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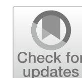
COMMENTARY



Transdisciplinary Imagination: Addressing Equity and Mistreatment in Perinatal Care

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Abstract
Inequities in birth outcomes are linked to experiential and environmental exposures. There have been expanding and intersecting wicked problems of inequity, racism, and quality gaps in childbearing care during the pandemic. We describe how an intentional transdisciplinary process led to development of a novel knowledge exchange vehicle that can improve health equity in perinatal services. We introduce the Quality Perinatal Services Hub, an open access digital platform to disseminate evidence based guidance, enhance health systems accountability, and provide a two-way flow of information between communities and health systems on rights-based perinatal services. The QPS-Hub responds to both community and decision-makers' needs for information on respectful maternity care. The QPS-Hub is well poised to facilitate collaboration between policy makers, healthcare providers and patients, with particular focus on the needs of childbearing families in underserved and historically excluded communities.

Keywords Reproductive justice · Transdisciplinarity · Health services · Mistreatment · Racism · Pregnancy and childbirth

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Introduction

Pregnancy and childbirth are the most common reasons for accessing health care services, and those services are vital to achieve optimal outcomes. However, significant disparities persist in outcomes and experiences of care among historically marginalized groups (Godley, 2018; National Academy of Sciences, 2020; Everett et al., 2019; National LGBT Health Education Center, 2016; National Academy of Sciences, 2020; Dunkel Schetter & Tanner, 2012; Earls et al., 2019). Disparities in health outcomes are associated with discrimination, lack of responsiveness, and dehumanizing behaviour by health care providers. (Altman et al., 2019; Crear-Perry et al., 2020; Hoffman et al., 2016; Turpel-Lafond, 2020). Over 84% of Indigenous people in Canada report discrimination when accessing health care, including delays in receiving care that led to death and morbidity (Turpel-Lafond, 2020). Research has demonstrated that Black, Indigenous, and people of color are less likely to receive the health services they need, and they are 2–3 times more likely to report mistreatment during pregnancy and birth (Vedam et al., 2019). These negative experiences are more common among people with intersecting identities and circumstances such as housing instability, poverty, substance use, or incarceration (Vedam et al., 2019).

Fear of disrespect, abuse, and loss of autonomy are linked to mistrust in the health care system and cited as drivers for planned unattended births, and reduced uptake of care (Reed et al., 2017; Sokol-Hessner et al., 2019). Indeed, mistreatment during pregnancy constitutes a violation of basic health human rights, and is recognized as an adverse outcome that is distinct from any associated physical or mental health consequences (Allan & Smylie, 2015; Miller et al., 2016; Reed et al., 2017; United Nations General Assembly, 2019). Yet, to date global health systems have limited tools to assess the extent of these problems; a lack of consensus on how to address them, and few mechanisms to ensure transparency, accountability, or recourse when harms occur. In this paper, we describe how an intentional transdisciplinary process led to development of a novel knowledge exchange vehicle that is urgently needed to improve health equity and enhance system accountability in perinatal services.

Perinatal Health Inequities and Misinformation

Ample evidence exists that during the COVID-19 pandemic, delivery of high-quality maternity services has been severely disrupted (Abdelbadee & Abbas, 2020; Asefa et al., 2021; Jardine et al., 2020; Rochelson et al., 2020). The potential for inequitable exacerbation of poor perinatal and maternal outcomes and human rights violations, due to pandemic conditions is immense (Stein et al., 2020). Across the globe, women and community health workers have reported increased mistreatment by care providers, denial of admission to facilities, separation from their babies, unwanted interventions, and lack of access to antenatal and postpartum care (Asefa et al., 2021; Reingold et al., 2020). Labouring women have been refused admission when presenting with symptoms of heavy breathing, and have died because of delays travelling to facilities due to fears of police brutality during overnight curfews (Shikha, 2020; KTN News, 2020). These disruptions overlay the existing burdens of high rates of maternal and perinatal mortality that low- and middle-resources countries report in the context of low health system capacity.

Similar health systems injustices have been reported in under-resourced communities in the United States (Warren et al., 2020). Asymptomatic pregnant Indigenous women in New Mexico were tested for COVID-19 based solely on their race and ZIP code and were separated from their babies while awaiting test results (Furlow, 2020). New York Public Hospitals serving primarily Black and immigrant populations denied access to doulas and partners. Increased rates of prophylactic intervention and reduced frequency of prenatal and postpartum care visits may increase adverse perinatal outcomes in Black, Indigenous and other marginalized populations. Frontline maternity healthcare providers, the majority of whom themselves are female, are also experiencing increased burdens because of the dual roles as paid

and unpaid caregivers. Gendered workforce inequities such as differences in career pathways and pay rates, decision making power, and access to education perpetuate systemic inefficiencies, limiting utilization and retention of female health care workers (United Nations Population Fund, 2021). Since the onset of COVID-19, medical teams and health care workers in low resource settings, many of them racialized and disadvantaged themselves, experienced inequities in access to critical equipment, and the trauma of observing increased gender-based violence and higher rates of morbidity and mortality due to lack of infrastructure (Corbett et al., 2020; Semaan et al., 2020).

Societal responses at the intersections of maternity care and COVID-19 offers both critical human rights lessons and valuable alternatives for service delivery. However, frontline health workers, and service users in low-resource and disenfranchised communities, report inability to access reliable information, guidelines, and training to implement these safer strategies (Asefa et al., 2021). Many are forced to rely on the information and misinformation shared via social and other media. They describe a need for guidance and data that is evidence-based to mitigate the 'infodemic' that occurs at times of crisis. In addition, several community-based NGOs are tracking and reporting on human rights failures with the hope that policy makers will correct-course, and guard against complacency and inaction. In anticipation of continued COVID-19 transmission and other humanitarian crises, we need pragmatic tools that expand the capacity of front-line health workers to provide high quality, rights-based care, and ability of health care systems to address the structural vulnerability that disproportionately impacts childbearing families.

Transdisciplinary Collaboration to Strengthen Health Systems

Transdisciplinary research, education, or engagement, involve stakeholders that are both inside and outside the "academy" in an ongoing process of discovery towards unanticipated strategies address complex social and structural issues, often termed "wicked problems" (Rittel &

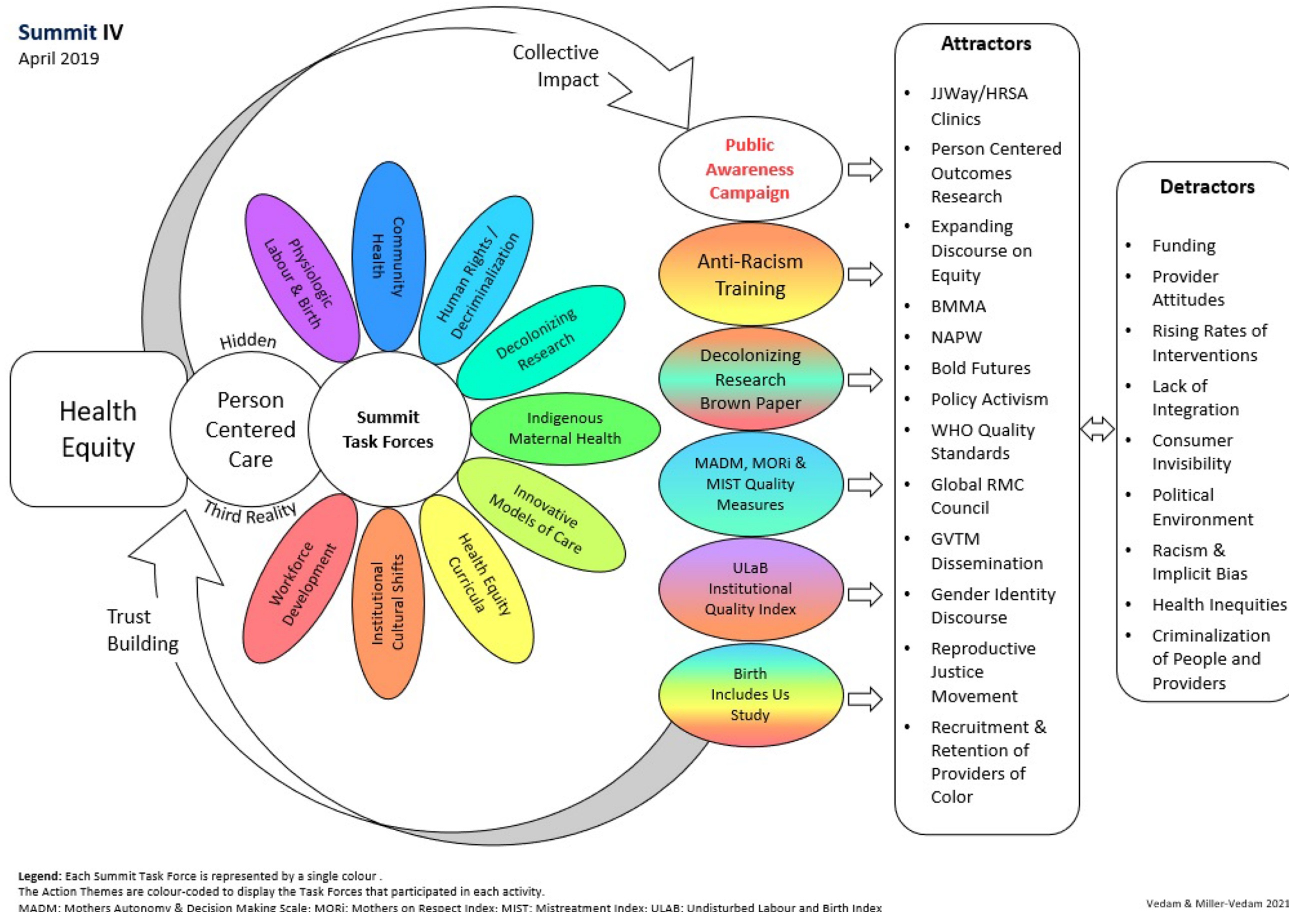

Fig. 1 US Birth Summit IV: transdisciplinary community-led impacts on health equity

Webber, 1973). The concept of transdisciplinarity is often credited to Piaget, who described it as a "higher stage succeeding interdisciplinary relationships... which would not only cover interactions or reciprocities between specialised research projects, but would place these relationships within a total system without any firm boundaries between disciplines" (Piaget, 1972, p. 138). Transdisciplinary initiatives drive pragmatic solutions based on new ways of thinking that are generated through engagement across disciplines, and especially with non-traditional partners (Szostak, 2015). Nicolescu names this new knowledge the "Hidden Third" reality, explaining that when exploring complex systems, with inherently interdependent factors, it is only possible to discover a new reality by centralizing the expertise of the Subject and Community (Nicolescu, 2014). For example, in the recent US Birth Summits, a multi-stakeholder process to address access to high quality birth care across settings, delegates discovered that the realities and priorities of providers, hospital systems, communities, women, and families intersect and overlap even when they are divergent. By centering the needs and priorities of service users, delegates uncovered their common ground within existing actions and initiatives that Black, Indigenous, and other people of color have led to enhance health equity (see Fig. 1).

A coordinated transdisciplinary approach to wicked problems in maternity care is rare. In 2019, Dr. Michael Lu predicted that the future of maternal child health would depend on our willingness to "work outside of our comfort zone, building collaborations across multiple sectors including education, housing, social services, economic and community development to address social determinants" (Lu, 2019). However, he notes that this future requires an intentional transdisciplinary process. Kania and Kramer (2011) described unprecedented success when community leaders "abandoned their individual agendas" to seek a shared approach. They termed this phenomenon "collective impact"—to describe the "commitment of a group of important actors from different sectors to a common agenda for solving a specific social problem" (p. 36). They established five conditions for successful transdisciplinary collaboration: a common agenda, shared measurement, coordinated and mutually reinforcing strategies, continuous communication, and a backbone organization.

In April 2020, in response to the pandemic, the Birth Place Lab (BPL) at the University of British Columbia convened a Global Task Force on Quality Perinatal Care during Covid 19. This coalition of researchers, community leaders, clinicians, policy makers, legal scholars, and health systems leaders were actively engaged in assessing and advancing high quality, perinatal services in their own jurisdictions. The task force comprised over 200 experts from 28 countries across midwifery, nursing, obstetrics, pediatrics, human rights, infectious diseases, pandemic and disaster planning, community health, health systems administration and policy. In the process of sharing their experiences of loss of quality, safety, and rights in perinatal services, task force members recognized that the main drivers of dysfunction were poor knowledge exchange and misinformation. They identified a common ground agenda: to collate and disseminate evidence-based policies and clinical guidelines that support the preservation of quality and rights-based care even during humanitarian crisis. To capitalize on the benefits of transdisciplinarity, applying their diverse expertise and skills, they self-organized into subcommittees along the WHO Strengthening Health Systems framework: Strategic Policy and Acceptability, Communications, Operations and Logistics, Clinical Workforce and Recruitment, Training and Support, Community Health Linkages, Legal Advocacy and Human Rights, and Research & Evaluation. Each group met weekly to generate principles, ideas, and best practice exemplars for a central repository. By remaining focussed on the needs of the end-users for knowledge exchange and accountability for equity, safety and respect, they elevated the process from multidisciplinary to transdisciplinary, co-creating curation metrics, thus reducing debate about inclusion and exclusion of resources.

To facilitate rapid response along the community-to-hospital-to-community continuum, our Global Perinatal Task Force collectively curated a repository of over 400 evidence-based resources on preservation of high quality, rights-based perinatal services from governments, professional associations, civil society organizations and academic centers. Each subcommittee reviewed and tagged the documents by relevance to specific stakeholder groups (e.g., frontline health workers, policy makers, system leaders); to various resource settings (low, medium, high); population setting (remote, rural, semi-rural, urban); and acuity (pre-crisis, crisis, post-crisis). The Indigenous-led research firm, Firelight Research Inc. moved this repository onto the Quality Perinatal Services Hub (QPS Hub), an online platform that is accessible, searchable, and adaptable to a range of connectivity contexts across multiple countries. Remarkably, all of this work was accomplished by global leaders donating their time and resources over an intensive two month period at the onset of the pandemic. Since then members have continued to meet to develop funding sources, update resources, and provide oversight to trainees and staff as we transitioned from a prototype version to a Hub platform ready for implementation.

Access to Public Health Information and Community Trust

Consistent, ready access to evidence-based information can build and enhance trust in the health care system when trust is most critical to community health and social cohesion.

Our participatory, multi-stakeholder development process considers local, national, and global perspectives that are central to ensuring equitable access to public knowledge. In the US, NGOs and community health workers that serve Black, Indigenous, and other racialized communities are logically positioned, not only as premier end users of emerging medical information and health services innovation, but as trusted sources of culturally safe health information. The Hub functionality ensures a bidirectional flow of information: community health workers will be able to both access and contribute resources and provide feedback on the utility and content of the Hub. To align with our equity approach, acknowledging a range of connectivity challenges in marginalized communities, there are multiple modes of access to the content and tools contained in the QPS Hub.

Applying a Human Rights Approach to Health Care Services and Information

The WHO affirms that freedom from discrimination, harm and mistreatment are not only health human rights, but they are also independent and important health outcomes that should be measurable (Halonen et al., 2017). Despite these realities, to date, minimal health care metrics capture the complex lived experiences of mistreatment during the core and formative life experiences of pregnancy and birth. Relevant indicators of institutional racism, intergenerational trauma trigger events, implicit bias, and disrespect, could link these experiences to factors such as birth environment, care provider, or models of care that support or reduce resilience, well-being, and confidence.

Human rights are invoked through both legal frameworks – international, regional, and local; and specific accountability measures such as Courts and Tribunals. On the ground, though, human rights are protected through awareness of human rights concepts, often raised by NGOs and community groups. In practice, protecting human rights requires awareness and commitment from people at every place in society, alongside the expansion of restorative or transitional justice processes. Communities may prefer reconciliation measures, prosecutions, reparations, systems and policy change, or community-led tribunals. National/local adoption, ratification, and codification of human rights into legal and justice systems varies widely, affecting enforcement and uptake of accountability mechanisms.

In addition to best practice clinical guidance, the Hub builds public awareness about the human rights dimensions of perinatal care, essential to the realization of such rights. The QPS Hub works in concert with the Office of the High Commissioner's recent efforts to engage health care providers in human rights reflection and conversation (OHCHR, Harvard FXB Center for Health and Human Rights, UNFPA, 2016). Human rights frameworks, accountability measures, and status of ratification are included in the QPS Hub to specifically address the needs of childbearing families for equitable, rights-based approaches to care during and after pregnancy and birth (United Nations General Assembly, 2019). The QPS Hub can collect data about mistreatment and violence against women, providing users with the information to advocate at the state and tribunal levels.

Community-Led Evaluation

Even when families experience the most egregious violations, there is often no avenue for feedback that could provide some accountability within health systems. With the input and guidance of taskforce members and end users from each implementation site, we have refined the user interface and feedback loop functions of the Hub to support continuous real-time evaluation. Digitization on the mobile platform of accountability measures of respectful care (Bohren et al, 2019; Vedam et al, 2017; Vedam et al, 2017) enable community monitoring through a rights-based feedback loop. End users (eg. community health care workers and families) will be able to use embedded video and voice apps to submit feedback, and to share innovative rapid response strategies they have implemented to modulate health services while maintaining culturally safe, person-centred care. The Hub collects basic information from end users, including roles/affiliations. In addition to tracking uptake, user-friendliness and navigability, we can collect and analyze data from the QPS Hub on need, knowledge, attitude, constraints, motivations, and avenues for acquiring perinatal health information and adoption and/or adaptation in real life settings and time.

Over the first year of implementation, the Hub will contain a post-then-pre self-report evaluation tool for end-users, to determine whether use of the Hub has increased their knowledge and skills. We will analyze gender-disaggregated data, gender and culture-responsive dimensions in health outcomes, RMC, human rights violations, response plans, policy and practice across jurisdictions before and after implementation. We will summarize who accessed the Hub monthly and evaluate the impact of the Hub through an online survey of stakeholders every 6 months. Feedback will inform the design and ongoing development and content of the digital platform to better respond to local needs.

In addition, our consortium has identified 8 global sites for in-depth data collection, via small community gatherings with health care workers, childbearing people and other key stakeholders. Grounded in health system responsiveness frameworks, focus group prompts will explore how the resources improved care and what additional resources might be needed. Participants will report whether quality of care improved after accessing reliable information on

the Hub and whether the information was relevant to their role and cultural context. By developing and evaluating the effects of access to the QPS Hub and uptake of the resources, we will identify gaps in equity and the lived experience of childbearing during and after the current pandemic and build infrastructure for the long-term realization of human rights goals.

Lessons Learned—The Potential for Transdisciplinary Imagination

Despite international, state and local guidance that essential health care services be maintained during COVID-19, and that human rights not be eschewed, we continue to see mistreatment and human rights violations globally (Asefa et al., 2021; Sadler et al., 2020). While large and fragile health systems have been unable to maintain or adapt capacity to ensure access to and availability of quality maternity care during COVID-19 (Semaan et al, 2020), Global Task Force members described 'real life' examples of how communities have adapted and developed rapid response protocols implementing culturally safe, pragmatic, and innovative models and tools for service delivery. This shift towards high quality community-centred maternity care, utilizing holistic solutions such as mutual aid, is possible, but requires collective awareness and action, borne out of a shared accountability, to drive widespread cost-effective, and timely, policy and practice reform.

The situation in the US mirrors the pressing problems in pregnancy and birth care that global experts have identified in low resource countries. Two recent Lancet series on maternal health and on midwifery highlighted the urgent need to expand access to models that prioritize person-centered care and greater collaboration across the health professions (Koblinsky et al., 2016; ten Hoope-Bender et al., 2014). Similar priorities were identified by the WHO in their recent Standards for Improving Quality of Maternal and Newborn Care in Health Facilities (World Health Organization, 2016). The Sustainable Development Goals (SDG Targets 5.5 And 16.7) (United Nations, 2017) clearly endorse person-centred approaches to research, practice, and policy development. The QPS Hub contributes to these priorities by "establishing and strengthening transparent participation and social dialogue… at the community, subnational and national levels" (Koblinsky et al., 2016).

Inequities in birth outcomes are finally accepted as the result of stratified experiential and environmental exposures that affect development and cumulative allostatic load over the life course. To address the expanding and intersecting wicked problems of inequity, racism, and quality gaps in childbearing care, we will need systems integration across multiple sectors—where community, education, and economic conditions are attended to throughout the life course, including and especially when families are forming. This integration will require the transition of the existing legislative, disciplinary, and service provision silos to an integrated system of distributed services, co-generation of knowledge across sectors, and a commitment to community-responsive models of care (Lu, 2019). It may be possible to eliminate disparities that determine patterns of mortality, morbidity, and suffering during times of intense disruption to already weakened health systems, if we embrace an ongoing transdisciplinary approach that keeps the person at the center of every conversation, and is not afraid to embrace the insights of a Hidden Third reality.

Transformation of Health Systems Through Knowledge Management

The development of the Quality Perinatal Services Hub has been an exciting transdisciplinary initiative that engaged multisectoral stakeholders on a global scale. The QPS-Hub is an innovative e-health platform that responds to decision-makers' needs for high quality information on respectful maternity care. As a result of an intentional process for multi-stakeholder co-creation, the QPS-Hub is well poised to facilitate collaboration between policy makers, healthcare providers and patients, with particular focus on the needs of childbearing families in underserved and historically excluded communities. Even as a prototype, the QPS-Hub is currently being used and accessed at multiple levels. For example, the Office of the United Nations High Commissioner on Human Rights (OHCHR) is using the QPS-Hub to disseminate a series of Reflection Guides on Respectful Maternity Care (RMC) that they produced to heighten awareness and personal accountability among diverse stakeholders in maternal newborn care.

The Global Perinatal Task Force demonstrated the potential of a transdisciplinary partnership to catalyze innovative ways of thinking and collaborate on quality improvement. We are currently working with provincial, national, and international partners in the US, Canada, Africa, and India to further disseminate, implement and evaluate the Quality Perinatal Services Hub (QPS Hub). Our collective, long term goal is to use this interactive e-platform to expand perinatal health care services that prioritize cultural safety and unconditional regard for all service users, support patient autonomy, and uphold freedom from mistreatment, prejudice and discrimination, as a human right. The QPS Hub has the potential to become the default site for health educators, trainees, health workers, service users, and health systems leaders, and policymakers to access trustworthy guidance,

and exchange best practices for high quality perinatal services.

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