimism is cruel when the object/scene that ignited a sense of possibility actually makes it impossible to attain the expansive transformation for which a person or a people risks striving. (Berlant 2011, 2)

In this passage from *Cruel Optimism*, Berlant (2011) directs our attention to the trouble with optimism—that feeling of hopefulness, that commitment to striving, grounded in an at-times impossible belief that things will get better. Secure work, medical coverage, the best new therapy become the means attached to that better future. For Berlant, the cruelty of these attachments is in their disregard for lived and material realities, the positivity and certainty they drum up for futures that might well be fantastical. As disability scholars who ourselves experience different forms of lifelong disablement, we argue that attachments to recovery mirror Berlant's affective structure of optimistic attachments when they entail returning to a state that no longer exists or is merely fantasy. There is nothing to return to, no "normal" embodiment or health state waiting in our futures. There is only an enduring now with a complicated history, and uncertainty about what will come next.

In this paper, we take up Berlant's theoretical framing of cruel optimism to ground our disability-based critique of normalizing scripts around disability, recovery, and healing. We argue that recovery scripts do little to account for the multitude of disability experiences that meet and continue to cycle through intersections of race, gender, class, culture, sexuality, and personhood. In what follows, we parse out depictions of recovery and healing by engaging with mainstream (Western) and cultural (Black, Indigenous, and disability) perspectives within a Canadian and North American context. Next, we describe the arts-informed counter-narrative methodology (Rice and Mündel 2018; Satija 2023; Simplican 2017) we used to create and analyze our digitized disability stories. We show how our counter-narratives, when brought together, challenge the "getting better" meta-narrative. We target notions of getting better because, like the cruel promise of recovery, they idealize a return to "normal" and dismiss histories that bear on the present in felt and embodied ways. Rather than "getting better," bound up in fantastical promises, we find the authenticity of our own failures and vulnerabilities generative, indecipherable, and enduring.

Depictions of Recovery

The concept of recovery in North America emerged in the 1980s following the anti-psychiatry and deinstitutionalization movements (Davidson 2016; Anthony 1993; De Ruysscher et al. 2019)—a violent and recent history (Reaume 2010)—garnering attention in fields of psychology, psychiatry, mental health, and rehabilitation whose practices are premised on ideals of normalcy. One well-cited scholar, Deegan (1988), defined recovery as the process most disabled people share regardless of their distinct disabilities. That is, recovery is the process of "*recovering* a new sense of self and of purpose within and beyond the limits of the disability" (emphasis in original), the real-life experience of "accept[ing] and overcom[ing] the challenge of the disability" (Deegan 1988, 11). With a focus on mental health, Anthony (1993) similarly viewed recovery as a process requiring a shift in one's attitude, sense of self, and skills to contribute meaningfully to society. However well-intentioned and critical in some ways—in arguing that disabled people are active in their care, in demonstrating that disability is complex, and in acknowledging the real material consequences of disability—the emphasis on changing one's attitude and on overcoming disability shapes disability as an obstacle or shortcoming.

The object of recovery has justified intervening in the lives of disabled persons (De Ruysscher et al. 2019; Groven and Dahl-Michelsen 2022; LaMarre and Rice 2020; Leamy et al. 2011) and building institutionalized care to fix disabled embodiments (Davidson 2016; Kaiser et al. 2020; Woods, Hart, and Spandler 2022). For instance, Leamy et al. (2011) developed a conceptual model for recovery: the CHIME model, composed of five recovery processes, specifically Connectedness, Hope and optimism about the future, Identity, Meaning in life, and Empowerment. Stuart, Tansey, and Quayle (2017) later added "difficulties" to the CHIME model, noting how the model disregarded the more grievous aspects of adapting to disability. While recovery is framed as a nonlinear process in the model, CHIME-D is still predicated on the possibility of "getting better," on ultimately overcoming disability. Where getting better is considered possible, recovery becomes necessary for living a full life and a responsibility to carry through.

This critique of recovery narratives is familiar to disability scholars who take issue with the insidious ways neoliberal capitalism individualizes health and the ways structural ableism problematizes disability (De Ruysscher et al. 2019; Erevelles 2011; Garland-Thomson 2005; McRuer 2018; Titchkosky and Michalko 2017). Clare (2017, 179) critiques cure as a seductive and violent ideology shaped by the institutions that benefit from sustained attachments to curative strategies: "the medical-industrial complex taps into our desires. …Through cure, it assures us that we can control and reshape our body-minds; restore them to some longed-for, imagined, or former state of being." This logic drives state-level normativity projects that promise to rehabilitate or convert away embodied differences with surgeries, therapies, diet plans, experimental treatments, and other assortments of snake oil. The promises themselves may well be false no matter how relentless and invasive the intervention. Drawing on Clare's *Brilliant Imperfection*, Kim (2017, 14) argues "cure is what actually frames the presence of disability as a problem and ends up destroying the subject in the curative process." This for Kim is a violence because when the cure is portrayed as the only route to a liveable life, no political or cultural space gets carved out for living with disability or in disablement. No social services or physical and architectural structures get built with disability in mind.

Related to recovery, healing is a process of striving for wholeness and good health (McNeal, Harris, and Oliphant 2024; Lavallee and Poole 2010; Scott et al. 2017). As a holistic approach to health, illness, and disability, healing takes into account the physical, emotional, cognitive, and spiritual aspects that comprise a person. Holistic care and justice-seeking practices, including community-based mental health and occupational therapy services (Bailliard et al. 2020; Davidson 2016; Groven and Dahl-Michelsen 2022), followed the recovery movement in response to calls for person-centred and culturally sensitive care. Despite these developments, Scott et al. (2017, 1), whose definition of healing most accurately portrays mainstream societal views and practices, understand healing as a process of "recovering a sense of integrity and wholeness after experiencing illness and suffering." This definition sits uncomfortably close to the previous definition of recovery by emphasizing (or promising) that it is possible for a person to overcome their illness, disability, or trauma, and that getting better is necessary if a person wishes to be whole.

While work has been done to sever the harmful ties between recovery and healing (Lavallee and Poole, 2010; McNeal, Harris, and Oliphant 2024; Satija 2023), much has been shouldered by Black, Indigenous, and racialized communities seeking justice (Doetsch-Kidder and Harris 2023; Gonzalez et al. 2023; Lavallee and Poole 2010; Mupotsa-Russell 2022; Page 2010). Turning to the accounts of Indigenous People in Tkaronto/Toronto Canada, Lavallee and Poole (2010, 279) describe healing as cultural practices that go "beyond Western notions of recovery" to establish balance and mend the spiritual wounds inflicted by colonization to Indigenous identity. For Indigenous Elders across Canada's Midwest, health and healing are grounded in spiritual connectedness and the Anishinaabe language (Gonzalez et al. 2023), underscoring a history of cultural practices that cannot simply be integrated into biomedical or rehabilitation practices, but that are cultivated within and by community.

Without conflating the injustices experienced by Indigenous, Black, racialized, and disabled individuals, the struggle for justice—against oppression, intervention, exploitation, and prejudice—is integral to healing (Doetsch-Kidder and Harris 2023). Yet, whereas Whiteside (2023) views healing as inseparable from justice, Clare (2017, 184) notes in contrast that any lingering attachment to cure "will never give us justice." For Lakshmi Piepzna-Samarasinha (2016, 27), healing justice is a praxis cultivated in political organizing work, representing a "fundamental—and anti-ableist—shift in how we think of movement work—to think of it as a place where many pauses, where building in healing as well as space for grief and trauma to be held, makes the movements more flexible and longer lasting." Whereas institutionally entrenched recovery models atomize the individual and build out strategies for personal restoration to wellness that function as conditions for (re)entry into full community membership, just forms of healing generate strategies to make room for embodied differences in order to restore communities to wholeness.

Digital Storytelling as Counter-Narrative: Introducing and Describing Our Stories

We, the authors of this paper, seek to find and interrogate the recovery and healing narratives threaded through our own lives. We each come to this work carrying with us our disability histories and confrontations with curative violences. We created our digitized disability stories in two separate digital storytelling workshops with the Re•Vision Centre for Art and Social Justice affiliated with the University of Guelph. The digital storytelling methodology developed by Re•Vision threads through a wide range of participatory action, arts-informed research projects (Rice et al. 2015; Rice et al. 2018). Under this methodological umbrella, varied research teams have spent over ten years bringing together researchers, participants, and artists for multi-day workshops that provide the video editing tools and support needed to produce short video documentaries two to ten minutes in length showcasing a wide representative range of disability and difference.

Digital storytelling begins with honing a short autobiographical script that is shared in a story circle with workshop participants then audio-recorded, typically but not necessarily in the voice of the script author. The digital story production process pairs that recording with visuals that could include animations, old and current photography, drawings and sketches, text, and special effects. The participant narrating their story has the editing tools, artistic insight, and decision-making power to create their own videos. Those creators are the owners of their own work, and can choose how and whether their work is used in research or public dissemination. Creators can also determine whether or not their name is featured in association with their video, and whether or not photography identifying them is used for visual content. Re•Vision's enormous archive of digital stories that accumulated across the last decade contains great variation, for expressions of embodied difference disrupt dominant narratives about disability and illness (Brushwood Rose and Granger 2013). This methodological approach is a kind of life-writing used in feminist disability scholarship to cultivate what Simplican

(2017, 54) considers "estrangement" from ableist assumptions that threaten conformity. By doing so, this approach aligns with Satija's (2023) claim that narrative writing and healing connect to reclaiming agency over one's (ill or disabled) body, and to cultivating communities of care and knowledge in the face of structural inequity.

Jen (one of this article's co-authors) participated in three separate digital storytelling research projects, serving as project lead for the later two. She created the digital story featured in this paper when she first joined Re •Vision as a study participant in 2013. The workshop took place on Toronto Metropolitan University campus, across the span of three intensive days. She contributed a video to a project called Mobilizing New Meanings of Disability and Difference, which took as its task studying how the counter-narratives of disabled people call into question cultural expectations around disability representation. Alanna (also a coauthor) attended the Digital Storytelling Workshop for Research and Advocacy hosted Re•Vision February 13 through February 27, 2024. The hybrid workshop consisted of four online evening sessions and two in-person daytime sessions for those able to travel to Re•Vision's Lab space at the University of Guelph. For workshops, participants are provided an overview of digital storytelling as a method and hands-on experience using video editing software. Attendees are given prompts and one-on-one support to create short digital stories that counter the harmful ways disability and lived difference are represented. While intensive, workshop organizers cultivate a relaxed space to carry out this emotionally demanding work.

The specificity to these personal narratives, their nonlinear and cyclical dimensions, their reconciliation with bodies that are never fully restored to factory settings—all these aspects to the two stories presented here carry the power to deconstruct and disassemble curative ideology. In what follows we first describe each story and their separate creation processes. Each author wrote a description of her story from her own perspective and included a screenshot from her story to ground descriptions. In our analysis of the themes that cut across these two digital stories, we seek to identify curative violences, to resist recovery scripts, and to imagine transformative and just healing. In order to accomplish this work we apply Berlant's (2011) theory of cruel optimism, its affective structure and examples of its attachments.[1]

Jen's Litany of the White Noise

The digital story *Litany of the White Noise* opens on black empty space with glowing orbs dancing across the screen. They are the throughline to the video, sparking flashes of colour like electricity, expanding and contracting to the rhythm of the script. My (co-author Jen Rinaldi's) voice, my opening lines, proffer a list of recommended goals found in the text of a '90s-era *Weight Watchers* plan, a booklet I once considered biblical: "Eight ounces per serving, 50 calorie limit, 30 minutes of exercise, 118 pound endgame—". It's an old song, an ongoing negotiation I remember keenly that attached numerical value to every meal, the *118* carved into neon-yellow post-it notes I had affixed to every box in the pantry. Those spheres of light, that visualization of voice, ricochet across a darkened photograph of a colonnade as I describe my first day in a competitive high-school course taught abroad. My narrative describes that turning-point moment of salvation the Vatican offered me—"I, the atheist, found redemption." The world opened up and held promise. This is all against a description of the sickly-sweet scent of chewing gum that gave away my favourite technique to avoid cravings for food.

My next reaching for redemption was the academy, riding a scholarship into a Philosophy degree. Grades were my new numerical thresholds, staving off student debt, all while a "clarity of purpose" kept death at bay. The crisis of an adolescent anorexia—the family interventions and emergency room visits and pronounced corporeality—were firmly in my rearview mirror by the time I reached the post-secondary story-beat in my life. I claim in the video this is all a past "long put behind me, archived and forgotten," compartmentalized and converted into tidy life lessons. But I admit that residue did remain in quiet moments of self-regulation. Balls of light and colour bouncing about the screen still follow my voice against backdrops of a leafy green path, then a cityscape at sunset. Those lights throb with kinetic energy as the voiceover tempo picks up pace and drops punctuation: "Drink some water have more gum no more dairy take another pill—". The synaesthetic light pulsates like a heartbeat, to the percussive line: "It's 5am and I've just popped another diet pill and my *heart* won't stop *pounding* as though it might *burst* from my *chest*." In the conclusion to the digital story I call all this inner monologue white noise, the radio static I can't shake, dulled over time but never gone.

It's jarring, returning to this video twelve years later. At the time I was transitioning out of my education and into my career path, comparable to my coauthor's current position. I recall the workshop weekend back in 2013: my stress over imagery especially, finally landing on the decision that I could not bear to put my body on screen. My old family photographs depicting diagnosis were too difficult to return to and felt like the wrong fit, if only because there is a propped-up-pretty, romanticized version of anorexic femininity I never achieved (Day and Keys 2009; Saukko 2009); my version had more body hair redistribution than jutting bones, was more pre-pubescent than modelesque. But also, I worried how my recovered body, or even my "recovered" body, in more current photography might be subject to scrutiny given how eating disorder recovery runs up against culturally embedded, medically reinforced anti-fatness sentiments (Lebesco 2009; Rice 2014). I remember wondering back in 2013 when I was first creating my digital story: how much weight can I gain back before incurring judgment? Eating disorder recovery in this light comes with constant regulation, some new target weight holding fast like the yellow post-it note.

What I wonder now: do I have an addendum to this narrative, any insight to offer so many years past my lowest points of pathology? Or perhaps more appropriately, since the digital story itself does not actually probe those much-earlier depths: have I recovered from this delicate depiction of recovery? School truly was my calling and fills up so much of my time and headspace I no longer bother with self-starvation rituals. If only all my markers for success, all tethered to educational achievement, did not come through an academic asceticism I first practiced as restrictive diet and relentless exercise. Where I treat the academy like my church, operating by litany proves effective, is rewarded. The words in this paper took shape through several 5ams, fuelled by caffeine found in the can rather than the capsule. The crack running through my molar from all the anxious grinding is not exactly an eating disorder symptom, but I think of it every time I chew: *no hard foods, nothing too sticky, must floss after, no large bites* form my latest song.

Alanna's Learning to Traverse Uncertainty

The digital story *Learning to Traverse Uncertainty* opens with a video peering up to the moon, clouds moving slowly across it as it illuminates the night sky. There is an audible exhale; a piano begins playing alongside my (Alanna Veitch's) voice: "I've learned that I'm always, *still*, learning. / Learning that my body doesn't always / want to learn; / that it doesn't always want to keep going because," and the image fades. The opening scene gestures to Lorde's (2007, 36) "poetry as illumination"; the moon, witness to the story about to unfold (itself, driven by a poetic narrative; hence, the line breaks) and bearer of histories that continue reaching forward into the present-future. A series of images follow—the first, a dimly lit room with a window through which the sunlight reaches. They are photographs of moments encountered, of feelings contained within each image. I continue reading aloud, "sometimes, it hurts; / sometimes, it pleads—it needs for everything to pause, / to go a little slower; / sideways, backwards, before the faster." I gesture to the ataxic gait I developed slowly and also too suddenly to adapt to the shift in my step and sometimes it is painful; this is one effect of living with lesions in my brain and spinal cord. The audience is left with a dark blank screen before the story continues, carried forward by a video of the world being passed by the train I was riding. For me, riding the train signifies the ongoingness of disability and disabled life, even when life seems to slow or be thrown off course, or when it is ended or erased (violently) by medical legal processes, legislation, and material circumstance tethered to fantastical notions of recovery and cure.

As the story continues, I reflect on my disrupted sense of self whose success (like my coauthor's) is bound-up in academic/creative achievement; the activities I once took for granted; the change in my body's choreography; the danger of a flight of stairs; and the people waiting for me to quicken my pace, get better, or move out of the way because I am a hindrance to their success. I fear walking farther than I am comfortable because any farther leaves me tripping and grasping; everyone is disappointed. So I ponder the grief I have learned to sit with, "to nestle into," in order "to tear myself away from the picture / of optimism we painted (was it together?)." Remaining stuck to any semblance of hope that *this*—my disabled body and mind; these disabling times; the disabling effects of a broken family—is temporary has arguably been one of the most painful and sinister of all affective attachments. The way that affect connects bodies to objects leaves me wondering: What does it mean to tear myself away from the picture of optimism? What does this tearing or ripping (Ahmed 2004) *feel* like? What parts of the picture remain attached and what parts of myself are torn in the process? To what extent did I participate in fabricating this picture of a "good" or "normal" life (Berlant 2011, 19)? In what ways am I still wishing to get closer to that better life tethered to institutions that feed on my anxieties, desires, and disability status?

I am privileged to have a good neurologist, especially when too many have no access to such care. Yet, the cycle of restlessness, fatigue, intervention, and worry never really ends because I cannot put multiple sclerosis behind me, even after loved ones say I am "doing better" during a two-day visit. While such optimism gets them by, it irritates my skin, tastes bitter, and sounds like a ringing in my ear. At night I count down from seven, breathing through the anxiety and heart palpitations that precarity and medication gifted me. My latest brain image shows I am not getting better, and while I want *this* to end, I also feel I need it; *it* is forever part of me.

The story finishes with a view from the passenger train window and the long passing of a cargo train, eliciting discomfort of that which endures. The piano has stopped but my voice-over continues: "And I'm still not *there*, / but, I'm not where I was; / instead I'm tripping, dreaming, / flying on a freight train, / in/towards someplace different and hope-full." Although hope, itself, has an attachment to cruel kinds of optimism, the hope-full place I am tripping in/towards is elsewhere than the present impasse where getting better is a cruel fantasy.

Countering the Cruelties of Getting-Better Assurances

We brought our digital stories into conversation with one another for how they both depict counter-narratives on disability recovery. Attachments to curative strategies are wedged between the lines of our autobiographical stories, binding us to the successes we envisioned for ourselves as good citizens, while keeping us circling in angst under the weight of our expected recoveries. Should we fail to recover, there is an impulse to keep these aspects of ourselves partly concealed for fear of rejection from the very social spaces that signify success through proximity. Our proximity to these spaces gives us proximity to what Berlant (2011, 19) refers to as the "good" or "normal" life promised by capitalist culture to anyone working to overcome their disability/difference. But contradictions abound in good life fantasies that fail in debilitating and cruel ways; this is especially so for those whose race, gender, class, citizenship, ethnicity, dis/ability, and sexuality are positioned outside normative categories of existence (Berlant 2011; Kafer 2013; Puar 2017; Spurgas 2021). In the themes we derive from our stories, we work out how curative narratives stick to disabled bodies and minds, create tears, and leave evidence of a historicity of curative violence (Ahmed 2015; Clare 2017; Kafer 2013). Next, we elaborate on the ordinariness of crises in disabled life to counter attachments between cure, getting better, and progress in academic and public life. Our final theme explores our refusal to show our bodies, finding affective possibilities in vulnerability through aesthetic ambiguity.

What Tears and What Sticks: The Historicity of the Curative

These two digital stories track the ways our bodies carry the imprints of recovery narratives. In Jen's *Litany*, incomplete breaks from disordered eating materialize in the stench of chewing gum on her breath and the rush of caffeine pumping through her bloodstream. Her body formed an archive of previous pathologized habits, all brimming beneath the surface and threatening to undo her optimistic effort toward worldmaking. But she cannot claim a culturally acceptable recovery, cannot manage under the pressure of expectation, without these secret strategies and the visceral feelings of disgust they are rooted in. In *Learning*, getting better binds Alanna to others' problematic expectations of her to continue being inspiring, to not be sad, to not be a burden, to not speak about discomfort, to persevere and be exceptional so that she does not become like other disabled folks who are rendered undeserving of care by society. The expectations are crushing, divisive, and marked with violence. For her failure—and refusal—to live up to these harsh demands, she slips apologies into nearly every encounter.

These story-beats read disability into affective theories of emotion (e.g., Berlant 2011; Ahmed 2015), where the "getting better" meta-narrative circulates between signs of a cure (Clare 2017; Kafer 2013) or the good life

(Berlant 2011) and the bodies that betray us. Optimism, as a social relation, works through attachments "to organize [and make sense of] the present. It is an orientation toward the pleasure that is bound up in the activity of world-making" (Berlant 2011, 14). The tearing or ripping of these attachments causes discomfort, even pain; it might leave traces of what each was previously stuck to—remnants of an incomplete break (Spurgas 2021). These remnants catalogue a historicity of events, bodies, objects, and signs that were once encountered but may not seem apparent in the present. In Ahmed's (2004) own words: "the ripping effect of emotions… move sideways (through 'sticky' associations between signs, figures, and objects) as well as backward (repression always leaves its trace in the present—hence 'what sticks' is also bound up with the 'absent presence' of historicity" (Ahmed 2004, 120). Inattention to these histories in dominant accounts of disability recovery is what Ahmed (2015), Berlant (2011), and others (Spurgas 2021; McNeal, Harris, and Oliphant 2024; Puar 2017) gesture toward in arguing that history has presence; it shapes what is happening now and how it is experienced (i.e., its affect). Berlant terms this the "historical present" (Berlant 2011, 195) to track a present that endures.

Being without some historical context makes understanding "what objects [and events] do to other objects [or bodies]" across time and space difficult (Ahmed 2015, 91) and so does violence to particular (raced, gendered, classed, and Othered) bodies surfaced by that often-violent history. These include the violences done to Black, racialized, and female bodies during the transatlantic slave trade and in the present (Erevelles 2011; McNeal, Harris, and Oliphant 2024); the ongoing colonial occupation of Indigenous lands and Middle Eastern states (among others) (McRuer 2018; Puar 2017); the institutionalization and socio-political exclusion of persons deemed disabled, defective, and/or lacking capacity (Clare 2017; Erevelles 2011; Rossiter and Rinaldi 2019); and the lived and material precarity still attached to these bodies. Recognizing critiques of Berlant's (2011) work in *Cruel Optimism* that dismisses (and reinforces) key racial, cultural, and geographic histories that shape how Otherness and disability are represented and lived, we still find use in tracing the affective structure and circulation of cruel optimism.

Reflecting on his encounters with the medical system, Clare (2017) makes clear the impossibility, even the cruelty, of desire for cure. Granted, "the desire for a cure" is not in itself "necessarily an anti-disability rights and justice position" (Clare 2017, 3). We (Jen and Alanna) both, after all, bear relationships to disablement that came with pain and distress. But an ideological commitment to cure erases the lived realities of disability and of surviving the disabling present. Cure is only convenient for a system committed to maintaining power by reinforcing a normative, oppressive, exclusionary, and eugenic politic.

Unsettling the Arc of Progress: Achievement as Recovery's Blanket

Varying temporalities of disabled life disrupt the expectation of a single trajectory of getting better, its unrelenting forward march. Achievement can involve exhausting and even debilitating kinds of labour, seen in the cyclical rituals Jen conducted through *Litany*. The story starts *after* the worst of diagnosis, depicting a recovery at progressive stages of schooling and its attendant pressures to produce and compete and project wellness. And yet, each key milestone is punctuated with a circling back, a repetition of the self-regulation that once invited prognosis. Meanwhile in *Learning*, Alanna describes the anxious work of traversing the turbulent terrain of a disability diagnosis with no clear prognosis (except progressive decline). The unsteady pace disrupts the possibility for success, making success for the emerging scholar-artist all the more desirous for its blanketing effects and protection it provides from those waiting for her to overcome or fail.

These moments in both digital stories convey how recovery may not move in a straight line. While Berlant has met critique in fat studies circles (e.g., Crawford 2017; Ward 2013) for granting too much credence to obesogenic environments (or structural arrangements that increase risk of weight gain, a site of study for scholars seeking to "end obesity"), *Cruel Optimism* and other works nevertheless introduce the helpful idea that lateral (rather than progressive) agency is born of eating and other habits that resist the acceleration of capitalist labour production processes. Lateral agency opens up a temporality that Berlant describes as "ongoingness, getting by, and living on, where the structural inequalities are dispersed, the pacing of their experience intermittent" (Berlant 2011, 99-100) because the agent is not acting in the "life-building way" (Berlant 2011, 99-100) expected of liberal subjectivity.

Where optimism is an orientation to the future, a future placed just out of reach for the liberal subject in order to prompt their strivings, Kafer (2013, 27) explains that "'the future' has been deployed in the service of compulsory able-bodiedness and able-mindedness." In what she calls "curative time" (Kafer 2013, 27), linearity is baked into recovery strategies and getting better narratives. In her own words: "Futurity has often been framed in curative terms, a time frame that casts disabled people out of time… Within this frame of curative time, then, the only appropriate disabled mind/body is one cured or moving towards cure" (Kafer, 2013, 27). The promise of progress defines recovery narratives despite recognition of recovery's nonlinearity (Leamy et al. 2011; Stuart, Tansey and Quayle 2017). For instance, relapse is often included as part of the recovery journey, whether due to an illness or pathologized disorder related to one's mental, psychical, neurological, or physical health; it is a backward/forward movement measured by how closely one's behaviours and lab results approach societal norms. The linearity of curative time might then rely on returning to a former state of being that better resembled the picture of good health and normality. For Clare (2017), the expectation of this impossible return is cruel, even violent. Moreover, since curative time is bound by normative expectations (Kafer 2013), impasse is imminent. Crisis, debility, and trauma, all outcomes of ongoing structural violence (Berlant 2011; Spurgas 2021), become mere obstacles one must overcome.

The expectation to overcome disability, trauma, or hardship is capitalist culture's "*curative imaginary*" (Kafer 2013, 27) from which the desire to move toward the good life is birthed. In need of assurance for a better life, those of us living with disabilities and differences weather the affects of structural oppression and precarity, and consequently latch onto normative activities and institutions that signify progress and possibility for recovery. For Kafer (2013, 27) the curative imaginary "not only expects but assumes intervention [into disability] but also cannot imagine or comprehend anything other.". The digital stories in this paper impart that, similar to the way recovery serves as a safeguard for the curative (Clare 2017), academic (and other public) achievement is the blanket we use to conceal those aspects of our disabled selves that have fallen off the recovery train or that never made it to the station; it also conceals the self- and socially-inflicted wounds and stresses that have become ordinary effects of living in disabling times. Achievement, then, becomes a tool of survival to defy—for ourselves and others—the ways in which disabled bodies and minds are regulated, stereotyped, and constructed as "obstacles to the arc of progress" (Kafer 2013, 27).

The Art of Refusal: Analyzing Aesthetic Ambiguity

Aesthetically, both digital stories featured in this paper leave viewers without the gratification of knowing what the storyteller looks like. By denying audiences the ability to view our bodies and make judgements about our disability claims, we ask our audiences to resist looking for signs of recovery and to, instead, wade gently, patiently into our stories. Jen in *Litany* focused a camera on a desktop screen while an audio synthesiser reacted to the script recording. This technique means the audience can catch her reflection staring back at them, but only obliquely, in fleeting moments. For *Learning*, Alanna assembled images and videos of everyday spaces that are as intimate as her body. Images appear as felt and experienced in/out of sync with a recording of her playing the piano that runs behind her narration.

These two digital stories do not satisfy an audience interest in attaching meaning to visual representations of disabled embodiment. Neither Jen's nor Alanna's body can be measured against the impossible futures their recovery narratives prompt them to strive toward. Nor do their stories permit audiences to see their bodies merely as sites or objects of tragedy and failure; rather, their stories apply an aesthetic of ambiguity to keep open the interpretive, creative, and knowable boundaries of disability and how it "appears as a visceral moment" (Berlant 2011, 15). Ambiguity, then, is our (both Jen and Alanna's) refusal to adhere to aesthetic conventions that flatten out the embodied and temporal "rhythms of [disability] survival" (Berlant 2011, 11) and to instead alter the affective structure of disability recovery narratives attached to cruelly optimistic ideals.

Refusal to be visible or easily read, nevertheless, requires vulnerability in the aesthetic portrayal of one's truth, as felt. While it may seem a far stretch, Lorde's (1980) critique of the oppressive structures that silence the particularities of disability and difference illuminates the transformative power of speaking differently—even in the face of fear and exhaustion—because *this* is difficult work. For Lorde (1980), refusing to be silent or adhere to normative scripts of disability and difference is the mobilizing force out of the impasse with which Berlant (2011) is concerned. The digital stories that make this paper possible take part in the unsilencing work, using ambiguity to attend to the ways disability recovery, as a cruel fantasy, circulates and sticks to disabled bodies and minds. Our refusal to be seen and easily decipherable generates anew the affective realities of failure that we find generative and authentic to our disabled lives and futures.

Conclusion: Disability as Generative and Enduring

In this paper we drew from our own digitized disability stories to develop a counter critique to the "getting better" meta-narrative. We utilized Berlant's (2011) theory of cruel optimism to argue that, like the "good" life fantasy promised by capitalist culture, recovery is bound up in the impossibility of returning to a former self, of cure, and/or of living a "normal" life. As disability scholars who ourselves experience different forms of lifelong disablement, we take issue with the curative violences of institutionally entrenched recovery models that discount diverse and enduring disability/disabling realities. The digital stories we shared, described, and analyzed were created during two separate workshops and utilized a counter-narrative digital storytelling methodology. From these stories, we articulated an analysis of how the stickiness of curative narratives leaves tears and evidence of curative violence on our bodies and minds; how the ordinariness of crisis and disablement are felt and defied through achievement; and how the ambiguity of our bodies demanded different affective engagement with our stories. In altering the affective structure of our attachments to the recovery narrative, we found meaning in our failures and vulnerabilities, and movement toward a more just future with room for embodied and enminded differences—and perhaps healing justice. The authenticity of our disability stories, with no clear prognosis for recovery, generated for us a way to endure, even thrive.

Endnotes

1. The digital stories referenced in this article can be found at the following link: https://www.idrr.ca/the-cruelty-of-the-curative (password curative).

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Making Space for All Body Sizes in Pre-, Peri-, and Post-natal Care in Atlantic Canada: A Patient-Informed Hospital Equipment Inventory

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Abstract: Background: Diverse, versatile, and readily accessible equipment is essential for healthcare provision, to maximize care quality, minimize complications, and eliminate weight stigma and discrimination. Hospital equipment inventories (inventories) and audits can be completed by internal or external reviewers and are not always publicly available or subject to peer review, despite hospitals receiving significant public funding for care and research. Objective: The objective of this research was to complete an inventory audit to identify, count, and describe (type, weight capacity) bariatric equipment in nine units/ clinics in the Women's Building of a maternal-newborn hospital in Atlantic Canada. Methods: Six registered nurses completed inventories using a standardized form, including type and weight capacity of all bariatric equipment, in 2018 and 2021, at nine units/clinic sites within an urban maternal-newborn tertiary care facility in Atlantic Canada. Results: The inventory audits conducted in 2018 and 2021 show that additional bariatric beds, stretchers, and blood pressure cuffs were purchased. Nonetheless, findings agree with existing peer-reviewed literature that show bariatric equipment is lacking in Canadian tertiary care settings. Conclusion: The objective of this project was met, confirming an increase in the availability of specific bariatric inventory between 2018 and 2021; however, the current availability and amount of bariatric equipment is not adequate. This quality improvement initiative highlights a strength of local clinician-researcher efforts, relationships, and engagement with patient-centred implementation science.

Keywords: women; weight; mass; obesity; fat; bariatric equipment; clinical practice guidelines

Résumé : Contexte : Un équipement diversifié, polyvalent et facilement accessible est essentiel pour la prestation de soins de santé, afin de maximiser la qualité des soins, de réduire les complications et d'éliminer la stigmatisation et la discrimination liées au poids. Des examinateur·trice·s internes ou externes peuvent effectuer les inventaires d'équipement hospitalier (inventaires) et les vérifications et ces derniers ne sont pas toujours rendus publics ni soumis à un processus d'évaluation par les pairs, bien que les hôpitaux reçoivent un financement public considérable pour les soins et la recherche. Objectif : L'objectif de cette recherche était de réaliser une vérification de l'inventaire afin de recenser, compter et décrire (type, capacité pondérale) l'équipement bariatrique dans neuf unités ou cliniques du pavillon des femmes d'un hôpital de soins maternels et néonataux du Canada atlantique. Méthodes : Six infirmières autorisées ont réalisé des inventaires à l'aide d'un formulaire normalisé, comprenant le type et la capacité pondérale de tous les équipements bariatriques, en 2018 et 2021, dans neuf unités ou cliniques au sein d'un établissement de soins maternels et néonataux tertiaire urbain au Canada atlantique. Résultats : Les vérifications d'inventaire effectuées en 2018 et 2021 indiquent l'acquisition de lits bariatriques, de civières et de brassards de pression artérielle supplémentaires. Toutefois, les résultats concordent avec les publications évaluées par les pairs, lesquelles montrent que l'équipement bariatrique est insuffisant dans les établissements de soins tertiaires au Canada. Conclusion : L'objectif de ce projet a été atteint, confirmant une augmentation de la disponibilité de certains équipements bariatriques entre 2018 et 2021. Cependant, la disponibilité et la quantité actuelles de ces équipements ne sont pas suffisantes. Cette initiative d'amélioration de la qualité souligne les efforts, les relations et l'engagement des clinicien·ne·s-chercheur·se·s locaux envers la science de la mise en œuvre centrée sur les patients.

Mots clés : femmes; poids; masse; obésité; graisse; matériel bariatrique; recommandations de pratique clinique

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Introduction

Weight stigma is a form of negative bias towards an individual based on their body size or weight. Weight stigma includes negative perceptions, stereotypes (e.g., higher-weight individuals are lazy, lack willpower, have bad hygiene, are less intelligent), attitudes, and beliefs, and can impact individuals across the weight spectrum, however, more predominantly impact higher-weight individuals due to widespread societal beliefs around thinness and health (Hill et al. 2021; Lacroix et al. 2017; Lawrence et al. 2021; Puhl and Heuer 2009; Nutter et al. 2018, 2019; Stoll 2019; Wu and Berry 2018). Weight stigma is pervasive not only in society and media but also in workplace settings, education, and in healthcare, where research has found that patients delay and avoid seeking care for fear of stigmatizing attitudes from providers and health systems (Amy et al. 2006; DiGiacinto et al. 2015; Merrill and Grassley 2008). Weight stigma has negative impacts on psychological and physical health and on morbidity and mortality. Weight stigma also reduces quality of care received from health care providers, including in women's health during the pre-, peri-, and post-natal periods and where gestational weight gain is closely monitored in pre-natal care visits (Alberga et al. 2025; Kirk et al. 2020; Puhl and Heuer 2009; 2011). A recent systematic review confirmed that a facilitator of weight stigma in the pre-, peri-, and post-natal periods is an unaccommodating environment, such as the absence of facility systems and equipment suitable for women living in larger bodies (Hailu et al. 2024a). Historically, feminist and fat studies scholars have highlighted the lack of consideration for women's and pregnant women's voices and experiences (Earle 2003; Verseghy and Abel 2018), including the body-related pressures to conform to (or "achieve") a certain size (Earle 2003; Friedman 2014; Verseghy and Abel 2018; Ward and McPhail 2019), and have made strides notably in the last decade to study this topic (Basinger and Quinlan 2024; LaMarre et al. 2020; Parker and Pausé 2017) in parallel with clinically oriented advocacy and research efforts (Alberga et al. 2025; Papini et al. 2025; Saw, Aung, and Sweet 2021). In women's health research, fear of weight stigma has been described by patients when attempting to "fit into" hospital gowns, blood pressure cuffs, clinic chairs, examination tables, and scales, that were noted to be too small to be functional (Amy et al. 2006; Merrill and Grassley 2008; Parker and Pausé 2017). Comparatively, Amy et al. (2006) found in their sample that not all (80% of N = 129) health care providers reported having access to equipment for larger bodies, such as longer speculums for pelvic exams.

Clinical Practice Guidelines (CPGs) guide best practices for clinical care management. Relevant to women's health, pregnancy, and weight management, are CPGs from the Society of Obstetrics and Gynecology of Canada (2019), Obesity Canada and the Canadian Association of Bariatric Physicians and Surgeons (2020), and Diabetes Canada (2018) (Maxwell et al. 2019a; 2019b; Piccinini-Vallis et al. 2020; Rasmussen and Yaktine 2009; Wharton et al. 2018; 2020), all of which have mixed reception by healthcare providers (Feig et al. 2018; Snelgrove-Clarke et al. 2020). SOGC (2019) states in their guidelines that "implementation of these guidelines … may increase obstetrical provider recognition of the issues affected pregnant individuals with obesity, including … equipment and human resource planning" (Maxwell et al. 2019a). This is in agreement with other Canadian CPGs, recommending that clinical environments be accessible, safe, and respectful for patients of all sizes (Wharton et al. 2020). That said, existing original and meta-analysis research describe several examples of the impacts that a lack of inventory has on patient risk, experience, and treatment (Amy et al. 2006; Broome et al. 2015; Chelmow, Rodriguez, and Sabatini 2004; McGinley and Bunke 2008; Parker and Pausé 2017). For instance, without appropriate equipment and routine care, atypical pressure sores can present in patients due to ill-fitting chairs, beds, and/or wheelchairs, pressure within skin folds, or pressure around tubes and catheters (Broome et al. 2015). Specific to pre- and post-natal care, women with higher weights are at a higher risk for postsurgical complications such as wound dehiscence and infection, whereas adapting wound closure procedures to larger bodies (e.g., reapproximation at C-section) can significantly reduce this risk (Chelmow, Rodriguez, and Sabatini 2004; Feig et al. 2018; Maxwell et al. 2019a, 2019b; Snelgrove-Clarke et al. 2020).

In both medical and social weight-related dialogues, it is essential to understand terms used, and/or any underpinnings or origin(s) of terms, to ensure everyone has a shared understanding of how terms are defined and applied, dependent on context and setting (Waugh et al. 2025). The term "bariatric" is derived from the Greek root word "baros," meaning weight (Wood 2024). In medical care, bariatric refers to specialized care of people with bodies classified as "obese." Historically, "obesity" has been defined by higher body mass index (BMI) (of 30 kg/m^2 or higher; resulting from a calculation using weight [in kilograms] divided by height [in metres] squared). In 2025, however, scholars continue to advocate for transition of the definition to consider more than BMI, including individual markers of risk and adiposity function impairment (Rubino et al. 2025; Rueda-Clausen et al. 2020), as science has found health can occur across body sizes, and language (i.e., how we describe bodies) can perpetuate weight stigma.[2] Although there is no universal weight range used to define bariatric, bariatric equipment is typically designed to support bodies weighing 270 kg (595 lbs) to 500 kg (1,102 lbs) (Wood 2024). Despite this, bariatric equipment weight capacities in practice (Table 1) can vary and are considered equipment for bodies up to and over 150 kg (350 lbs). Canadian surveillance and monitoring data, specifically the Canadian Community Health Survey (2018), found 27% of Canadian adults are classified as obese (as defined by a BMI of 30 kg/m^2 or higher), with prevalence in Nova Scotia (NS), New Brunswick (NB), and Prince Edward Island (PEI) at 34%, 35%, and 38%, respectively (Statistics Canada 2022; Wharton et al. 2020). Furthermore, for women of childbearing age, prevalence of obesity defined by BMI is also high in the Atlantic provinces. For instance, 31% , 26%, and 37% of women aged 18 to 34 years are considered obese defined by BMI in NS, NB, and PEI, respectively. Even higher rates of obesity rates are found in women aged 35 to 49 years in Atlantic Canada, with 49.5% in NS, 45% in NB, and 34% in PEI (Statistics Canada 2017). Twells et al. (2014) estimate class II (BMI 35.0 to 39.9 kg/m^2) and III obesity (BMI $\geq$ 40 kg/m^2) make up a little less than 5% of the Canadian population, increasing since 1985. However, Twells et al. (2014) used 2011 data, meaning rates have likely increased in the past decade, given current population health records. While Canadian data is collected based on BMI data and not weight status (e.g., how many Canadians are over 270 kg/595 lbs or 500 kg/1102 lbs [Wood 2024]), it is impossible to extrapolate to how many Atlantic Canadian women require bariatric equipment during their medical care. Instead, it is known that many Atlantic Canadian women of childbearing age, thus including pregnant women, have higher BMIs or are living in larger bodies, meaning hospitals should be equipped with bariatric-sized equipment to provide inclusive care.

Bariatric equipment is more expensive than standard-sized equipment, both to purchase (e.g.; "extra-large" blood pressure cuffs cost $179.99 Canadian dollars while "classic" cuffs cost $59.99 Canadian dollars) and use (i.e., staffing, service, and space) (Diconsiglio 2006; LifeSource n.d.). For instance, a bariatric hospital bed can support a weight of more than 227 kg (500 lbs) and has a width of 90 cm (35 inches) which requires three staff to move it (Alberta Health Services 2022). Equipment availability is also important for the safety of the health care providers as musculoskeletal injuries are common especially when providing care to heavier patients (Choi and Brings 2015; Muir and Gerlach 2003). Additionally, the use of appropriately fitting equipment is essential to accurate use/measurement and monitoring outcomes, one example being blood pressure cuffs (Ashline 2020; Pickering et al. 2004).

Patient rooms must be spacious enough to accommodate all bariatric-sized equipment if needed for a given patient (Broome et al. 2015; McGinley and Bunke 2008). Equipment is frequently transferred from unit to unit through hallways, doorways, and hospital rooms that accommodate equipment of this size (Broome et al. 2015). In some accommodations, patients may have to be placed in larger rooms, such as negative pressure isolation rooms, which can be problematic, especially as seen during the era of COVID-19. Moving forward, it is important to consider facility design when renovating hospitals or adding to existing units (McGinley and Bunke 2008). Regionally relevant, an initiative known as Access By Design 2030 aims to make Nova Scotia more inclusive by 2030, which includes making "buildings, streets, sidewalks, and shared spaces accessible to all" (Government of Nova Scotia 2017).

Process-mapping or systems-based approaches have been deemed useful to help determine the equipment, assistance, and/or space needs for a given patient and facility (Alberta Health Services 2016; Broome et al. 2015; Clarkson et al. 2018; Pearce n.d.). Canadian health authorities such as Alberta Health Services provide open-access resources (e.g., Bariatric Friendly Hospital Initiative & Guidelines for the Care of Hospitalized Patients with Bariatric Care Needs) and step-wise checklists to begin creating more accessible and inclusive healthcare spaces for larger body sizes (e.g., Equipment and Environment Checklist for Office and Clinical Settings) (Alberta Health Services 2016; 2022; Pearce n.d.). Systems-based approaches can be extremely valuable as a problem can be addressed from not only the perspective of the patient and healthcare providers but also the system and design, while considering risks involved (Clarkson et al. 2018).

Survey research and quality assurance projects, in the form of audits or inventories, are a common and effective means of engaging in systems-based care evaluation and best practice(s) (Khaleghi 2017; Merchant et al. 2022; Mulepo, Niwa, and Date 2011; US EPA 2020; WHO 2011; 2023). Several agencies and organizations, including the World Health Organization and Health Canada, disseminate and apply audit and inventory results as part of ongoing needs assessment, intervention evaluation, knowledge translation, and gap analysis (Health Canada 2017; US EPA 2020; WHO 2011; 2023). There are several methods that can be used in surveying research, including hospital equipment inventories (e.g., beds, protective personal equipment, ceiling track hoist systems), which are not always publicly available data. This type of inventory garnered increased attention during the COVID-19 pandemic due to preventable interruptions and delays in healthcare supply chain that impacted care and safety of patients and hospital staff (Cohen and Rodgers 2020; Merchant et al. 2022; Pearce n.d.). Publicly available data and research are lacking on if and how Canadian hospitals are meeting the equipment needs of all healthcare providers and patients, including for women living with obesity or in larger bodies, which is essential to creating more inclusive healthcare spaces. The objective of this inventory audit reported here was to identify, count, and describe (type, weight capacity) bariatric equipment in nine units/clinics in the Women's Building, of a maternal-newborn hospital in Atlantic Canada.

Methods

Bariatric equipment inventory improvement efforts (led by Maxine Bernard), in collaboration with nurses and other healthcare providers at the facility, have occurred at the facility since 2008 (initial inventory audit), with a focus on equipment available for larger body sizes and prevention of healthcare provider injuries. The inventory was organized by unit and type of equipment, focusing on equipment frequently used in pre-, peri-, and post-natal patient care, as women are a key population that the facility serves. Information related to equipment specifications was collected through discussion with unit representatives, managers, the hospital's Clinical Engineering team, and through Community of Practice (CoP) meetings. The TEEMOB (Translating Evidence to Enhance Maternal Newborn Outcomes—Obesity) CoP is an intersectional women-led group made up of clinicians, researchers, and policy makers from various disciplines (e.g., nursing, physiotherapy, dietetics, medicine, psychology, communications) with various professional (and personal) lived experiences with body size, ethnicity, sexuality, and (dis)ability. Input from women with lived experience was also considered throughout the inventory efforts to echo marginalized accessibility efforts: "Nothing about us without us" (Government of Canada 2020).

In 2018 and 2021, six nurses recorded weight capacities of equipment using a standardized form in nine hospital units/clinics in the Women's Building, including the Birth Unit, Perinatal Centre , Prenatal Special Care Unit/Adult Surgery/Obstetrical Day Unit, Postpartum Discharge Clinic, Early Labour Assessment Unit, Family Newborn Unit, Ambulatory Clinics, Fetal Assessment & Treatment Clinic, and Diagnostic Imaging. Data collection included type and quantity of each piece of bariatric equipment available at the hospital in both 2018 and 2021. For this inventory, all equipment designed to support bodies greater than or equal to 350 lbs was included. Quantities are expressed in counts, and all weight capacities available are included in rounded brackets. Reported data was descriptive, using counts. Comparisons were done using simple differences (subtractions) between the 2021 and 2018 counts.

Results

Improvements (increases) were found in the availability (number) of bariatric equipment in the inventory in 2021 compared to the earlier inventory audit in 2018 (Table 1). Between 2018 and 2021, six exam tables (400 lb capacity) with built-in stools were purchased for the Perinatal Centre. For the Birth Unit, two operating beds with width extensions (1000 lb capacity), three stretchers with width extensions (1000 lb capacity), and eighteen "extra-large" and "large" blood pressure cuffs were purchased (2018-2022). No additional purchases were made in seven of the nine units/clinics, including the Postpartum Discharge Clinic, Early Labour Assessment Unit, Family Newborn Unit , Ambulatory Clinics, Prenatal Special Care Unit/ Adult Surgery/ Obstetrical Day Unit, Fetal Assessment & Treatment Clinic, and Diagnostic Imaging. Higher inventory numbers noted for the Early Labour Assessment Unit is reflective of a newer space and purchases made as part of recent renovations and development costs. Most recently (2022), hospital funding was confirmed to purchase five additional stretchers/beds for the Birth Unit. In both inventory audits (2018 and follow-up in 2021), bariatric stretchers and beds were found to be available in lower quantities compared to other pieces of equipment such as wider (wheel) chairs, step stools, and scales combined.

Table 1. Bariatric equipment inventory at study hospital in 2018, 2021, and purchases completed between 2018 and 2021.

Unit name	2018	2021	Purchases (2018-2021)
Perinatal Centre (PNC)	Quantity (count)	Quantity (count)	Quantity (count)
Exam table (600 lb)*	4	4	0
Exam tables with stool built in (400 lb)	3	9	6
Scale (880 lb) - Shared with ELAU	1	1	0
Waiting room chair (700 lb)	1	1	0
Postpartum Discharge Clinic			
Chairs (500 lb)	3	3	0
Early Labour Assessment Unit (ELAU)			
Wider chairs (500 lb)	7	7	0
Stryker Stretcher (495 lb)	7	7	0
Birth Unit (BU)			
Operating room bed with extensions (1000 lb)	1	3	2

Stretchers Stryker (495 lb)	3	3	0
Stretcher (500 lb)	1	1	0
Stretcher (700 lb)	1	1	0
Stretcher (850 lb)	1	1	0
Stretcher (1000 lb), with extensions	0	3	3
Wheelchair Medline (unknown capacity)	4	4	0
Commode (1000 lb)	1	1	0
Sandel Ergo Step Stool (500 lb)	20	20	0
Yellow Fin Stirrups (500 lb each stirrup)	2	2	0
Affinity III beds (600 lb)	2	2	0
Affinity IV bed (500 lb)	7	7	0
Birthing balls (600 lb)	3	3	0
Peanut balls (variety of size)	10	10	0
Extra large and large blood pressure cuffs	2	20	18
Friction reduction devices for moving patients			
rollers	1	1	0
sliders	2	2	0
AirPal	1	1	0
Wedge – for intubating (e.g. difficult airway)	1	1	0
Ultrasound (for epidural placement)	1	1	0
Floor mounted toilets (in all rooms and public bathrooms)	18	18	0
Family Newborn Unit (FNCU)			
Scale (770 lb)	1	1	0

Commode (550 lb)	1	1	0
Wheelchair (600 lb)	1	1	0
Bed (1000 lb)	1	1	0
Blood pressure cuffs 5B	2	2	0
Ambulatory Clinics			
Lift (600 lb)	1	1	0
Scales (880 lb)	2	2	0
Prenatal Special Care Unit (PSCU)/ Adult Surgery/ Obstetrical Day Unit (ODU)			
Scale (440 lb)	1	1	0
Fetal Assessment & Treatment Clinic (FATC)			
Waiting room chairs (700 lb)	2	2	0
Diagnostic Imaging			
XRAY			
Ysio (660 lb)	1	1	0
Proteus (484 lb)	1	1	0
BCL (Gastric Room) (440 lb)	1	1	0
CT			
Table (450 lb). Bore diameter 78cm.	1	1	0
MRI			
(350 lb). Bore diameter 60cm.	1	1	0
Nuclear Medicine			
Symbia (450 lb)	1	1	0
GE (500 lb)	1	1	0
Bone Density (350 lb)	1	1	0

Ultrasound (500 lb)	1	1	0

**Note.* All weight capacities are in brackets.

Discussion

The inventory audit identified, counted, and described (type, weight capacity) the available bariatric equipment in nine units/clinics in the Women's Building of a local maternal-newborn hospital in Atlantic Canada. This study demonstrates the lack of universal weight ranges for bariatric equipment. Of all units surveyed (Table 1), the lowest weight capacity for a piece of equipment was 350 lb and the highest was 1,000 lb. This finding highlights the need for accurate labelling within facilities and the importance of provider awareness, training, and education, which agrees with existing research (McGinley and Bunke 2008).

Stretchers are rectangular, traditionally made of two poles and fabric stretched between them, and are used for transporting patients who are unable to mobilize on their own (Cambridge Dictionary n.d.). When the initial inventory audit was completed (2008), the availability of bariatric stretchers for patient transport was very low, with one per unit in most units. In practice, this is challenging if more than one patient requiring a higher-weight capacity item is admitted at one time. The five additional stretchers/beds purchased (2022) for the Birth Unit are predicted to increase the ease of patient transport and decrease physical stress on nursing staff; when motorized stretchers are not available, nursing staff must co-lift or transfer the patient themselves without the help of appropriate equipment. In the case of purchasing bariatric equipment alongside construction of a new unit (Early Labour Assessment Unit), incorporating these purchase costs into the overall cost of building the facility can be more efficient than trying to secure funding as part of capital equipment (i.e., operational costs). Funding for capital equipment upgrading is competitive and bariatric purchases may not be identified as a "critical need," which is a challenge in procurement efforts.

Blood pressure cuffs also increased in quantity since 2018, as they are used frequently in terms of number of patients, in triage efforts, and in and across units such as outpatient units/clinics. Correctly fitting blood pressure cuffs are essential for several reasons including receiving accurate readings for proper care, intervention development, medication prescription, and maintaining patient dignity (Ashline 2020; Pickering et al. 2004).

Given the thousands of women attending this hospital each year and the prevalence of obesity, the current availability and amount of bariatric equipment is not adequate. Relevant to women's health, the hospital also equips 3,646 women's health surgeries and 7,242 mammograms yearly (data from 2019) (IWK Health n.d.). This is not considering the 206,791 outpatient clinic visits and 14,606 acute inpatient admissions yearly that are split between maternal and pediatric care. Based on these statistics, 4,498 women gave birth in 2019 at the facility, meaning approximately 1,339 (30.5%) women living with obesity (defined by BMI) delivered at the hospital that year and had the potential to require bariatric equipment (IWK Health n.d.; Government of Canada 2017; McPhee 2020). This comparison agrees with survey research in Canada conducted 10-20 years ago (Kirk et al. 2010; Singh et al. 2007). In Atlantic Canada, previous research found three quarters of respondents reported equipment with higher weight capacities (e.g., delivery beds, operating room tables, hospital beds) were needed but not available in birthing care delivery (Kirk et al. 2010). Additionally, a Rapid Response Service review by the Canadian Agency for Drugs and Technologies in Health (CADTH) found the lack of clinical trials and randomized designs in the literature on this topic suggests further research is needed on the demand/needs, utility, and cost of appropriate equipment and technology to provide equitable healthcare for higher-weight patients (CADTH 2012).

In a Canadian emergency department, questionnaire scores collected in 2005 found an inverse relationship between nurse equipment adequacy scores and patient BMI (Singh et al. 2007). In 2021, a survey of clinical nurse managers of acute hospitals in Ireland (*N* = 132) found two of three principle barriers for the provision of care for bariatric patients were lack of equipment (75.0%) and lack of training (57.6%) (Dockrell and Hurley 2021). Availability, utility, and training for bariatric equipment are essential for enhanced patient care, safety, and health care worker injury prevention (Muir and Gerlach 2003). Inclusion of proper training and team lifting programs has been shown to reduce patient handling-related employee injuries by 38.5% (13 to 8) (Walden et al. 2013). This is important not only for safety of the patient but also for safety of the healthcare providers, as musculoskeletal injuries are common especially when providing care to higher-weight patients (Choi and Brings 2015; Muir and Gerlach 2003). Beyond education related to caring for patients in larger bodies, staff should be aware of weight capacities for standard equipment (e.g., commodes, beds, scales, chairs) available to them and be familiar with operating procedures (Alberta Health Services 2016; Broome et al. 2015; McGinley and Bunke 2008). Having an easily accessible and known protocol or standard operating procedure (SOP) for patients of larger body sizes can aid staff in not only being familiar with the equipment to use but also knowing how many people are needed to safely move a patient of a given weight (McGinley and Bunke 2008). Alongside this, unit-specific education related to caring for and procedures specific to patients living in larger bodies and/or living with obesity is essential for patient dignity and evidence-informed practice. Areas for improvement have been noted in the literature, such as epidural administration and fetal monitoring for bodies with higher amounts of adipose tissue (Basinger and Quinlan 2024). Education efforts should also include inclusive language and respect driven person-first communication strategies to minimize weight stigma and promote equitable and affirming healthcare operations (Basinger and Quinlan 2024). Conceptual models like SWIPE (Stigma of Weight in the Preconception, Pregnancy, and Postpartum Experience) and the WOMBS (Weight gain, Obesity, Maternal-child Biobehavioral pathways, and Stigma) framework have been developed specifically with an aim to inform interventions for women during pre-, post-, and peri-natal periods to reduce weight stigma (Hailu et al. 2024b; Incollingo Rodriguez and Nagpal 2021).

Inventory-based research was a growing topic of interest during the COVID-19 pandemic and put a spotlight on the need for adequate amounts of protective equipment for all staff (Cohen and Rodgers 2020; Merchant et al. 2022; TruMed 2022). For patients, lack of bariatric equipment in hospitals has been a historical problem due to many factors, such as cost, education, and space. Policy and procedure-based action are required to provide respectful, evidence-based care which includes use and availability of adequate and appropriately sized-equipment for all body sizes (Alberta Health Services 2016; Pearce n.d.). While audit and inventory-based research is often seen as less valuable than more empirical forms of research, such as clinical trials, clinical trials did not help prevent inaccessibility of equipment (e.g., personal protective equipment) during the COVID-19 pandemic; audits and inventories are an important starting point for effective clinical practice guideline implementation (Feig et al. 2018; Maxwell et al. 2019a; 2019b; Merchant et al. 2022; Rasmussen and Yaktine 2019; Snelgrove-Clarke et al. 2020; Wharton et al. 2018; 2020). Research led by allied health care providers and clinicians is invaluable and necessary to integrate "on the floor" experience into facility-specific program planning, research, and practice, all of which inform one another (Cordrey et al. 2022; Wenke et al. 2017). Furthermore, inventory audits are not always peer-reviewed or publicly available, both of which bring a level of rigor, accountability, and advocacy for future quality improvement and patient and provider safety efforts.

Traditionally, women have been excluded from health research and women's health research has been underfunded (Smith 2023; Yakerson 2019). Echoing calls for health equity, inclusion of women, and sex-specific outcomes in research (Gahagan and Grant 2023; Yakerson 2019), future research should explore the experiences of women living in larger bodies navigating pre-, peri-, and post-natal care and sex-specific healthcare (e.g., breast exams, vaginal and uterine health) and the stigma they continue to face. For example, a study from 1990 showed that women with higher BMIs reported trouble accessing birth control from their gynecologists, citing their providers "had difficulty believing the women were sexual" (Packer 1990, 162, quoted in Merrill and Grassley 2008). More recent examples include Basinger et al.'s 2023 survey study, which explored structural barriers for women living in larger bodies navigating pre-, peri-, and post-natal care. In that survey, women recalled their bodies being blamed in their experiences rather than the inadequately equipped medical facilities. For instance, women described experiences where they had birthing balls taken away, were told by nursing staff that the balls would not support their weight, reported that "even though the room had a tub, I was not a 'good candidate' for it," and were given smaller gowns than appropriate for their bodies when waiting for a mammogram (Basinger et al. 2023, 3073; Robinson et al. 2024). Appropriate equipment is essential for the physical safety of patients and providers and the emotional safety of patients; the toll of systemic weight stigma needs to be considered more widely for patients. For instance, research has documented experiences of women with higher BMIs being denied care (Basinger and Quinlan 2024; LaMarre et al. 2020), such as fertility treatment or their desired mode of birth, receiving negative weight-focused and presumptive comments (e.g., incapable of feeling pressure changes in labour and birthing due to their weight), and being recipients of judgmental stereotypes (e.g., "fat mothers are bad mothers") (Basinger et al. 2023; Nutter et al. 2025a). Notably, weight discrimination does not have concrete legal protections in Canada (Nutter et al. 2025b). In Nova Scotia, the media has covered poor patient experiences such as being denied breast cancer surgery due to BMI stipulations per facility, and in this case, the Nova Scotian woman eventually did receive care due to her self-advocacy efforts (Macdonald 2025). Research shows this self-advocacy is often essential for women living in larger bodies to receive adequate healthcare (Buxton and Snethen, 2013; LaMarre et al. 2020; Nutter et al. 2025a). This hospital equipment inventory audit is one example of advocacy and mobilization efforts by clinicians, also essential to addressing systemic weight stigma (Tran et al. 2025). Future research initiatives by the co-authors of this paper and CoP include a chart audit and interviews with healthcare providers at the study's facility to further examine implementation of the SOGC's CPGs to support women living with obesity (defined by BMI) during pre-, peri-, and post-natal care.

Conclusion

There are calls within and beyond women's healthcare to eliminate weight bias, stigma, and discrimination (Rubino et al. 2020). Appropriately fitting equipment is essential to provide safe, just, and evidence-based care to all body sizes. Lack of equipment with higher weight capacities is a barrier to supporting care for larger bodies and the solution requires system-level problem solving, considering not only funding but also space and healthcare provider education and training. Hospital equipment inventory audits are not commonly publicly available data or research, despite the importance of adequate equipment for health equity for all. Calls for awareness of the importance of EDIA (Equity, Diversity, Inclusion and Accessibility) in teaching, care provision, and research by the public are increasing, and it is our responsibility to address inequities and "-isms" in healthcare settings (e.g. #Metoo, #BlackLivesMatter, #MMIW, #HealthAtEverySize) (American Medical Association n.d.; Balch 2020; Khubchandani, Kumar, and Bowman 2019; Penney and Kirk 2015; Tribal Health 2022). Healthcare and wellness institutions, healthcare provider training programs (e.g., teaching hospitals), and others, are actively trying to engage in anti-racist, anti-ableist actions, such as revising policies, protocols, and procedures that promote such -isms. High-quality evidence that supports person-focused care is the best care, and it cannot be performed without correct fitting equipment or inclusive healthcare spaces for all bodies (Maxwell et al. 2019a, 2019b; Wharton et al. 2020).

Endnotes

1. Rachel Waugh and Maxine Bernard are first authors of this paper.

2. While fat studies scholars advocate for the use and reclamation of the word "fat" to describe body size, the authors instead use terms like "larger bodies," "higher-weight," and "obesity defined by BMI" in an aim to reach diverse audiences (e.g., search terms and review methods), minimize perpetuating weight stigma, and in alignment with literature summarizing patient perspectives on weight-related terminology (Puhl 2020).

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Literary

Epilogue: I found my voice

by Barbara Hamilton-Hinch

I found my voice
Not that I lost it but…
It was silenced because of the truth I
Speak
It was silenced because of the beliefs I
Share
It was silenced because they could silence other
Voices

However, what they did not remember
Is when one strong African voice
Is silenced, another will rise and still
Another will rise

Those voices rise in Word Iz Bond,
Those voices rise in the writings of George Elliott Clark
Those voices rise in the films of Sylvia Hamilton
Those voices rise in the stories of our ancestors
Told over and over again

So what right do I have to allow
My voice to be silenced
What right do I have to give up the struggle of my ancestors?
What right do I have to use the excuse of
A mortgage, a family, an education

I cannot allow my voice to be silenced
When students continue to struggle for equality
When students have to prove they can not only speak and write the
Queens English but can speak languages others cannot even pronounce

When students prove they can be single moms, work fulltime, return to school and get a PhD
When students are able to travel thousands of miles
Leave family, children
Familiarity for an education for a better life

I have no business to allow others to silence my voice
I have found my voice and I will continue to use my voice to help others
I will continue to use my voice to speak for those who can't
I will continue to use my voice because I know it can
It will make a difference

Barbara Hamilton-Hinch is an eight generation African Nova Scotia woman, who is a mother of three amazing adult children. She is currently employed at Dalhousie University as a Professor in the School of Health and Human Performance and the Assistant Vice Provost of Equity and Inclusion. For most of Barb's academic career she has worked to advance research and opportunities for individuals who have been marginalized, particularly people of African descent. This poem reflects Barb's commitment to continuing to make a change and using her voice to advocate for others.