



Health Perspectives

Undergraduate Health Studies Journal
Volume XIII | March 2021
University of Toronto

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Director's Foreword

Welcome to the 2020-21 edition of the Undergraduate Health Studies Journal. This year's effort was put together by the dedicated work of a number of Health Studies students during the darkest days of the SARS-CoV-2 global pandemic. Indeed, we come upon the one year anniversary of when the different responses -- by countries, states, provinces, cities, communities and individuals -- to the spread and consequences of this coronavirus were instigated globally. Curiously arriving almost exactly 100 years after a previous global pandemic, which had arguably a far greater impact on the health of global communities, the 1918-19 H1N1 flu pandemic had many of the outlines and responses that are now familiar to new generations of people.

It was during this current pandemic that our colleagues in the Health Studies Program persevered in putting together another excellent issue of the Undergraduate Health Studies Journal. To the credit of the various authors of this edition, the topics here remind us that, despite the grim consequences of the current pandemic, particularly on older members of global populations as well as on other marginalized communities, there remain myriad issues affecting the health and well-being that persist. These articles suggest that our desire to "return to normal" need to be tempered by the reality that the structures and processes in our societies that produce the differential outcomes on the health and wellbeing of local and global communities, existed before the appearance of SARS-CoV-2, and remain well entrenched.

A final word of gratitude for the outstanding work of the Co-Editors-in-Chief, Sophia and Nammal for driving this project forward under uniquely-difficult circumstances. Also to the Senior Editors, Madeline and Brenna for their work and mentorship of the Junior Editors, Ava and Xeome. Of course this work could not be done without the skills of the reviewers Sylvie, Joyce, Anna, Johanna, Meaghan and Deirdre, and the brilliant layout skills of Jayden.



PAUL A. HAMEL

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A Note from the Editors

We are thrilled to bring you the latest edition of the Undergraduate Health Studies Journal, *Health Perspectives: Volume XIII*. Founded in 2009, *Health Perspectives* has provided opportunities for countless University of Toronto undergraduates to publish original work and for Health Studies students to gain first-hand experience in editing and publishing as members of the Editorial Staff. The Health Studies program's commitment to understanding and analyzing health through a multidisciplinary lens is reflected in *Health Perspectives'* annual publications.

This year has undoubtedly been a challenge for many, and students are no exception. With the ongoing pandemic, students have had to adapt to many changes, not excluding the shift to online learning during times of physical and social isolation. However, despite these difficulties, students have sought to push the limits to our current knowledge systems and build upon our current understandings of health policy. The work of eight student authors published in *Health Perspectives: Volume XIII* exemplifies students' commitment to tackle the multifaceted health issues that persist today in Canadian and international societies. Though the content of each article is different, the authors take a critical approach to engage with and challenge the biomedical definition of health—namely the presence and absence of disease—and demonstrate how social, cultural, economic and political factors interact to shape health and well-being. To our authors and those who submitted their work for consideration: thank you for sharing your writing with us and contributing to a dialogue that fosters a holistic sense of health and well-being. Without you all, this volume would not have been possible.

We are so grateful for the support of Dr. Paul Hamel, the Health Studies Director, and the Health Studies Students' Union. To our diligent and thorough editorial staff: thank you for dedicating your time and energy, especially during such a difficult time, to making Volume XIII our strongest publication to date! We would be unable to do this without you.

And finally, to our readers: we hope that *Health Perspectives: Volume XIII* presents you with another collection of fresh ideas and analyses of health in all its forms. We hope you take away a greater understanding of the various components which contribute to health and the inequities that exist. It is important that you not only understand this, but continuously ask questions and look further to understand why various health inequities exist and what we can do to address these factors at a systemic and structural level in order to enact change.

Yours in health,



SOPHIA DiNICOLO

Co-Editor-in-Chief | 2021



NAMMAL KHAN

Co-Editor-in-Chief | 2021

Youth Homelessness, not Houselessness: Transitioning Away from Economic Framing to a Health-Centred and Communal Approach in Ontario Policy

CHRISTIE KWOK

Currently, the Ontario government frames youth homelessness as an immediate issue of housing and economic concern for the youth, in need of reactive rather than preventative care. While this is a somewhat sufficient strategy, a different framing approach is needed to reduce homelessness amongst youth now, and, more importantly, in the future. The transition to a more long-term, human-centred approach, where health care and social alienation are at the heart of both the issue and the solution, will improve the policy's intent and effectiveness. Ultimately, youth homelessness is an epidemic that extends beyond the issues of financial and home security. Therefore, this analytic piece will provide context regarding youth homelessness in Ontario; explain the economic lens in which the issue is framed by Premier Ford; and demonstrate how a reframing of youth homelessness, centred around health care and community, will provoke more impactful and long-term changes for this marginalized population.

1) Youth Homelessness in Ontario: A Contextual Understanding

Youth homelessness is a critical issue in Ontario. Adolescents ages 16 to 25 are considered a population with one of the fastest growing proportional contributions to Canadian homelessness (Quirouette et al., 2016). Approximately 50,000 youth are recorded as homeless in Canada annually, and this number is likely higher due to unrecorded individuals (Gaetz & Redman, 2016). Of those homeless youth, over a third of the population reside in Ontario (Gaetz & Redman, 2016). Thus, the province has over 2,100 youth sleep in shelters or on the streets every night, amounting to 16,600 every year (Gaetz & Redman, 2016). This raises concern, as these youth are struggling to maintain their physical and mental health, safety, financial stability, and more. Homeless youth experience unique challenges compared to homeless adults, such as lack of education, abusive households, intergenerational homelessness and addiction, and stunted development (Kulik et al., 2011).

As a result of these challenges, homeless youth are one of the most health care-reliant groups, as they often require the services offered by health care systems more frequently than other groups (Kulik et al., 2011). It is the intersectionality of being a part of the homeless and adolescent communities that renders this population highly vulnerable and susceptible to homeless- and developmental-specific health issues. For example, compared to the average person, homeless

youth have an exponentially higher risk of experiencing and contracting HIV/AIDS, STDs/STIs, hepatitis, malnutrition, pregnancy, post-traumatic stress disorder, addiction, depression and other mental illnesses, damaged reproductive health, musculoskeletal disorders, and other chronic medical conditions which result from poor hygiene (Kulik et al., 2011).

The majority of these health issues are specific to homeless youth in that they are influenced by intergenerational trauma, whereby traumas, life experiences and predispositions, and disease-susceptibility are passed down from previous generations (Kulik et al., 2011). As a result, these youth experience constant food insecurity, housing insecurity, and a general lack of guidance and protection from a young age, which severely hinder the way in which they can develop mentally, emotionally, and physically (Kulik et al., 2011). For example, in response to these predisposed challenges, many homeless youth are forced to engage in sexual activities, in their early adolescent years, to trade for basic living necessities, such as food, water, clothing, shelter, and/or money (Kulik et al., 2011). This may also contribute to their increased risk of poor reproductive health (Kulik et al., 2011).

Despite their elevated need for provincial health care services, most homeless youth experience health care inequality: this marginalized population does not receive the same quality of and access to health care as others (Kulik et al., 2011). Health care inequality for homeless youth may be due to factors such as lacking proof of health insurance (i.e., not having an OHIP card); being unable to find “low-threshold health care services” (i.e., community health centres, drop-in clinics); being unable to afford medical fees for low-threshold health care; and having their illnesses viewed as not urgent and/or serious enough for medical care (Khandor et al., 2011). Individuals who experience homelessness are constantly trying to survive day by day, and as a result, they may neglect chronic symptoms of an underlying health issue if they only hinder life minimally (Khandor et al., 2011). In extrapolation, health care for this demographic has been described as inaccessible, inconsistent, discriminatory, and careless in that the system only serves for reactive and not preventative care (Kulik et al., 2011). The health care system currently in place fails to deliver the necessary services to homeless youth who are experiencing barriers in accessing health care.

Lastly, it is not only the youth who experience these consequences of homelessness. From an economic perspective, taxpayers are taxed more in total, and for longer, based on the heavier reliance on shelters, prisons, and emergency services (Quirouette et al., 2016). Therefore, due to the moral, social, and economic obligations Ontario has towards the population, youth homelessness is an issue policymakers must prioritize on their agenda.

As of 2019, the Ontario Government has allocated over \$1 billion towards Ontario’s Community Housing Renewal Strategy (McLaughlin, 2019). The strategy aims to alleviate long wait times for affordable and supportive housing, as unaffordable housing is forcing individuals, especially older adolescents, to seek refuge in homeless shelters and other places on the streets (McLaughlin, 2019). Furthermore, the Ontario government has invested \$148 million in homeless shelters and other means of long-term housing as of 2020, funding food banks,

shelters, and municipality needs (Morello, 2020). In addition to these funds, \$150 million more was distributed for COVID-19 relief, specifically to renovate shelters to better accommodate physical distancing measures (Morello, 2020).

Apart from prioritizing housing insecurity for the homeless, the Ontario government has made significant efforts to reduce hospital overcrowding, or “hallway health care” (Ferguson, 2019). Their plan includes investing in 15,000 new beds within the next 5 years (Ferguson, 2019). While this issue does not pertain to homeless individuals specifically, it is a factor which may address some health care inequalities for the youth. As mentioned previously, the homeless youth are one of the fastest-growing populations, and are more vulnerable to mental and physical illnesses than other groups (Kulik et al., 2011). However, health institutions such as hospitals and addiction centres are often overcrowded (Ferguson, 2019), making them largely inaccessible to vulnerable and marginalized groups. Furthermore, a portion of homeless youth are turned away at health care centres to make room for more ‘deserving’ patients due to internalized stigma and discrimination (Kulik et al., 2011). Therefore, Premier Ford’s efforts to eliminate hallway health care, although not directly intended to help the homeless, will somewhat benefit this population as well. However, while the reduction of overcrowding in healthcare institutions is advantageous for the homeless, it does not solve the problems of health care inequality and inaccessibility for this population.

Overall, the foundation of the Ontario government’s approach to homelessness is built upon relieving housing insecurity for homeless individuals (McLaughlin, 2019; Morello, 2020). Unfortunately, no distinct plan has been made to target the unique challenges that are specific to youth who experience homelessness. Furthermore, the provincial government has proposed little to no strategies to help reduce, end, and prevent homelessness in other dimensions apart from housing and shelter. Potential strategies for policy intervention would include targeting urgent health care inequalities, health care inaccessibility, and the community segregation against homeless individuals, specifically adolescents.

2) Youth Homelessness as Framed by Ontario

Youth homelessness is currently framed as an immediate issue of housing concern for the youth, in need of reactive as opposed to preventative or proactive care. (McLaughlin, 2019; Morello, 2020). Solutions are strategized to address the issue only after it has occurred. As previously mentioned, current strategies that address homelessness aim to alleviate housing concerns, with little to no support delegated towards other challenges homeless youth experience such as food insecurity, health care concerns, and lack of education, among others. The specific way in which homelessness is addressed by the Ontario government may be attributed to the collapse of the Canadian national housing strategy from the 1980s to 1990s (Gaetz, 2010).

The collapse of the national housing strategy occurred due to the federal government’s shift towards favouring home ownership in policy (Gaetz, 2010). The new agenda transferred federal housing funds to provincial jurisdiction, and forced provinces to reduce their own program funding for “housing and social spending” (Gaetz, 2010). The decentralization of the national housing program

also incentivized the federal government to transfer the responsibility of funding social housing to provincial governments (Gaetz, 2010). This final decision worsened homelessness in Canada. It left the country as one of the only developed nations without a national, strategic plan for housing, creating a disjointed and incomprehensive plan for homelessness (Gaetz, 2010).

As a result of these past shifts in policy, Premier Ford's strategy to alleviate homelessness in Ontario is likely to combat the effects of the dismantling of the national housing strategy by imposing the Community Housing Renewal Strategy. However, creating a solution solely based on the initial inducement of the issue will not suffice any longer. Arguably, as homelessness increased, the issue has become multi-faceted in ways that sole housing security and economic compensation cannot fix. The narrow scope of Premier Ford's solution cannot be enough to impactfully reduce homelessness long-term or be proactive enough to prevent at-risk youth from experiencing homelessness in the future.

A study conducted in Canadian urban settings examined the most common way in which the youth are able to successfully navigate out of homelessness (Kidd et al., 2013). The greatest contributors were found to be maintaining good mental health and community integration (Kidd et al., 2013). Participants of the study were more likely to be able to obtain stable housing and employment if they had fewer mental maladies and had access to a community to which they felt they belonged (Kidd et al., 2013). Framing youth homelessness as an issue of social stigma, rather than one of poverty, allowed the researchers to gain more insight into why community integration after experiencing homelessness is difficult for homeless adolescents (Kidd et al., 2013).

These findings suggest that the most commonly successful pathway out of youth homelessness is to ensure adequate health care, specifically mental health services, and create systems which offer the youth support as they transition (Kidd et al., 2013). Premier Ford's plan arguably lacks the measures to secure urgent and mental health care services for the youth, alongside social support services and proper advocacy to destigmatize homelessness and promote community integration. While prioritizing affordable and supportive housing will help a portion of homeless youth, it cannot protect youths who are too young, financially unstable, or otherwise unable to secure such homes. Therefore, the Ontario policy must be reformed to extend beyond housing, in order to help the youth help themselves. When one policy fails (i.e., secure housing), youth should be able to have alternate solutions and options to fall back on (i.e., adequate health care, active campaigns to destigmatize homelessness, etc). The current framing of youth homelessness creates an agenda that is reactive rather than preventive, narrow-scoped, and has a general disregard for the multi-faceted ways in which youth struggle to exit homelessness.

3) Reframing Youth Homelessness: Health and Community

Perhaps a more effective and impactful way to enact change for adolescents is to reframe youth homelessness as an issue of health care inequality and inaccessibility, and community exclusion, rather than one of home instability. This proposed shift in framing can be utilized to understand youth

homelessness through the narratives of those experiencing it, encouraging long-term preventative strategies, as opposed to immediate and short-term housing relief. The provincial government's affordable housing plan cannot accommodate all homeless individuals, and leaves little to no alternate options for youth who are unable to secure housing this way (McLaughlin, 2019; Morello, 2020). The current way of framing the issue desensitizes the urgency and damaging nature of homelessness for adolescents. youth who experience homelessness are seen as nothing more than a body to put in a house.

To make impactful change, both reactively and proactively, the Ontario government must consider more diverse solutions for this population. For example, framing youth homelessness as an issue of health care inequality, health care inaccessibility, and community exclusion allows for diverse, creative solutions in greater numbers. In response to the proposed framing, the province could delegate spending towards improving health care accessibility for homeless youth by increasing emergency and low-threshold health care services in communities where homelessness is most prominent (Kulik et al., 2011). Additionally, the proposed framing makes way for programs such as peer support practices, in which young people who have experienced homelessness become health ambassadors and/or health care workers to support and engage with current homeless youth (Kulik et al., 2011). These programs would help mitigate the health care inequality homeless youth experience in regular facilities, where health care providers cannot understand or relate to their struggles and experiences of being homeless (Kulik et al., 2011). Health care workers may also be required to attend province-mandated training to improve their understanding of youth homelessness and their specific health care needs, as well as strategies to work with disadvantaged populations (Kulik et al., 2011).

In extension, when homeless youth are viewed in this humanistic approach, they are less likely to be seen as the culprit of their situation, rather a victim of poor structural forces. Since a large majority of adolescents are homeless due to generational trauma, more community programs can be created to increase intervention and prevention for at-risk youth (Kulik et al., 2011). These programs could include counselling for dysfunctional or high-conflict families; parenting programs; and mental health services for families (Kulik et al., 2011). The implementation of these services could ultimately reduce the stigmatization of homeless youth in communities, providing easier and more frequent opportunities for community integration for youth who are trying to exit homelessness.

4) Reframed: The Likelihood of Success

The likelihood that the proposed new framing of youth homelessness will prevail in the policy stream and the general public is good. A 2017 study examined hope- and empathy-based appeals to diabetic and cancer treatment, contrasted against non-emotional health care approaches (Kemp et al., 2017). The findings suggest that hope and empathic health care appeals are more successful and persuasive than non-emotional tactics (Kemp et al., 2017). While treating an illness arguably requires less multidimensionality in problem-solving compared to addressing social issues, these results can be applied to how the Ontario

government frames and defines youth homelessness. Currently, Premier Ford is enforcing change through a non-emotional approach: securing housing will ensure a reduction in the number of homeless youth (McLaughlin, 2019; Morello, 2020). However, this approach fails to comprehensively consider the entirety of the marginalized population, their experiences, struggles, and the structural forces which contribute to youth homelessness, rendering the current strategy largely ineffective at addressing the issue. As such, the proposed humanistic, health- and community-centred framing has a better endurance in the policy stream than the single-stream solution that is currently being offered.

Notably, while the proposed health- and community-based approach may be better-suited to address the intersectionality and multidimensionality of youth homelessness, the government functions largely around economic incentives. Therefore, it is critical to depict the economical burden of allowing youth homelessness to continue without intervention. For example, in 2013, homelessness was found to cost the Canadian economy \$7 billion annually, and this number increases yearly (Gaetz et al., 2013). It is estimated that each homeless Canadian costs \$53,144 annually to support (Distasio, 2017). Similarly, it costs the province approximately \$900 million annually to support the 18,000 homeless youth in Ontario (Distasio, 2017; Gaetz & Redman, 2016). 40% of these funds are spent towards health care services, such as “substance-use treatment, emergency room visits and psychiatric services” (Distasio, 2017), as opposed to shelters. Therefore, Premier Ford’s current strategy of tackling youth homelessness by securing housing may not save the province as much money as if he were to reframe the issue as one of health care concern.

Lastly, it will cost less to help youth transition out of homelessness than continue funding expensive social services that act in response to aid the homeless (Quirouette et al., 2016). Reframing the issue allows for the aforementioned policy suggestions to be implemented. The suggested collaborative ways in which youth can gain better access to health care services (i.e., peer-led health ambassadors, health care workers’ mandated-training on homelessness, etc.), will reduce the dependency on emergency care, thus reducing health costs in the long-term (Kulik et al., 2011). In addition, the proposed intervention and prevention programs for at-risk youth and high-conflict families will decrease the need for substance abuse treatment and psychiatric services in the long run, thus reducing the cost of these services as well (Kulik et al., 2011).

Concluding Statements

Understanding youth homelessness as an urgent epidemic emphasizes the unique challenges and vulnerabilities to which this group is susceptible. The Ontario government’s policy plan for eradicating youth homelessness is strongly rooted in a single, economic solution: to secure affordable housing and undo the effects of the 1980 dismantling of the national housing strategy (Gaetz, 2010). However, by analyzing the deficiencies of the current framing and exploring other aspects of youth homelessness, a health-centered and empathic approach is decidedly the most effective approach to enact impactful and long-term change for youth homelessness. After all, finding a house for a young person does not

equate to securing a home for them, nor does it entail health, community, or good quality of life.

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Social Isolation in Ontario's Seniors: The Implications of Defining Social Isolation as An Objective Experience

SERENA THAPAR

Social belonging is critical for human beings to survive, to reproduce, and to maintain their well-being (Hawkey & Cacioppo, 2010). People experience feelings of loneliness when their social needs are not satisfied by their relationships' quantity or quality (Hawkey & Cacioppo, 2010). The Government of Canada commissioned a report in 2012 from The International Federation of Aging, which concluded that "the number one emerging issue facing seniors in Canada is keeping older people socially connected and active" (International Federation of Aging, 2012, p. 71). Indeed, 16% of Canadian seniors are socially isolated (National Seniors Council, 2017), and an additional 30% are at risk of becoming socially isolated (Keefe et al., 2006). Globally, the World Health Organization (WHO) has acknowledged the impact of social isolation on public health (WHO, 2015). Research has demonstrated that social isolation –both the objective quantity of one's social contacts and the perceived quality of one's social connections— is associated with increased morbidity and mortality (Cacioppo & Cacioppo, 2014; Freedman & Nicolle, 2020; Holt-Lunstad et al., 2010). Social isolation is also associated with increased healthcare service usage among older adults (Cohen et al., 2006; Freedman & Nicolle, 2020; Government of Canada, 2017; Landeiro et al., 2016).

In Ontario, seniors are the fastest-growing age group, with projections indicating that they will comprise 25% of the population by 2041 (Government of Ontario, 2017). Therefore, the growing number of socially isolated seniors is concerning for the healthcare system; the burden that socially isolated seniors put on the healthcare system may contribute to a public health crisis. Ontario's social isolation policies frame the lack of objective social contact as the reason for seniors' social isolation. Social isolation has a subjective component, and therefore, cannot be reduced solely by interventions focusing on increasing seniors' number of social contacts (Newall & Menec, 2019). This essay will argue that the current framing of social isolation does not address perceived social isolation. Therefore, re-defining social isolation as a subjective experience, rather than an objective experience, is necessary to reduce the overall burden of social isolation on older adults and the healthcare system. First, the essay will consider the central features of social isolation in Ontario's senior population; it will then unpack the argument by analyzing the implications of Ontario policymakers defining social isolation as an objective issue. Lastly, the essay will consider how re-defining social isolation as a subjective experience and re-framing the problem through a cost-savings perspective will induce change.

Central Features of Social Isolation in Older Adults

Distinguishing Between Objective and Subjective Social Isolation

When considering social isolation as a policy issue, it is essential to define the construct of social isolation. Objective social isolation is a construct that can be measured by the lack of social interaction that one has (Nguyen et al., 2020). In contrast, perceived social isolation is synonymous with loneliness; it refers to one's perception of their social relationships as lacking quality and quantity (Nguyen et al., 2020). Loneliness and objective social isolation exist on distinct continuums that intersect (Newall & Menec, 2019). Individuals may be experiencing both objective social isolation and loneliness, only one of the constructs, or neither. Depending on where one exists on these continuums, one may benefit from different interventions (Newall & Menec, 2019). That being said, policymakers often focus solely on alleviating objective social isolation, as reflected by policies that aim to increase social contact (Burholt & Scharf, 2014). For example, many initiatives encourage living in communal settings to reduce social isolation (Burholt & Scharf, 2014). Yet, 10% to 43% of older adults living in collective residences, such as long-term care homes and retirement facilities, feel socially isolated (Nicholson, 2012). The reduction of social isolation into an objective construct prevents loneliness from being addressed. Research has found that 50% of Canadian seniors over the age of 80 report feelings of loneliness (National Seniors Council, 2014).

Demographic Dimensions

Social isolation occurs most frequently during adolescence and older adulthood (Nummela et al., 2011). In 2017, 17% of the Canadian population was above 65-years of age (Canadian Institute for Health Information [CIHI], 2017). By 2041, the older adult population is expected to have doubled in size (CIHI, 2017). The growing elderly population emphasizes the need for policymakers to understand the aging population better. The majority (93%) of older adults in Ontario live in private households (Government of Ontario, 2017). Of those living in private residences, most (63%) live with a partner, 11% live with relatives, and 2% live with non-relatives (Government of Ontario, 2017). Approximately one-quarter of those living in private households live alone (Government of Ontario, 2017).

Many variables increase the risk of seniors becoming socially isolated (National Seniors Council, 2017). These variables include, but are not limited to: living alone, being over the age of 80, having medical comorbidity, lacking family connection, lacking access to reliable transportation, having low-income, and performing caregiving duties (National Seniors Council, 2017). Although there are general risk factors, social isolation has differential effects on various demographic groups within the senior population (National Seniors Council, 2017). Indeed, certain groups of seniors, including those who are Indigenous, who are part of the LGBTQ community, and who are immigrants or refugees, experience social isolation to a greater extent (National Seniors Council, 2017). Regardless of the number of older adults' social contacts, they may experience perceived social

isolation due to social exclusion (Victor et al., 2012). For example, Indigenous seniors often experience loneliness because historical oppression and colonialism have contributed to their social exclusion (Duran, 2006). Seniors who belong to the LGBTQ community may also experience social isolation due to discrimination (Government of Canada, 2018a). Despite their number of social contacts, 53% of these individuals feel lonely (Government of Canada, 2018a). Similarly, immigrant and refugee seniors may experience perceived social isolation due to family dependence, cultural barriers, and language differences (Government of Canada, 2018b). Their perceived social isolation is further complicated by discrimination and racism towards particular immigrant groups, such as Muslim immigrants (Salma & Salami, 2020).

Political-Economic Dimensions

In addition to the effects on individual seniors, social isolation is an enormous burden on society. Older individuals are more vulnerable to social isolation, which negatively affects their health status (Government of Canada, 2017). The adverse effects of social isolation, such as increased morbidity and mortality, can increase healthcare costs (Landeiro et al., 2016). For example, socially isolated seniors are more likely to experience rehospitalization and delayed discharge from the hospital (Freedman & Nicolle, 2020; Landeiro et al., 2016). Compared to their non-isolated counterparts, seniors who are socially isolated also make more frequent visits to doctors' offices and emergency departments, consume more medications, and enter long-term care homes earlier in life (Cohen et al., 2006). In some cases, isolated seniors will delay accessing healthcare services until there is a significant decline in health, rendering the care they require more extensive and costly than it initially might have been (Government of Canada, 2017).

Emergency departments are currently operating beyond their capacities because of the increased demand for emergency medical services (Agarwal et al., 2019). This increase has resulted in a cost-containment issue in the acute care sector, prompting financial deficits and overcrowding in many Ontario hospitals (Agarwal et al., 2019). These issues have become a central concern for the current provincial government (Agarwal et al., 2019; Ontario PC Party, 2018). Given the growing population of seniors in Ontario and the connection between social isolation and increased use of hospital services, ongoing policy discussions have primarily focused on addressing seniors' health (Agarwal et al., 2019; Syed et al., 2017). Indeed, Premier Doug Ford has recognized the cost of providing care to seniors (Ontario PC Party, 2018). Royal assent has been given to Bill 175: Connecting People to Home and Community Care Act 2020, which would restructure home and community care (Elliot, 2020). Bill 175 aims to centralize publicly funded home care through Ontario Health Teams, instead of the Local Health Integration Networks, so that providers can supply more care in the community (Elliot, 2020). The centralization of care is intended to reduce hospital overcrowding and expenditures (Ontario PC Party, 2018). Aging in place is a recurring idea previously proposed by the Liberal government in response to older adults' wishes to age in place (Government of Ontario, 2017). However,

aging in place may perpetuate social isolation because of the growing number of seniors living alone (Government of Canada, 2017).

Current Perception and Framing of Social Isolation in Older Adults

Social isolation in older adults has been on Ontario's policy agenda for several years. In 2013, the Ontario Liberal government developed the Aging With Confidence Action Plan (Government of Ontario, 2017). This plan was created in response to the rapidly aging population and the increased costs associated with caring for older adults (Government of Ontario, 2017). It identified three main focuses: increasing community engagement, increasing spending on homecare, and shifting away from aging in the hospital towards aging in the community (Government of Ontario, 2017). In 2017, the Liberal government updated the Aging With Confidence Action Plan, which reinforced the importance of allowing seniors to age in the community (Government of Ontario, 2017). Through this amendment, the government planned to support more community arts programs, technology classes, and naturally occurring retirement communities for seniors (Government of Ontario, 2017). One intention of the updated plan was to enable older adults to remain connected to their communities, thus reducing isolation (Government of Ontario, 2017).

The Aging With Confidence Action Plan frames social isolation using a narrative that individuals should increase their social contacts and support in the community in the hopes of lessening the burden on the acute care sector (Government of Ontario, 2017). The disregard for perceived social isolation is common in government policies under both the Liberal and Conservative administrations. In 2020, the Conservative provincial government increased funding through the Seniors Community Grant Program to reduce social isolation by making outdoor spaces accessible during the COVID-19 pandemic (Office of The Premier, 2020). These policies and programs suggest that increasing seniors' opportunities to engage with one another in the community would reduce social isolation.

In Ontario, policies currently define social isolation as the state where one experiences an objective lack of human contact (Government of Ontario, 2017). Existing policies and discourse focus on implementing community-based programming to increase seniors' social interactions while ignoring the quality of those interactions. For example, the 2017 Ontario Action Plan for Seniors contends that the government would support residential areas where many seniors live close to one another to promote social interaction (Government of Ontario, 2017). This plan defines social isolation as an issue that results solely from a lack of social interaction, preventing perceived social isolation from being addressed. The current framing of social isolation implies a one-size-fits-all solution, such that increasing social contact in the community can reduce isolation in all older adults. However, reducing social isolation to an objective construct diminishes seniors' perceptions of their social relationships (Newall & Menec, 2019). Current policies aimed at increasing seniors' number of contacts do not address loneliness. Such policies do not induce change because other factors may contribute to seniors' feelings of loneliness (Burholt & Scharf, 2014).

Policymakers must consider loneliness and social isolation concurrently since existing policies that solely focus on social isolation's objective nature do not help seniors whose social isolation results from their individualized perceptions and feelings of loneliness (Newall & Menec, 2019).

Re-framing of Social Isolation in Older Adults to Enable Change

Existing policies must be re-framed and re-defined to enable change and to reduce the challenges associated with social isolation in the older adult population. Social isolation in older adults must be re-defined as a subjective experience of distress (i.e., loneliness). This re-definition intends to strategically shift current policies' priorities from addressing seniors' number of relationships to addressing their relationships' perceived quality. Thus, perceived social isolation should be framed as a public health risk because of the inverse relationship between perceived social isolation and well-being.

The narrative of social isolation as a public health risk will emphasize fiscal responsibility and economic savings in keeping with the current government's stated priorities. Therefore, alleviating perceived social isolation in all seniors would be framed as a preventative measure that would decrease downstream healthcare costs. Bill 175 demonstrates the current government's priorities of reducing hospital overcrowding and expenditures by providing care to older adults in the community (Crawley, 2020). Building on the momentum of Bill 175, framing a policy that reduces loneliness in seniors as a strategy to minimize hospital overcrowding, thereby increasing economic savings, will be useful.

Re-framing perceived social isolation as a financial issue that affects the acute care subsector is strategic and likely to be successful. Although social isolation in seniors may be an issue of the community and social care subsector, framing it as a problem that places a burden on the acute care subsector exploits the existing power imbalance. Peckham et al. (2018) have suggested that the acute care sector receives the majority of interest from policymakers, often "at the 'expense of' the community subsector" (p. 4). Even when the community sector does receive attention, it tends to be readdressed to assist the acute care sector (Peckham et al., 2018). Thus, the narrative that the community subsector is solving a problem in the acute care sector is likely to be effective.

The Effectiveness of This Re-Framing for Advocacy Efforts

Advocacy and reform efforts are required to ensure that Ontario's policy agenda will reflect updated policies on perceived social isolation in seniors. The issues with the existing policies must be made apparent to both citizen activists and professional policy analysts. These are the stakeholders who can assign issues to the political process (Bryant, 2009). A media campaign consisting of seniors' stories may be an effective strategy to promote the narrative and lobby for policy change. Older adults in Ontario can attest to their personal experiences of loneliness and the implications these experiences have for their well-being and their use of healthcare services. These testimonies would demonstrate that current interventions focusing on increasing social contact are not alleviating seniors' loneliness. Also, highlighting the stories of those most affected by social

isolation, such as refugees or Indigenous seniors, will likely evoke empathetic altruism (Batson, 2011). The stories of those most affected by social isolation would provide heuristics representing the extent of the problem and produce a strong public response (Crow & Jones, 2018).

Given the current political climate during the COVID-19 pandemic, this advocacy effort may align with most public discourse regarding socially isolated seniors, thus inducing an immediate response. Older adults in Ontario's long-term care facilities have been disproportionately affected by the pandemic, and Ontarians have recently become increasingly aware of the difficulties that older adults face due to objective and perceived social isolation (Chu et al., 2020). The pandemic has exemplified that despite living in communal settings, such as long-term care homes, older adults still experience loneliness because of a perceived lack of quality relationships (Chu et al., 2020). Also, loneliness is currently affecting individuals across all age groups in Ontario (Korzinski, 2020). Therefore, policymakers are presently more likely to address perceived social isolation due to the pandemic's effects.

The lack of adequate policy to remedy social isolation in older adults may be attributable to the absence of a governmental body that confronts loneliness in seniors. In the UK, the Jo Cox Commission on Loneliness was established in 2016, and recommendations were made for alleviating perceived social isolation in the country's elderly population (May, 2018a). Since then, a Minister of Loneliness has been appointed (May, 2018b). National strategies, such as increased funding for social prescriptions, have been implemented to address perceived social isolation (May, 2018b). Advocacy campaigns, such as the Campaign to End Loneliness, resonated with parliament members who encouraged these paradigmatic policy changes (May, 2018a). Therefore, to be successful, advocacy campaigns in the Ontario context should similarly convey the individual experiences of older adults who are lonely. This advocacy effort may resonate with various state actors who can encourage a committee's development to address this issue. It is not likely that a committee will be developed immediately because the government's current priority is to manage the short-term impacts of the COVID-19 virus. However, a committee to address loneliness is likely to form following the pandemic's end as the lingering effects of objective social isolation and loneliness become apparent.

Conclusion

Ontario's policy makers currently frame the social isolation of the elderly as resulting from an objective lack of social connection. Despite the fact that seniors' social isolation has been on the political agenda for several years (Government of Ontario, 2017), there has been minimal change. The current framing of social isolation in this population negates the individual perceptions of isolation felt by many older adults. As a result, solutions to increase older adults' social contacts only address part of the issue. Individuals experiencing loneliness and poor-quality relationships remain isolated and thus experience adverse health effects (Landeiro et al., 2016). The growing senior population in Ontario, and the resulting burden placed on the healthcare system by socially isolated seniors, is problematic given the budget constraints in the acute care sector (Agarwal et al., 2019). Re-defining

social isolation as a subjective experience, rather than an objective experience, is required to generate more focused interventions targeted at seniors' loneliness. This re-definition, coupled with an emphasis on cost-reduction, is likely to initiate policies that reduce social isolation in Ontario's older adults.

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Information Transmission: Benefits and Challenges in the Production and Dissemination of Healthcare Knowledge Within the Transmasculine Community in Toronto

BRENNAN SNOW

Navigating the healthcare system can be daunting for anyone, but transgender people often face specific challenges when trying to access gender-affirming care. Throughout much of history, this care simply has not existed in a consistent, formal way. Even now, in Ontario, many health care providers are unwilling to assist trans patients in achieving transition-related goals, or are unaware of how they can best do so (Giblon & Bauer, 2017). As a result, knowledge of what is possible through medical transition and how to go about obtaining desired procedures or medications tends to be passed around the community (Ross & Scholl, 2016; Scheim et al., 2014). This research project involved interviews with a small sample of transmasculine individuals who have lived in Toronto at some point during their transition, revealing a tension between formal expertise and informal (lay) expertise as sources of transition-related information. While community sources may be more likely to spread inaccurate information, there seems to exist a certain trust for people within the community, whereas formal sources may be less accessible, openly hostile, or may not even exist in some places or on some subjects.

Introduction and Literature Review

The queer community has a history of having to advocate for their own healthcare. Perhaps most famously, in the early years of the AIDS epidemic, many marginalized communities (such as gay men, sex workers, and injection drug users) became frustrated with perceived corruption in government and pharmaceutical companies, lack of progress, and a lack of knowledge about how and why the virus spread (Remis & Sutherland, 1993; Miller et al., 2002). They not only came together to protest and raise awareness around the existence of HIV/AIDS, but in many cases also had to become “lay experts” in biomedical science out of necessity (Epstein, 1995).

Similarly, many transgender people have had to become lay experts of their own bodies and transition-related healthcare in order to navigate the healthcare system and access hormone replacement therapy (HRT) and surgery, if they so chose. Early accounts of people who medically changed their bodies to alter their outwardly perceived gender tend to note how they did this outside of formal, supervised medical care. For example, Spade (2013) recounts the 1950s case of “Agnes” who began what could be considered medical transition

when she started to take her mother's estrogen pills as a teenager. While this kind of unsupervised hormone use may seem unlikely in the present day, the Ontario Trans Pulse Study reported that roughly 25% of the transgender people they surveyed who were using hormones had, at one point or another, gotten them from a nonmedical source (Rotondi et al., 2013). Rotondi et al. (2013) also note that reduced access could be partially attributed to the minimal amount of training that physicians in Ontario receive regarding trans healthcare, with some unaware that family doctors can even provide HRT.

Additionally, there are often specific processes that must be followed in order to access transition-related care, some of which can have long wait times (Ashley, 2019). Depending on local processes and what type of care is being sought (hormones, various types of gender affirming surgeries), this can include assessments and letters from multiple psychologists and doctors, which can leave people feeling like they must articulate a certain narrative to prove that they are transgender receive the supports they need (Ashley, 2019; Spade, 2013). This phenomenon was similar even with the limited transition options available in the 1950s, when "Agnes" actually had to convince doctors that she was intersex in order to prove her need for gender affirming surgery (Spade, 2013). While the standards were different in the 1950s, the need to evade medical gatekeeping in order to access transition is remarkably similar.

Aside from simply supervisors and dispensers of medications and performers of surgery, most of the general public tends to rely on doctors and health professionals as sources of health information. But what if the doctor does not know the answer, or refuses to treat trans people either from a personal beliefs standpoint or a lack of knowledge about trans health care? What if someone's experience of gender does not fit a traditional narrative? If this information is not coming from a formal medical source, how do people find out what transition related healthcare is even available to begin with? One way is through community. Queer community centres began to spring up in Toronto in the 1970s, with The 519 and 58 Cecil St. providing a space for trans people to meet and find peer support (Raj, 2017). Beginning in the 1980s, Lou Sullivan in the United States and Rupert Raj in Toronto (both transgender men) began sharing information and support through mailed newsletters (Scheim et al., 2014). Raj's newsletter, *Metamorphosis*, covers topics ranging from innovations in gender-affirming lower surgery, tips for "passing" as male, book recommendations and reviews, and a discussion of the potential impacts of testosterone on the cardiovascular system (Raj, 1982a; Raj, 1982b; Raj, 1984). Notably, it also includes advertisements for other, similar newsletters, as well as for in-person peer support groups and healthcare providers (Raj, 1982a; Raj, 1982b; Raj, 1984). Newsletters such as *Metamorphosis* may have been very important community-building tools for people living outside of city centres (especially at a time when there was much less visibility), but also to connect people living in or close to cities to in-person community, resources, or healthcare professionals who were competent in trans healthcare. Now, some scholars point to the internet as a medium where very similar interactions and health information sharing takes place (Ross & Scholl, 2016).

The effort to create knowledge about, by, and for trans bodies is an application of Arjun Appadurai's (2006) "right to research". The questions of who

gets to produce knowledge about whom, and of what knowledge is considered credible, is central to Appadurai's (2006) argument. James C. Scott's (1998) framework of state power is also applicable to these knowledge creation questions. Scott describes how the state often ends up oversimplifying the people and the land in its effort to organize and make sense of them. In contrast to this, he describes the concept of "mētis" as the rich lived experiences and informal, applied knowledge of communities, which goes far beyond (and exists without) the organizational structures of the state (p. 6-7). Similarly, by rejecting the state's imposed legibility in the form of a strictly categorized view of gender (and therefore a medicalized view of transgender people), trans community members creating lay knowledge are rejecting prescribed standards and expectations and embracing mētis.

I intend to build off of this framework to explore how and why health or healthcare knowledge is generated and transmitted within the transmasculine community in Toronto and analyze what the benefits and challenges of this type of information production and exchange might be. I will be approaching community-produced information by people in a non-professional/medical capacity as an extension of lay or informal knowledge, and that from medical professionals, academic researchers, and healthcare organizations as an extension of formal knowledge.

Methods

To answer these questions I performed semi-structured interviews with 3 transgender men (ranging from 45-90mins) about their experiences in finding and accessing healthcare, and about their transition-related health knowledge. I created an interview guide to assist in focusing the interviews, but in recognition of the holistic and multifaceted natures of health, I allowed the participants flexibility to guide the direction of the conversation to some extent. While my initial approach was to focus geographically only on Toronto, as the interviews progressed, it became clear that while all of the informants had lived in Toronto during some point in their transition, all 3 had also accessed transition-related healthcare in other places. Many drew interesting comparisons or noted contrasts with their hometowns or places where they began their transition. As Brown-Saracino (2015) argues, place can take an important role in the formation of sexual identity (and therefore potentially also gender identity). However, all of the informants used similar words to describe their identities as "man" or "trans man", perhaps indicating either a level of consistency across place or that they spent an influential period of time in Toronto. This broadened my scope to still take into account geography, but in a way that considers differences between places, rather than focusing only on the knowledge production and sharing that occurred within Toronto.

This research question is partially informed by my own experiences as a trans man navigating the healthcare system. I feel that my experiences not only guided my research, but also benefited the interview process itself, in that there was a level of mutual comfort and trust by virtue of talking to someone else who identifies as transmasculine. Additionally, given the limited time, I reached out to people within my network who I knew would respond quickly. I had therefore met all of my participants before the interviews, either through mutual friends or an in-person peer support group for trans men. While this may provide an

additional layer of trust, this convenience sample likely also artificially narrows the diversity of perspectives from that which actually exists within the large, diverse community that makes up the category of transmasculine individuals. It is therefore important to acknowledge that this research is based on the experiences of very few (relatively privileged) informants, who cannot necessarily speak to the universal experiences of transmasculine people in accessing healthcare. All three participants are either college or university educated and white, but with differing socio-economic backgrounds and sexualities. However, these interviews do provide insight into common themes experienced by these individuals.

There are a number of challenges that came up throughout the research process. The first was that due to the pandemic, I was not able to perform in-person interviews, and instead had to use video conferencing software. This software generally worked quite well, however it would very occasionally freeze or the sound would cut out, sometimes contributing to issues with the transcribing process. Additionally, while participants consented to the risks outlined in the consent form, including those of inducing stress or the slight risk of being identifiable, I took caution in approaching difficult topics and took extensive steps to reduce the chance that informants could be identified (including assigning pseudonyms and redacting the names of smaller cities and towns and of people they had mentioned).

Analysis of the transcripts revealed tensions between these formal and informal sources of information. While within-community sources seemed more likely to spread inaccurate information, there also exists a certain trust of people within the community. In contrast, formal sources may be nonexistent, difficult to access, or outright hostile towards trans folks. This theme came out of five major common codes that were evident in the interviews. All of the participants talked in some way about how misinformation, positionality/trust, medical gatekeeping, a lack of formal research, and place impacted the ways in which they accessed and shared information (see Table 1 for examples). I systematically classified the interview transcripts using these five codes to arrive at this theme.

Table 1:

Code	Example	Category
Misinformation	“...not everybody has the wherewithal to question where is this coming from and why, so you may have seen it on the internet, but especially in communities like Facebook and twitter and things like that, there’s misinformation that is circulating all the time.” (Reilly) “I don’t think it’s really a concern because like... misleading medical information gets disseminated on the Internet in so many ways...” (Joshua)	Informal

Positionality/ trust	<p>“Even as like mainstream resources have become more accessible just because people are more likely to trust it when it comes from somebody within the community who can like share their experiences with a particular provider...” (Joshua)</p> <p>“[the doctor] was a trans woman, which was another thing that I liked, like it seemed... less daunting to me to speak to someone who was trans.” (Theo)</p>	<p>Informal</p> <p>Formal</p>
Medical gate-keeping	<p>“...and prior to doing that I had to go to a gender therapist for 5 counseling sessions... to I guess say that I was trans” (Theo)</p> <p>“Yeah, so at the time, you needed to have... a psychologist diagnosis of gender dysphoria... you needed to have been on hormones for a year, and you had to have like a referral from a physician. So those were 3 pieces that you needed and with all of those pieces you still had to apply and then you had to get on the waitlist, so even with all those 3 pieces, the wait time was still about 2, 2 and a half, 3 years.” (Reilly)</p>	Formal
Lack of formal research	<p>“I think that also just because it’s such a new field of healthcare for there to be research done on it, there’s just not enough of us for there to have been significant studies in the past.” (Joshua)</p> <p>“...we’re not very well researched. Um for example, like, I have no idea exactly how testosterone is going to affect my body in the years to come and nobody’s really done any long-term research on it” (Reilly)</p>	Formal

Place	“... I started seeing a therapist in New Orleans because that’s how far I had to go to find somebody who knew what they were doing regarding trans patients.” (Joshua)	Formal
	“I actually started my transition in [small Northern ON city], and so it’s been really interesting seeing the difference from [small city]... to Toronto... and so for example... I travelled 5 hours to get my testosterone” (Theo)	
	“Yeah, so my endocrinologist was in [smaller city 2-3hrs outside of the GTA], I went through [city]... partly because I have that community connection... that was where I met... the original trans person who talked about kind of his experiences, he’s like this is what it is, so I was like great! I didn’t have those connections established in Toronto yet.” (Reilly)	Informal
Theme: Tension between formal and informal sources of information. While community sources may be more likely to spread inaccurate information, there exists a certain trust for people within the community, whereas formal sources may be less accessible or openly hostile, or may not even exist in some places or on some subjects		

Discussion

Interestingly, when the structures and processes that influence how people understand their gender and access medical transition are examined (coded as medical gatekeeping), Scott’s (1998) framework of power can be applied very effectively. Here, the concept of legibility is being applied to the space of the body, where in order to gain access to hormones or to surgery, informants describe having to jump through a series of hoops and feeling the need to present or act in a certain way in order for a medical professional to diagnose them, thus rendering them legible to the state. For example, when Theo says “I mean all trans people have been through it, where you have to talk to a doctor, and like prove that you’re like trans... it’s such a weird experience of being like well when I was a little kid, I liked to play with the boys, or I liked short hair”. Reilly also touches on this when describing the process to get chest surgery covered through health insurance.

Informal knowledge, especially that which is generated and transmitted within the community, can be seen as an example of Appadurai’s (2006) “right to research”. Many of the participants talked about either directing others to resources or being directed to trans-friendly doctors and resources through friends or online communities. One pitfall of this community-generated research, however, was the occasional spread of misinformation, such as what Reilly describes with post-surgical scar care, or Joshua’s acknowledgement of inaccurate information on the internet. Additionally, for all of the informants, their first acknowledgement of

their gender identity came not from a doctor or medical professional's diagnosis, but from talking to and connecting with other trans people. This step of self-determination based on the experiences of people around them and their own experiences rather than formal diagnoses is likely something Appadurai (2006) would consider research in a broad sense, in the face of a medical establishment that may not recognize the legitimacy of someone's claims about themselves and what they may want for their bodies, or that has deemed that population less worthy of attention in formal research. Some also noted the lack of formal research, or the lack of accessibility of formal research as potentially being a factor in this community-generated information gathering for themselves. For example, Joshua says "I think that also just because it's such a new field of healthcare for there to be research done on it, there's just not enough of us for there to have been significant studies in the past", whereas Reilly notes having the educational background necessary to be able to parse the existing literature on trans health topics.

While I structured the responses into two categories, in reality, things are rarely so simple. While I had initially imagined "formal" knowledge as inherently coming from outside of the community, two of the three informants described either healthcare providers who were trans or trans peers who were healthcare providers. For example, when Theo states "[the doctor] was a trans woman, which was another thing that I liked, like it seemed... less daunting to me to speak to someone who was trans". Similarly, Reilly speaks about a family friend who is a pharmacist and transgender woman who "kind of continues to kind of be a resource for [him], and particularly with hormone things, 'cause that's what she does. Like she does compounding, like she makes a whole bunch of different prescriptions and things like that so... was really interesting to talk to from that perspective as well". He also noted the barriers she has faced within her practice and that "she has some of that medicalized knowledge that's not necessarily accessible by all members of the queer community, because you can't replace education, and education is a privileged system, and it's a classist system as well, so not everybody's able to access those things" (Reilly). Both of these examples demonstrate a blurring of the formal/informal categories, especially in the case of Reilly's family friend, who was not necessarily giving advice in a professional capacity, but who is a medical professional. This prompts a revisiting of Rupert Raj's 1980s Toronto-based newsletter *Metamorphosis*. Although the newsletter highlighted a number of community voices that weren't necessarily medical professionals or researchers, Raj himself was trained as a psychotherapist, perhaps lending some level of professional credibility to the project (Lorinc et al., 2017).

Both Reilly's family friend and Raj are examples of a generally marginalized population using the tools of the state to achieve a sort of self-determination through formal means, by bringing what Scott (1998) might describe as "métis" into the existing legitimization structure of the medical establishment. However, this is not without issues as well. For example, Theo's therapist (a trans man) "told [him] that he didn't think [Theo] was very masculine... because [he] liked to take baths, and like... paint". He describes how this impacted him in saying "so that like really hit me, because I'm like there's this person who identifies as a trans man...and like somehow policing my masculinity... he was kind of like parroting what my dad was telling me, like 'oh like you can't be a guy because you like these

y’know artsy things’ or whatever” (Theo). Even with bringing lived experiences or *métis* to the formal position, this therapist is reproducing the power structures of a system that seeks to legitimize trans people by placing them in neat, easily understandable categories. It therefore seems clear that the tension between informal and formal knowledge exists even within these medical structures.

Conclusion

It is clear that the transmasculine people interviewed experience a tension between lay expertise and formal information. But then what is the solution for balancing the risks of misinformation coming from people who are not necessarily trained in medicine, versus a medical establishment that seeks to strictly categorize and police access to reliable transition related care and information? One solution may lie in Reilly’s family friend and Rupert Raj, who are both healthcare professionals and part of the trans community, allowing them to potentially ensure dangerous misinformation is not being spread within the community. Participants noted that health care professionals who were also transgender often put them more at ease, indicating that the positionality of formal health care sources is crucial, however we must continuously question and remain critical of (even other transgender people) working within existing power structures that gatekeep access to transition.

Additionally, it is evident that there is a need for further research in transgender health, as well as for the resulting information to be more accessible to trans people who may not have the educational background needed to parse the existing academic research. The responsibility of communicating this information back to the community that is being studied should fall on those doing the research, with community centres and healthcare centres as potential places to disseminate this information. Emphasis on community-based or participatory action research can also help to ensure that the research being done is meaningful to and being guided by transgender communities, rather than simply benefitting structures that seek to categorize and medicalize transgender bodies (Ibáñez-Carrasco et al., 2019; Fine & Torre, 2004).

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How to Achieve Access for All? — A Critical Analysis of the Campaign Advocating for Coverage of Advanced Glucose Monitoring Technologies in Ontario

MARLEY GREENBERG

There are almost 100,000 people in Ontario living with type 1 diabetes (T1D), a chronic disease that requires constant and intensive self-management (Juvenile Diabetes Research Foundation [JDRF], 2020). New evidence demonstrates that T1D is most effectively managed through the use of advanced glucose monitoring technologies, such as flash glucose monitors (FGMs) and especially continuous glucose monitors (CGMs), with the latter system providing revolutionary data and empowerment to individuals living with T1D (Prahalad et al., 2018). Although CGMs deliver large benefits to people with T1D, they often bring along large out-of-pocket costs, due to a lack of public funding for these devices. The Juvenile Diabetes Research Foundation (JDRF) is working towards ending the individual financial burden and consequent inaccessibility of FGMs and CGMs in Ontario. JDRF is currently leading an advocacy campaign, named Access for All, which aims to convince the Government of Ontario to fund advanced glucose monitoring technologies for all Ontarians with T1D (JDRF, 2020).

This research essay will provide a critical analysis of JDRF's Access for All campaign. First, this paper will explain the issue of inequitable access to CGMs and FGMs in Ontario by (i) highlighting the health and economic considerations that deem the issue deserving of a place on the policy agenda, (ii) describing where the issue currently stands in relation to Ontario's policy agenda, and (iii) pointing out problems in the political perception of the issue. Next, this paper will analyze the current framing of the issue by discussing the Access for All campaign's strategies and strengths. The essay will then outline a proposal to partially reframe the campaign. Specifically, the paper will suggest the integration of a rights-based approach as well as the inclusion of narratives from bereaved parents whose children have died due to diabetes. The paper will then proceed to evaluate the likelihood that the campaign will be successful.

The Issue: Inequitable Access to Advanced Glucose Monitoring Technologies in Ontario

Why it Matters — Health and Economic Considerations

In Ontario, there are approximately 96,570 people living with T1D (JDRF, 2020). Individuals with T1D must constantly and meticulously manage their blood sugar levels, and yet despite this ongoing attention, people with T1D still run the risk of dangerously high and low blood sugars, which can result in serious health

complications, hospitalization, and even death (JDRF, 2020). These extreme blood sugar levels are costly to the public purse: each year, the Ontario health care system spends over five million dollars on care for extreme low blood sugars, referred to as severe hypoglycemic episodes (JDRF, 2020). There is strong evidence that new technologies, namely CGMs and FGMs, improve blood glucose control (Health Quality Ontario [HQO], 2018, 2019). Improved blood glucose control increases quality of life for people with T1D, reduces use of scarce hospital resources, and lowers health care costs in the long-term (Pralhad et al., 2018). However, in Ontario, an issue of access to CGMs and FGMs currently exists: despite their clear benefits, these devices remain out of reach for most people with T1D due to a lack of public funding (JDRF, 2020). The introduction of public funding for CGMs and FGMs would create equitable access to these advanced glucose monitoring technologies, drastically improving the lives of people with T1D while also reducing the hallway medicine problem. As such, this matter deserves a place on the Ontario policy agenda.

Current State — On and Off the Ontario Policy Agenda

The issue of inequitable access to CGMs and FGMs is on the radar of decision-makers in the provincial government and has made brief appearances on the Ontario policy agenda. Politicians are now starting to give this issue attention largely because of two recent reports from Health Quality Ontario (HQO) that discuss advanced glucose monitoring technologies. HQO, relying on the guidance of the Ontario Health Technology Advisory Committee, released a report in 2018 analyzing the cost-effectiveness of CGMs for people with T1D (HQO, 2018). In 2019, HQO released an additional report evaluating the cost-effectiveness of FGMs for people with T1D as well as for people living with type 2 diabetes (T2D) (HQO, 2019). Although both of the HQO reports contain final recommendations that encourage public funding for advanced glucose monitoring technologies, the recommendations vary in the extent of the funding suggested (HQO, 2018, 2019). Furthermore, despite some positive movement towards FGM coverage, the provincial government has yet to fully take-up and implement either recommendation.

Coverage for FGMs has appeared on, yet disappeared from, the Ontario policy agenda. In 2019, HQO recommended publicly funding FGMs for all people with T1D in Ontario and for a small segment of Ontarians with T2D who require intensive insulin therapy (HQO, 2019). Following this recommendation, FGM coverage materialized onto the Ontario policy agenda — in September 2019, the Ministry of Health amended the Ontario Drug Benefit (ODB) program to include funding for FGMs (JDRF, 2020). The inclusion of FGMs in the ODB program is a positive step forward in the campaign for advanced glucose monitoring coverage, however, an issue of inequitable access remains: there are many people with diabetes in Ontario who do not qualify for the ODB program and consequently, have been left behind without access to FGMs. Although FGM coverage has made a brief appearance on the policy agenda, more advocacy work is needed to move the issue back onto the agenda, persuade decision-makers to fully implement the HQO recommendation, and achieve equitable FGM access for all in Ontario.

Coverage for CGMs, on the other hand, has the attention of decision-makers in the provincial government but is still in the process of making its way onto the policy agenda. CGMs are the most advanced type of glucose monitoring devices available and are distinct from FGMs in that CGMs possess the ability to issue life-saving audible alarms to their users and warn them of impending high and low blood sugar levels (JDRF, 2020). In 2018, HQO recommended publicly funding CGMs for a portion of the T1D population: the report recommended providing CGM coverage for individuals with T1D who are hypoglycemia unaware, that is, those who are unable to recognize their low blood sugar symptoms (HQO, 2018). Although this HQO recommendation is seemingly positive, it is a double-edged sword — the recommendation is beneficial as it provides evidence for publicly funding CGMs but is harmful by only suggesting coverage for some people with T1D. JDRF's campaign, notably named Access for All, is lobbying for CGM coverage for the entire Ontario T1D population. The HQO recommendation, by only supporting coverage for those with hypoglycemia unawareness, partially contradicts JDRF's request for coverage for all Ontarians with T1D. Additionally, despite the fact that this recommendation for CGM coverage was issued before HQO's FGM recommendation, only the FGM recommendation has seen some progress as the Ministry of Health is still reviewing the CGM recommendation and has yet to take action (HQO, 2018, 2019).

Problems of Perception — Policy Awareness Gap

A major contributor to the provincial government's lack of action with regards to HQO's CGM recommendation is a policy awareness gap (MacLachlan et al., 2018) in which decision-makers do not understand the critical and often life-saving differences between FGMs and CGMs nor do they recognize that partial FGM coverage does not replace the need for CGM coverage. Patrick Tohill, JDRF's National Director of Government Relations and Advocacy, is the primary organizer of the Access for All campaign and describes why remedying this gap in awareness is crucial to a successful advocacy campaign. Mr. Tohill explains that there is a reoccurring problem with politicians perceiving FGMs and CGMs as equivalent devices, and consequently, not seeing the need to publicly fund CGMs as FGM coverage is already included in the ODB program (P. Tohill, personal communication, January 23, 2020).

Although both CGMs and FGMs provide more frequent and detailed data to people living with diabetes than conventional blood glucose meters, FGMs are not as advanced as CGMs (Heinemann & Freckmann, 2015). As such, FGMs are regarded as a halfway house, or a hybrid, between traditional glucose meters and CGMs (Flash glucose monitoring, 2014). The key difference between FGMs and CGMs pertains to alarm abilities: CGMs are capable of automatically alerting their users of impending high and low blood sugar levels, whereas FGMs lack any type of alarm ability. For many people who use CGMs, these audible alerts are indispensable as they can prevent dangerously high and low blood sugars, hindering the likelihood of serious health complications, hospitalization, and diabetes-related death (JDRF, 2020). Despite some efforts from JDRF to educate decision-makers on the crucial differences between FGMs and CGMs, many of

them still seem to lack this essential knowledge. In order to move public funding for CGMs onto the policy agenda, bridging this awareness gap is crucial —going forward, lobbying bodies such as JDRF must do more to illuminate the differences between FGMs and CGMs by focusing advocacy narratives on the unique life-saving abilities of CGMs.

The Campaign: Current Framing — Strengths and Strategies

JDRF's Access for All campaign utilizes a handful of strong framing tactics that aim to push the issue of inequitable access to advanced glucose monitoring technologies onto the Ontario policy agenda and create policy change. Strategic framing techniques are demonstrated throughout the campaign documents and are even apparent in the name of the campaign, "Access for All", which succinctly and immediately outlines the issue to be one of (insufficient) access. In addition to outlining the issue, the name "Access for All" also points to the ultimate goal of the campaign, which is to establish equitable access for all.

JDRF's 2020 Ontario Pre-Budget Submission focuses entirely on the issue of advanced glucose monitoring technologies and furthering the Access for All campaign. The pre-budget submission employs a number of framing strategies: the document appeals to clinical expertise, leverages personal narratives, and echoes the language used in the electoral platform of the current provincial government. In the pre-budget submission, under the heading "Stories from the Community", there is a story highlighting a globally-respected and prominent Toronto endocrinologist (JDRF, 2020). This appeal to local clinical leadership is a framing strategy intended to add legitimacy to the document by invoking an air of clinical neutrality and objectivity. As Jones and Exworthy (2015) note in their study on framing in hospital planning documents, appeals to clinical leadership are often paired with appeals to public involvement. This coupling appears in JDRF's pre-budget submission, as the clinical narrative is directly followed by stories from members of the public who are affected by T1D (JDRF, 2020). These community stories are part of a framing strategy intended to demonstrate public support for the content of the pre-budget submission. Additionally, these individual narratives, which are centred on the suffering of children and their families, strategically frame the issue in a personal manner in the hopes of invoking empathy-induced altruism from decision-makers.

Furthermore, the language used in the pre-budget submission mirrors the language found in the electoral platform of Ontario's governing party. This deliberate phrasing is part of a framing strategy that aims to appeal specifically to current decision-makers. In June 2018, the Progressive Conservative Party of Ontario, with leader Doug Ford, won the Ontario general election and formed a majority government (Russel, 2018). Ford and his Progressive Conservatives (PCs) ran on a platform that revolved around five key promises, the fifth being to "cut hospital wait times" and "end hallway health care" ("Plan for the people", n.d.). Notably, JDRF's pre-budget submission leverages this call to end hallway health care. The pre-budget submission requests that the Government of Ontario "provide access to advanced glucose monitoring technologies" to all people with T1D in order to achieve "improved health care" and to end "hallway medicine"

(JDRF, 2020). Invoking the concept of hallway medicine in the pre-budget submission clearly and quickly aligns JDRF's goals with the goals of the PCs, and frames the proposed policy solution in language that will hopefully persuade decision-makers to act.

The Campaign: Proposal to Reframe

Expanding FGM Coverage — A Rights-Based Approach

Although FGM coverage has made a brief appearance on the Ontario policy agenda, JDRF will need to utilize new framing tactics in order to move the issue back onto the agenda and persuade decision-makers to expand FGM coverage to all Ontarians with T1D. To strategically reframe the issue, JDRF should employ a rights-based approach. A rights-based reframing would illuminate how the current eligibility criteria for FGM coverage is unjustly restrictive and as such, has lead to health inequities.

Durocher et al. (2019), in an article discussing equity and assistive technology, argue that equitable access to assistive technology is not merely a question of accessibility, or 'just access'. Rather, they take a rights-based approach, proposing that equitable access to assistive technology is a right and a necessary component of a 'just' society (Durocher et al., 2019). Furthermore, Durocher et al. (2019) suggest that health justice requires public financing for assistive technology devices and explain how restrictive eligibility criteria results in health inequities. Specifically, they propose that public funding for assistive technology must be inclusive across age categories and socio-economic statuses to avoid health inequities (Durocher et al., 2019). The authors explain how a public financing program that targets people with low income, in the absence of a comparable program for people with 'less low' income, is inequitable: many individuals in the 'less low' income category may lack sufficient funds to purchase assistive technology without government aid, and as such, their ineligibility for low income restricted programs leaves them disadvantaged and without necessary health devices (Durocher et al., 2019).

The ODB program in which FGM coverage is currently included is hindered by age restrictions and socio-economic cut-offs. The ODB program "covers most of the cost of more than 4,400 prescription drug products" for Ontario residents who fall into one or more of the qualifying categories (Government of Ontario, 2020). For example, the ODB program provides substantial drug coverage to people over the age of 65, people aged 24 or under who lack private insurance coverage, and to individuals who receive assistance from Ontario Works or the Ontario Disability Support Program (Government of Ontario, 2020). A few of the categories that enable people to qualify for the ODB program are criteria related to low income, and in the absence of commensurate 'less low' income programs, Durocher et al. (2019) would deem these low income criteria inequitable. Additionally, the overall lack of government funding available through the ODB program for those aged 25-64 is an age restriction that leaves many people with diabetes in Ontario ineligible for ODB program benefits and consequently, without access to FGMs. To achieve equitable FGM access for all in Ontario, JDRF should apply a rights-based framing

strategy and focus on the narratives of people aged 25-64 who do not qualify for the ODB program and are in turn, suffering serious health inequities.

Attaining CGM Coverage — New Narratives to Close the Policy Awareness Gap

In order to move the issue onto the agenda and attain public funding for CGMs, JDRF must bridge the policy awareness gap by utilizing new framing strategies that elucidate the crucial differences between FGMs and CGMs. Current Access for All framing tactics and campaign materials lump FGMs and CGMs into one category, blurring their distinctions and exacerbating the policy awareness gap. When reframing, the Access for All campaign could learn from the framing strategies utilized in the successful campaigns of other advocacy organizations, such as Mothers Against Drunk Driving (MADD). MADD has arguably been one of the most impactful public-health advocacy organizations in recent memory in North America (Fell & Voas, 2006). MADD's success has in large part been due to the organization's framing strategies, tactics which include repeated appeals to personal narratives of suffering and bereavement. MADD has been widely successful in shaping an image of impaired driving in which the impaired act leads to the loss of a child and to bereaved parents who are tragically mourning this loss (Siegel & Lotenberg, 2007).

Similar strategies, which leverage the narratives of bereaved parents, have been employed in the realm of diabetes advocacy, and specifically in advocacy efforts addressing the exorbitantly high cost of insulin in the United States (US). Insulin inaccessibility is a serious issue in the US, where a quarter of people with diabetes report rationing insulin due to the drug's high cost (Teare, 2018). Insulin rationing is a dangerous practice that can lead to death, as occurred in the case of Alec Smith, a young man who could not afford his insulin and died from rationing the drug (Jackson, 2020). Following Smith's death, his mother Nicole Smith-Holt began sharing the story of her tragic loss with government officials and lobbying decision-makers for change on the issue of insulin inaccessibility (Sable-Smith, 2018). Smith-Holt's advocacy efforts are now paying off: in April 2020, The Alec Smith Insulin Affordability Act was passed in Minnesota, establishing an emergency insulin program in the state (Jackson, 2020). Smith-Holt, similar to parent advocates from MADD, utilized her heartbreaking story of losing a child to successfully move a policy issue onto the agenda and create policy change.

To close the policy awareness gap and push for CGM coverage, JDRF should incorporate the framing strategy used by both the aforementioned successful advocacy campaigns. Specifically, the Access for All campaign should incorporate the narratives of bereaved parents who have lost children to diabetes-related deaths, deaths which could have been prevented through the use of a CGM, but not an FGM. With their unique alarm abilities, CGMs can alert children with diabetes and their caregivers of dangerous nocturnal low blood sugars, allowing for treatment of the low blood sugar and thereby preventing 'Dead-in-Bed' syndrome, a term used to denote sudden nocturnal diabetes-related death (Weston, 2012). Highlighting the narratives of bereaved parents who have lost children to 'Dead-in-Bed syndrome, and having these parents explain how only a

CGM could have saved the lives of their children, would close the policy awareness gap by elucidating the differences between CGMs and FGMs. Furthermore, these narratives would tug on the heartstrings of decision-makers, just as similar narratives did in the cases of MADD and Nicole Smith-Holt, moving the issue closer to the agenda and a policy solution.

The Campaign: Likelihood of Success

The Access for All campaign is likely to succeed in some capacity over the next few years, however, the timeline for success and the extent of the coverage that might be obtained is difficult to predict, especially in light of the current COVID-19 pandemic. Since the campaign launched in March of 2019, Access for All has seen substantial engagement from community members as well as decision-makers (“#AccessforAll”, n.d.). Provincial politicians and senior policymakers, including the Minister of Health and Executive Director of Policy in the Ontario Premier’s office, have partaken in over twenty meetings with T1D advocates (“#AccessforAll” n.d.). These T1D advocates are champions of the cause and have educated decision-makers about the life-changing and life-saving benefits of CGMs, building support for public funding of these devices (“#AccessforAll”, n.d.). JDRF has also held five community forums throughout Ontario. These events saw over two hundred attendees from a variety of stakeholder groups, such as clinicians, industry partners, and elected officials (“#AccessforAll”, n.d.). Additionally, the online Access for All petition has garnered thousands of signatures, and over seven hundred people have taken action and reached out to their members of provincial Parliament (“#AccessforAll”, n.d.). These advocacy efforts are moving the campaign in the right direction by building momentum and putting the issue on the radars of decision-makers.

In evaluating the likelihood of success for this campaign, an important factor to consider is the COVID-19 pandemic. COVID-19 is affecting economies and governments worldwide and changing the political-economic environment in Ontario. In this century, a pandemic of this type and magnitude is unprecedented (Reilly, 2020) and as such, anticipating its political and economic outcomes is challenging and speculative at best. However, confident predictions can be made that Canada is approaching a recession, as unemployment rates skyrocket and social distancing measures continue to take a toll on the country’s economy (“Canada will fall”, 2020). With a public health crisis on hand and a recession on the horizon, the Government of Ontario has already invested more than three billion additional dollars into public health (Ontario Newsroom, 2020) and will likely continue to stimulate a struggling economy by making further public health investments.

Although it is difficult to predict where these public health dollars will end up, recent occurrences in the US indicate that governments may now be more likely to invest in advanced glucose monitoring amid and after Covid-19. In March 2020, the US Food and Drug Administration (FDA) gave authorization for hospitals to start utilizing CGMs to monitor the glucose levels of people with diabetes and also expressed encouragement for the expanded availability of these devices (Freeman, 2020). This FDA authorization was given because CGMs allow

health care providers (HCPs) to remotely monitor the blood sugar levels of people who have diabetes and Covid-19. CGMs enable HCPs to remain physically distant from patients, preserving the supply of scarce personal protective equipment and preventing transmission of Covid-19 (Freeman, 2020). Additionally, since the FDA issued this authorization, CGM manufacturers have donated thousands of CGM devices to US hospitals (Freeman, 2020), thereby expanding access to CGMs and altering hospital management of diabetes for the foreseeable future. These changes in the US will likely influence Canada. As the Government of Ontario continues to make investments in public health and prepare for future health crises, investment in advanced glucose monitoring technologies would be a wise decision.

Although Covid-19 makes for especially uncertain predictions, the Access for All campaign is likely to see some success in the near future. The pandemic is highlighting the need for expanded access to advanced glucose monitoring technologies. In Ontario, substantial advocacy work has already been undertaken with current decision-makers, and as such, it is quite plausible that the campaign will make progress in the upcoming year or two, before the next provincial election. Additionally, the CGM recommendation from HQO is encouraging, and although this recommendation may only lead to CGM coverage for a portion of the T1D population, it is likely to result in a 'win' of some size. Maintaining the strengths of the campaign, while also integrating new narratives and framing strategies, will ensure that the campaign continues to build momentum, meaningfully engage decision-makers, and hopefully establish equitable access to advanced glucose monitoring technologies for all in Ontario.

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Black Motherhood- A Fight for Life Analysing Anti-Black Racism Within the Canadian Childbirth Sector

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Present systemic discrimination against Black mothers during childbirth within hospitals has resulted from thousands of years of anti-Black discrimination, sentiment, and prejudices (Davies, 2018). Anti-Black racism and its impacts on Black women can be traced back to forced sterilization, Black women being objects of experimentation, and forced reproduction for slave owners (Fitzgerald et al., 2017). The reproductive lives of Black women have constantly been controlled, damaged, and dismissed. Though modern circumstances have changed, anti-Black racism is still prevalent within Canada's healthcare system, and has taken a more subtle form which continues to cost Black mothers and children their lives (Fitzgerald et al., 2017).

Though slavery was abolished in Canada in 1834, racist and dehumanizing ideas and ideologies did not disappear. They continue to live on and take different forms in Canadian systems and institutions. Within the pre- and post-natal sectors of hospitals, Black women have significantly higher rates of miscarriage and mortality than their white counterparts, even after controlling for variables such as socioeconomic status, employment, and age (Taylor, 2019). Additionally, maternal morbidity amongst Black women in North America is still increasing at a steady rate (Davies, 2018). Thus, this essay will address how the Canadian childbirth sector reinforces anti-Black racism through three methods: the lack of acknowledgment of Black mothers' pain; the scarcity of culturally specific support and services for Black women during childbirth; and the inadequate assistance provided to Black women postpartum.

This paper would also like to acknowledge that there is a severe lack of race-based data collected within Canada's healthcare system, which has resulted in incomplete and inconsistent information pertaining to health inequities within the childbirth sector. This lack of adequate information is instrumental to the denial of and silence concerning anti-Black violence and racism within Canada's healthcare system. This neglect acts as a form of refusal to recognize the impacts of anti-Black racism in healthcare delivery. Thus, this essay includes information within the context of the United States, where more race-based data has been collected and similar results for Canadian counterparts can be mirrored.

Lack of Regard for Black Women's Pain

One factor that contributes to inequitable childbirth assistance for Black women is how their pain is responded to during childbirth, which stems from racist

and discriminatory prejudices and stereotypes. According to a study conducted by the Ontario Health Coalition, the amount of pain relief that a patient receives at a hospital in Ontario is directly correlated to their skin tone (Gillis, 2020). Dr. Naveen Arya, a gastroenterologist, also conducted a meta-analysis that showed that Black patients were 22% less likely than their white counterparts to receive medication or treatment for their pain (Arya, 2020). This lack of regard for Black women's pain during childbirth is rooted in the historical dehumanization of Black women and their bodies. During the 1800s in North America, the use of enslaved individuals for human experiments without informed consent or safety precautions was normalized (Wall, 2006). Many Black individuals were subjected to the brutal pain and torture of medical experimentation that involved inflicting wounds on these individuals or exposing them to harmful bacteria and diseases (Holland, 2017). The justification behind using Black individuals for experiments was that they were seen as incapable of feeling pain in the same way that white individuals do (Holland, 2017). Black women were perceived as being insensitive to pain, a dehumanizing assumption given that pain is a common biological response in most humans (Wall, 2006). This led to Black women being used as human subjects in medical experiments without consent or medications such as painkillers or anesthesia (Holland, 2017).

An example of medical experimentation on Black women was James Sims, an American physician and surgeon who became known for his unethical research on severe childbirth obstructions (Wall, 2006). To conduct further research on obstructed childbirth, Sims took ownership of numerous enslaved Black women and conducted experiments on them without their consent or the use of anesthesia (Wall, 2006). His harmful and dehumanizing experiments on Black women had involved experimenting with Black women's anal fistulas (Fitzgerald et al., 2017). Following these trials, Sims' procedures were approved for use in the rest of the population, granting access for white women who needed treatment (Fitzgerald et al., 2017). However, many white women failed to complete the procedure due to intolerable pain induced during operation, despite the use of anesthesia (Walls, 2006). This illustrates how traumatic and painful these experiments would have been on Black women undergoing them without the use of painkillers.

The fact that a man who forcibly used and dehumanized Black women to advance his research on female reproductive issues is now referred to as the modern father of gynecology is disturbing (Wall, 2006). James Sims' "legacy", ideas, and research have impacted the way Black women's pain is perceived, as well as how Black women are treated during childbirth. James Sims' dehumanizing stereotypes of the lack of pain perceived by Black women have contributed to prenatal and postnatal care practices today. Black women across Canada have reported numerous cases of being denied pain killers, having their pain underestimated, and having a lack of overall patient-centered care within the pre- and postnatal wards (Gillis, 2020). Moreover, according to a study conducted by Hoffman et al. (2016) on racial bias in pain assessment, several medical students believed that there was a biological difference in the perception of pain by Black and White individuals, and viewed Black individuals as having thicker skin. These beliefs resulted in these same students recommending less accurate and efficient treatments for Black individuals (Hoffman et al., 2016).

Studies as recent as 2019 have also found that Black individuals were 40% less likely to be prescribed drugs for pain, and 34% less likely to be prescribed opioids (Rapaport, 2019). The lack of pain treatment of Black individuals can also be attributed to harmful racist ideologies such as Black individuals being perceived as drug seekers, which has repercussions for the health of Black mothers and their babies (Holpuch, 2016). A study of birth disparities among Black and white individuals in the Canadian and American contexts was conducted by McKinnon et al. (2015). McKinnon and her colleagues discovered that racial bias in pain assessment has resulted in underdiagnosis and undertreatment of pregnancy-related illnesses, which has caused preventable pregnancy complications, as well as avoidable fatalities (McKinnon et al., 2015). Within the Canadian context, in the provinces of Quebec and Ontario, African-born women had a statistically significantly higher rate of preterm birth compared to Canadian-born women (McKinnon et al., 2015). This disregard for the pain of Black mothers dates back to the dehumanization of Black individuals and the negation of their ability to feel pain in the same way as white individuals. This prejudice has informed present medical principles and knowledge, which has greatly contributed to the stark negative outcomes that Black mothers face when giving birth (McKinnon et al., 2015).

The Lack of Culturally Specific Support and Services for Black Women During Childbirth

Canada's healthcare system has a long history of implementing a one size fits all approach to health issues by failing to account for the social conditions that Black women experience (Davies, 2018). This dismissal of cultural and social awareness is ongoing and detrimental to the lives of Black mothers and their children. The lack of knowledge and implementation of culturally-specific support for Black women during pregnancy is illustrated in evidence from a data survey of national pregnancy-related mortality, which illustrated that Black women are 3-4 times more likely to die from childbirth and have pregnancy complications than their white counterparts (Davies, 2018). Despite the health inequalities identified amongst the scarce Canadian race-based data, there continues to be a lack of adequate effort by Canadian hospitals to train staff in anti-oppression, anti-racism, and cultural safety practices (Goode et al. 2017). This training is needed to close the large prenatal and postnatal inequity gaps and ensure that Black mothers feel safe, understood, and supported during childbirth (Fitzgerald et al., 2017).

In a study conducted on the main contributors to the stark health disparities between Black and white individuals regarding maternal health, a large contributor to infant and mother morbidity among Black women was social circumstances (Adams & Thomas et al., 2017). More specifically, Black mothers are exposed to social stressors which are caused by their exposure to discrimination (Adams & Thomas et al., 2017). According to Taylor (2019), Black mothers are often treated with a lack of respect, dignity, and support from healthcare workers, which may result in patient distrust of doctors and nurses. This distrust may cause pregnant Black women to fear for their lives, in addition to the average

stresses of pregnancy and childbirth (Taylor, 2019). There are also implications of anti-Black racism which affect the biological processes of Black mothers' bodies (Davies, 2018). For example, the emotional toll of anti-Black racism places Black mothers at an increased risk of developing preeclampsia (a high-blood pressure disorder), eclampsia (similar to preeclampsia, but causes seizures), and embolisms (the blockage of blood vessels due to high blood pressure) (Taylor, 2019). The heightened likelihood and the disproportionate number of Black women developing these disorders during pregnancy are directly correlated with the experience of anti-Black racism (Taylor, 2019). An equitable healthcare system should account for the social and environmental barriers that Black women face, providing adequate healthcare that is responsive to their specific situation. It is vital to have intentional and evidence-based designs of resources that aid Black women in navigating through the healthcare system and receiving adequate healthcare services and support.

Providing equitable healthcare for Black mothers could also be more effective if there was appropriate representation of Black physicians in the childbirth sector, who would likely have a better understanding of the social, cultural, and biological circumstances of Black individuals (Nnorom, 2020). However, Black nurses and physicians are underrepresented in Ontario not just within the childbirth sector, but also amongst the healthcare services sector more generally due to the systemic impacts of anti-Black racism (Rao & Flores, 2007). The lack of diversity of healthcare professionals plays a large role in inequitable health outcomes (Rao & Flores, 2007). Black individuals represent 4.7% of Ontario's population, yet make up only 2.3% of physicians in Ontario, illustrating the extreme underrepresentation of Black individuals in this field (Nnorom, 2020). Dr. Onye Nnorom who is a Black health team lead at the University of Toronto's Faculty of Medicine, has expressed an urgent need for Black physicians in the provincial healthcare delivery fields (Nnorom, 2020). The severe underrepresentation of Black physicians across Ontario, paired with a general lack of understanding, expertise, and training in Black population health, has resulted in a lack of safe and culturally sensitive healthcare delivery for Black individuals (Nnorom, 2020). This lack of culturally sensitive care is costing the lives of many Black mothers and infants, as racial bias and prejudice begin to fill in experience and knowledge gaps, causing vital decisions about care for Black individuals to be made with clinical uncertainty (Nnorom, 2020). These harmful decisions not only result in violence and unfavorable health outcomes for Black women, but also serve as a source of preventable stress and anxiety (Adams & Thomas et al., 2017).

Inadequate Assistance Provided to Black Women Postpartum

In addition to Black women being at a higher risk of exposure to pregnancy-related illnesses, infant mortality, maternal mortality, and childbirth complications, Black women also face insufficient care after they give birth (Sandoiu, 2020). This inadequate care contributes to an increased risk of developing postpartum depression (PPD) (Sandoiu, 2020). According to a study conducted at the Icahn School of Medicine in New York, African American women were more

than twice as likely to develop PPD than their white counterparts (Sandoiu, 2020). Researchers from this study also predicted that the numbers of Black women who face PPD are likely substantially higher than reported by about 50%. Sandoiu (2020) attributes this gap to a reluctance on the part of Black women to report symptoms due to the fear of legal repercussions they might face. In addition to the disproportionate number of Black women who face PPD, Black women are less likely to seek support and assistance for their postpartum depression due to the policing of Black mothers (Sekharan, 2016).

Additionally, Black women are more likely to have their children taken away from them by public enforcement officers, a pervasive fear that may prevent Black women who are going through PPD from getting help and seeking support (Cenat et al., 2020). Black individuals make up about 4% of Toronto's population, yet comprise 41% of children involved with the Toronto Children's Aid Society (Sekharan, 2016). In a study conducted on the causes of the disproportionate representation of Black individuals within child welfare systems, research revealed that when child welfare agencies receive a report to investigate a situation, Black families are investigated twice as thoroughly and frequently as white families are (Cenat et al., 2020). This results in a larger number of Black children being taken away from their families and placed into the child welfare system (Fluke et al., 2003). The cause for this targeting of Black families is due to systemic racism, which is based on the prejudice that Black families are less capable of raising children, and that Black mothers are unfit and unable to fulfill the needs of their children (Sekharan, 2016). This discrimination that undermines the bond that Black mothers have with their children has led to many of them being fearful of the child welfare system (Roberts, 2020). As a result, Black mothers tend to make an extra effort to steer clear from any kind of situation that could indicate to authorities that they are not capable of raising children (Fluke et al., 2003).

This fear has been identified as a cause of Black mothers not seeking help for their postpartum depression (Roberts, 2020). Black mothers fear mental health professionals reporting their family to Children's Aid Services, which can get their children unnecessarily taken away from them (Remar et al., 2018). A Black mother was interviewed about her battle against PPD and stated: "You're afraid to say it because you think the next step is to take your children away from you...You're young and you're African American so it's like [people are thinking], 'She's going to be a bad mom.'" (Pattani, 2019: p.10). Within the article written by Feldman et al. (2019), many BIPOC women echoed the sentiments of Portia Smith, stating that they had to choose between suffering from PPD without help or having their children taken away by Children's Aid authorities (Pattani, 2019). Black women feeling obliged to suffer through postpartum depression without support is not only detrimental to their mental and physical health, but can also negatively affect their children (Kozhimannil et al., 2011). If PPD goes untreated, infants can suffer by forming an insecure attachment with their mothers, which can have negative behavioral implications for these children in the long term (Kozhimannil et al., 2011). Suffering from PPD without support can also result in substantial losses in areas including housing and employment (Remar et al., 2018). Thus, it is critical for maternity care professionals to provide culturally safe support for

Black mothers, allowing them to feel safe and supported after they have given birth, without feeling obliged to suffer in one way or another.

Research conducted by Negron et al. (2013) on support for postpartum mothers has also revealed that inadequate social support is a large predictor for postpartum depression. Many forms of social support lack cultural specificity, and fail to address the needs of mothers who are not Caucasian (Gray et al., 2000). It is important to account for different support and resource requirements that mothers from different ethnicities and races may need. For example, Black women typically rely heavily on family members such as their partners, mothers, and sisters to support them after they have been discharged from the hospital (Negron et al., 2013). In contrast, white mothers usually rely on more formal means of support which can include doulas, midwives, and maids (Negron et al., 2013). Thus, offering formal and institutionalized services for Black women may not be a culturally sensitive method of offering support. Providing resources and support via informal caregivers of Black mothers, such as their sisters, mothers, and partners, may be more impactful. When thinking about culturally sensitive solutions to support Black mothers, it is also vital to understand that Black mothers have been policed and criminalized by the child welfare and protection system (Pattani, 2019). This system functions under the assumption that Black mothers are inadequate in comparison to white mothers (Roberts, 2020). Due to this systemic discrimination, Black mothers tend to be wary of institutionalized forms of care and support, which can use any small sign of abuse or neglect as a means to take their children away. Thus, when looking to adequately support Black mothers after childbirth, it is important to consider these social circumstances which should shape the approach taken to effectively assist them.

Conclusion

This essay has expanded on how Canadian childbirth services and providers reinforce anti-Black racism through the lack of culturally specific support and services for Black women during childbirth, the lack of acknowledgement of Black mothers' pain, and the inadequate assistance provided to Black women after giving birth. This paper has illustrated the implications of these inadequacies, which have resulted in a heightened risk of Black mothers developing avoidable pregnancy-related illnesses and has caused avoidable infant and maternal mortality among Black mothers. Additionally, Black women are significantly less likely to be prescribed drugs for their pain and are more than twice as likely to develop postpartum depression than their white counterparts (Sandoiu, 2020), yet are less likely than white women to seek help for PPD. This is due to systemic discrimination, in which Black mother's symptoms for PPD are exaggerated, and can result in an unnecessary escalation of the situation (Carter & Carter, 2019).

For many years, Canada has refused to acknowledge the damaging anti-Black prejudices and discrimination within the healthcare delivery field, which leaves Black women fighting for their lives. Anti-Black racism has only recently been declared a public health emergency by Ontario Health (Canadian Public Health Association, 2018). Canada's complacency towards anti-Black racism within the healthcare field is amplified through the lack of collection of race-

based data, which contributes to growing health disparities. Consequently, Black women and infants are forced to live lower quality lives and have fewer life chances than their counterparts socially, culturally and physically.

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The Dismissal of Indigenous Environmental Leadership, its Impact on Health, and Teck Resources' Proposed Frontier Oil Sands Mine Project

HODMAN ABUKAR

In an era of global environmental change and climate change (Smith, 2010), environmental concerns have become an increasingly pressing matter to be addressed by states and those in positions of power. More specifically, the use of unsustainable practices like the mining of fossil fuels has been under increasing scrutiny, as a result of various markers of climate change, including but not limited to the melting of polar ice caps (Smith, 2010). However, to many, it appears that this pressure has not led to substantial action in halting or dramatically decreasing unsustainable practices in Canada.

Introduction

Detriment to the environment is by definition detrimental to the health of humans and wildlife. The environment, and more specifically, the impacts of climate change as a determinant of health, is wide-ranging in its scope. From pollution and air quality to walkability, the accessibility of green spaces, where we live, and the health of our surrounding wildlife, has a clear impact on our physical and mental health (WHO, 2012). This is particularly relevant to certain Indigenous communities, many of which are afflicted by a lack of access to traditional foods which directly impacts rates of chronic disease (Sharma et al., 2013). With that said, it is critical that environmental leadership in Indigenous communities in Canada are engaged with and paid attention to, considering the negative effects a degraded environment has been documented to have on human health. Unfortunately, this is often not the case.

Throughout history, issues of climate change and unsustainable practices have frequently intersected with Indigenous affairs and violations of First Nations rights in Canada (Amnesty International, 2016). This has been demonstrated, for instance, in the 'Idle No More' movement under Stephen Harper's Conservative government. At that time, the federal government sought to amend parts of federal legislation protecting First Nations environmental rights in order to expand natural resource projects (Webber, 2016). Canada has a long history of this kind of state-sanctioned infringement on First Nations rights and treaties. This was evident during the Oka Crisis of 1990, a historic standoff in Quebec regarding the expansion of a golf course onto a historical Indigenous burial ground (Morris, 1995), and the more recent Wet'suwet'en Pipeline Dispute, regarding Teck Resources' pipeline project in British Columbia (Snyder, 2020).

In this paper, I argue that the discourse occurring in both public and private spheres regarding Indigenous affairs in Canada and environmental endeavours holds significant influence in the way we think about these issues. Further, as a result of the historical and systematic ignorance of and rejections to Indigenous peoples' environmental leadership in Canada, I argue that news media (among other mediums) continues to frame Indigenous environmental concerns as mere "complaints" (Snyder, 2020). This is detrimental to Indigenous communities' pursuits that aim to disrupt the progression of what are often state-sanctioned economic endeavors that threaten various environments and wildlife, and therefore human health.

The trajectory of this paper is as follows. First, I critically analyze an article published by the National Post in February of 2020 using a discourse analysis approach. This analysis will be contextualized by a brief overview of the historical erasure of Indigenous environmental concerns and objections in Canada. My intention for this paper is to make the specified claims above with the broader lenses of health equity and Indigenous equity in mind, by suggesting that the willful ignorance of Indigenous communities' environmental concerns and demands has trickle down effects that impact the health of First Nations on the individual and community level.

A Discourse Analysis of Snyder on the Frontier Oil Sands Mine Dispute

In a piece titled "Latest First Nations complaints could complicate Liberal review of Frontier oilsands mine" for the National Post, author Jesse Snyder assumes a neutral voice, at least at first glance, considering the article is filed under the 'news' section of the National Post website, as opposed to 'opinion' or 'comment.' (Snyder, 2020) In reference to claims made by Chief Allan Adam of the Athabasca Chipewyan First Nation that the provincial government "has failed to properly accommodate several of [the Athabasca Chipewyan First Nation]'s demands around the Frontier oilsands mine," Snyder uses the words "tells," "claims," (twice) and "demands." I argue that the latter two terms would have served as better word choices in opposition to the term "complaint." While it may seem unnecessary and extraneous to analyze the use of a single word, the use of the single word "complaint" is featured in the title of the article, (which is arguably the first introduction to the article any reader will have) over the words "claim" and "demand." It may be tempting to ask what the difference is between the quasi-synonymous words claim, demand and complaint at this point, but even despite the appearance of a neutral voice, Snyder uses the term 'complaint' which is not neutral. The argument can be made that the word 'demand' is also neutral in its meaning, but even when carrying negative or aggressive connotation, it also carries power in its assertiveness. The word 'complaint,' however, carries no power, but carries the connotation of a statement that is not important enough to be considered a proposition of feasibility—a statement unworthy of consideration. The word 'demand' has intrinsically attached meanings of action, whereas 'complaint' implies unidirectional conversation given that a complaint is a statement of critique, and nothing more. Further, the use of the word 'latest'

in the title (however unintentional this phrasing was) implies that there is such an excess in First Nations' 'complaints,' that the only way to efficiently categorize the disputes over Teck Resources' proposed pipeline was to deem it the most recent of the bunch. In referring to First Nations' environmental concerns as the 'latest complaints,' the discourse used in this article perpetuates certain historical notions regarding Indigenous Canadians and environmentalists, primarily that concerns grounded in both traditional knowledge and science can be regarded as yet more 'complaints,' that are unattainable or unrealistic.

Historical Erasure of Indigenous Land and Environmental Concerns and Objections

The problematic framing of Indigenous environmental leadership as 'complaining' occurs in the context of a historical dismissal of environmental pursuits from various Indigenous communities. In this section, I discuss this context by examining key events in Canadian history where similar types of dismissal are apparent—all of which have direct implications for Indigenous health and wellbeing.

The legislation that laid the groundwork for Indigenous-government relations in 1763 was an infringement upon rights in many ways, namely by setting out the ways in which the government could acquire Indigenous lands (Morden, 2016). The infamous Indian Act of 1876 is also a prominent event in Canadian history, in afflicting First Nations populations with injustice for generations. (Morden, 2016) Along these same lines, in 1969 the Trudeau government announced the government's plan to completely dispose of the concept of Indian status as well as the Department of Indian Affairs. The goals of this proposal were aligned with historical assimilation, and would have had profound effects on reserve lands, fishing and hunting rights, use of land, and economic development on reserve lands (Morden, 2016). Although the plan was never finalized, it is evident that Indigenous voices have been historically brushed aside, especially in the context of disputes regarding land and environmental affairs.

The dismissal of Indigenous Environmental leadership, post-Indian Act of 1876, can be cited at different points throughout Canadian history. One consequence of this dismissal can be seen in the "Idle No More" movement (Webber, 2016). The Harper government received backlash 2012 in response to the proposed Bill C-45, which set out to amend "key components of the Indian Act, the Fisheries Act, the Canadian Environmental Assessment Act, and the Navigable Water Act..." along with other legislative alterations, which would have allowed for additional corporate pursuits on Indigenous territories, specifically in the natural-resource sectors (Webber, 2016). The 'Idle No More' movement from 2012 to 2013 (Webber, 2016) began as a small campaign across several provinces regarding the negative impacts of Bill C-45 ("Jobs and Growth Act," 2012). It quickly gained speed when Chief Theresa Spence of the Attawapiskat Cree Nation announced that she would be participating in a hunger strike to bring attention to the unacceptable housing conditions on her reserve in northern Ontario, raise awareness about the potential detriments of Bill C-45, and to stand in solidarity with the emerging Idle No More movement. Various forms of protest erupted

across major cities, including the occupation of public spaces with traditional dancing and drumming, as well as community-led conferences, teach-ins, and public panels (Webber, 2016).

Amnesty International, in response to the proposed changes and the “Idle No More” movement (Webber, 2016), argued that the bill would have negative impacts on Indigenous peoples’ rights in Canada—even those protected by international human rights standards (Amnesty International, 2016). It is evident that not only were the environmental concerns of Indigenous people dismissed for the prioritization of economic pursuits (namely natural-resource related endeavours), but the actual health and well-being of Indigenous people (e.g., proposed changes to Environmental Assessment Act) were not prioritized. The proposed changes to the Canadian Environmental Assessment Act, for instance, would have given the federal government a wide-ranging capacity to approve natural-resource projects in spite of a negative environmental assessment or without an assessment at all (Amnesty International, 2016). This amended piece of legislation could have provided the basis for habitat loss (potentially leading to a loss of traditional ways of hunting which has been linked to chronic disease (Sharma et al., 2013)) or other environmental destruction for the sake of economic development.

In each of these instances, Indigenous concerns may have also been seen as the ‘latest First Nations complaint’ (Snyder, 2020). It is clear that historically, Indigenous voices have had less sway than that of corporations with interests in development, especially involving natural resources and land usage.

Provincial and Federal Governments’ Neglect of Climate Change

In an article titled “Choosing not to see: Canada, climate change, and the Arctic,” Heather Smith discusses the discourse that frames the conversation regarding the Canadian arctic, and suggests that discourse once used by then-Prime Minister Harper that romanticized the Arctic as “our Arctic waters” and “Our country,” actually minimizes the “depth and breadth of climate change impacts” (Smith, 2010). Although written a decade ago, Smith’s piece is incredibly impactful, as she discusses how vulnerable the Arctic is to climate change, considering its “annual average temperature has increased at almost twice the rate as the rest of the world over the past few decades” (Smith, 2010, p. 938). Further, she discusses that while melting sea ice will grant access to new natural resources (which can be taken advantage of by various private corporations or the provincial and federal governments of Canada), climate change will have a devastating impact on the habitat of polar bears, seabirds and seals (Smith, 2010). Smith also discusses the devastating cultural and economic impacts that will be experienced by Indigenous peoples, considering that traditional ways of knowing and ways of life are being “undermined by rapid environmental change” (Smith, 2010).

Snyder (2020) discusses that Chief Allan Adam’s concern regarding Teck resources’ new endeavour lies not with the project itself, but rather that the Alberta government had not fulfilled promises it previously made to mitigate the impacts of the pipeline on nearby Indigenous resources and communities. Namely, the Alberta government has failed to provide funding to restore caribou habitats

(Snyder, 2020), a key feature in the livelihood and sustenance of the Athabasca Chipewyan First Nation (Government of Canada, 2019). In this discussion, the news article omits a key piece of information: the project, which has since fallen through, would have cleared 29,000 hectares of land, some of which was inhabited by wildlife (Report of the Joint Review Panel, 2019), and would have produced 4 million tonnes of greenhouse gas emissions per year (Vaessan, 2020). It is evident that this project would have had negative environmental impacts, and thus negative impacts on nearby Indigenous communities. To omit this context from Chief Allan Adam's concerns is to provide an incomplete, weakened perspective, making it easier to dismiss. Further, the article only represented the concerns of Chief Allan Adam. It neglected to mention "Reject Teck", a mass movement occurring across Canada at the time, aimed at bringing light to similar environmental concerns (Vaessan, 2020). By not including the perspectives of any other key players in the Teck Resources dispute who shared the views of Chief Allan Adam, the article diminishes not only the importance of environmental activism and Indigenous environmental leadership, but the issue's importance.

It is clear that there is substantial scientific evidence to quantify the effects of climate change. Nevertheless, actions at the state-level continue to prioritize economic and natural-resource-related endeavours—the latest of which would have been the Teck Resources proposed project. Related Indigenous environmental concerns continue to be dismissed, be it regarding a pipeline proposal, the development of a golf course on sacred Indigenous lands (Morris, 1995), or even the security of safe drinking water (Amnesty International, 2016).

Intersection of Indigenous Affairs in Canada, Health Equity and Environmental Concerns

The dismissal of Indigenous environmental leadership has had extremely detrimental implications for the health and wellbeing of Indigenous peoples. For instance, it was only recently that the provincial and federal governments made the decision to pay for the cleaning of Boat Harbour in Nova Scotia. This decision came decades after the harbour began to be contaminated with mercury, chloride, dioxins and other toxins via a nearby paper mill. The toxins afflicted the Pictou Landing First Nation with skin conditions, elevated rates of cancer, and respiratory problems (Mercer, 2020). This contamination further prohibited Indigenous communities nearby from using the harbour to fish (Mercer, 2020). It is well researched in the literature that a lack of access to traditional foods has a profound impact on First Nations Canadians, especially with respect to food insecurity and chronic disease (Ford & Beaumier, 2011).

The neglect of environmental leadership, and specifically that of Indigenous Canadians, manifests itself as disparities in health outcomes. In turn, it must follow that environmental concerns and objections from Indigenous communities in Canada are taken seriously. This, combined with evidence from scientific literature, seems to be a far cry from a mere 'complaint' (Snyder, 2020). It seems to be an unfortunate reality that concerns voiced by Indigenous communities regarding environmental detriment are addressed only after physical and mental realities have manifested themselves in Indigenous populations. And even when

physical and mental consequences are predicted with evidence before trickle-down effects can be observed, these predictions are dismissed. For instance, members of the Pictou Landing First Nations have said their efforts to close the paper mill that wreaked havoc on Boat Harbour in Nova Scotia had been ignored for decades (Baxter, n.d.).

Conclusion

In analyzing the discourse used by Snyder (2020), it should be acknowledged that one National Post contributor is not the sole or largest perpetrator of hundreds of years of neglect of Indigenous and environmental affairs alike. However, discourse analysis of this news article is extremely relevant, especially in an age of information, when we consider that analysis of the way we discuss issues allows for a better understanding of those issues. When Indigenous environmental concerns are characterized as mere ‘complaints,’ concerns that are rooted in scientific fact, valuable traditional knowledge and often public support are given no power. In brushing aside the perspectives of Indigenous communities in Canada, a long history of neglect and shame is perpetuated, that will in time re-emerge, with a different face, in various ways—be it in health disparities today, or the extremities of climate change in the near future.

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Patient Non-disclosure in *The Farewell*: A Case of Cancer, Culturalism, and Clinical Ethics

AMBER XINYANG YE

The *Farewell* (Wang, 2019) depicts the issue of disclosure of terminal diagnosis to patients in a non-Western setting. Set in contemporary China, the movie explores the shock and ambivalence experienced by a “westernized” Chinese-American, Billi, as she encounters the complex ethical web surrounding her grandmother’s terminal cancer diagnosis. Billi’s great-aunt is the first to receive the grandmother’s cancer diagnosis and the prognosis that she has mere weeks to live (Wang, 2019). The great-aunt, who is the grandmother’s younger sister, decides to conceal the news from the grandma. This lie becomes a family lie when relatives decide to host a mock wedding as an excuse for all extended family to visit the matriarch one last time.

Although the film avoids an explicit moral statement, it challenges several major principles of Western biomedicine – including transparency and patient autonomy. The story presents a convincing argument for patient deception in the case of terminal diagnosis, at least in its specific cultural context. My essay will analyze the moral underpinnings of the non-disclosure approach represented in the film, and the assumptions that the film makes about cultural differences. Utilizing concepts from medical anthropology, I argue that the film portrays a coherent ethical context within which the motivations for patient deception or non-disclosure are valid; however, the story does not critically reflect on the potential of the non-disclosure approach, and instead offers a problematic example of culturalism in public discourse and medical practices.

Culturalism, according to anthropologist Didier Fassin, describes the discourse in global health that attributes any clinical non-compliance or variance to the “cultural factors” or “traditional attitudes” of the population in question (Fassin, 2001, as cited in Ugwu, 2019, p. 1). This essay will include a discussion of the negative impacts of such assumptions. By incorporating scholarship on cancer, care, and terminal-diagnosis communication, I will first unpack the moral values surrounding patient deception in the film, and then criticize the overuse of the culturalist discourse in the film and related review articles. Media plays a significant role in shaping the public understanding of medical ethics and morals of care (Blidook, 2008). Therefore, through this cautionary analysis, I intend to point out the risk of representing the issue of diagnosis disclosure through the cultural lens alone. This essay calls for a critical examination of culturally-specific disclosure practices and further research on how terminal illness disclosures affect the health outcomes or experiences of different patients.

Unpacking Deception

The Farewell follows the protagonist, Billi, as she gradually consents to lie to her grandmother; in this process, various members in Billi's family bring up strong arguments explaining that hiding the diagnosis from the family matriarch is the right thing to do (Wang, 2019). The relatives' argument involves two key points: first, fear would kill the patient sooner than cancer; second, it is the family's responsibility to share the emotional burden of the disease for the patient (Wang, 2019).

The first argument focuses on the fear of cancer, which produces so much discomfort that it would only compound the physical suffering of the sufferer. The relatives believe that by hiding the cancer diagnosis, the grandmother would be spared from this tremendous fear. In the film's context, cancer is considered a death sentence: "we have a saying...if you get cancer you die," says Billi's mother (Wang, 2019, 0:12:08). Similarly, Susan Sontag, in *Illness as Metaphor* (2001), theorizes that the fear and secrecy around cancer has to do with the difficulty of coming to terms with death (p. 8). This connotation of the cancer diagnosis contributes to the widespread fear of the disease in various cultural contexts, and the assumption that fear itself can fuel the progression of the disease: as Billi's mother explains, "it's not the cancer that kills, it's the fear" (Wang, 2019, 0:12:15). The family believes that the news of the diagnosis would instill tremendous worry and despair that would harm the matriarch's spirit; this belief could also stem from their own discomfort around talking about cancer. Sontag (2001) points out that "any disease that is...acutely enough feared will be felt to be morally...contagious" (p. 6). In other words, the fear of cancer and death impacts how the relatives themselves process the news of the matriarch's illness. As Sontag (2001) succinctly concludes, "all this lying to and by cancer patients is a measure of how much harder it has become...to come to terms with death (p. 8); the fear of cancer and death that the relatives experience could contribute to their decision of avoiding the disclosure conversation.

On the surface, the family's reason for lying is their concern for the grandmother's mental wellbeing, which they believe is correlated with her physical condition (Wang, 2019). However, there might be deeper layers of assumptions regarding the conceptualization of illness. The idea of allowing the patient to avoid mental suffering differs from western psychiatry's approach, which emphasizes treatment over prevention. The family wants to prevent further emotional suffering or worsening of conditions, and to manage the patient's experience of illness. They want to let the grandmother continue with her demeanor. As Aunt Ling puts it, "if you tell her, you'll ruin her good mood" (Wang, 2019, 0:35:15). The relatives' act is simultaneously preventative and preservative. It prioritizes preserving the patient's current mentality, behavior, and quality of life. It also acts upon the wish of keeping peace and normality, both within the patient herself and the family. Managing the patient's illness experience seems strategic according to Arthur Kleinman, who claims that illness experiences—both inner and social experiences—can "either amplify suffering...or dampen symptoms and therefore contribute to care" (Kleinman, 1988, xiii). A patient's experience is an important part of healthcare, where a positive experience may have therapeutic value. By

keeping the patient in the dark and putting on a show, the family attempts to create better inner and social illness experiences for the grandmother in order to improve her life chances and outlook. The second argument showcases the relatives' specific interpretation of care.

Stevenson (2012) alerts us to an issue in public health and medical practices that she terms "bureaucratic care," which involves the worry that "one cares, but indifferently" (p. 593). She argues that while the state and its institutions attempt to maintain the physical life of the sick, the "care" is impersonal (Stevenson, 2012). This impersonal care by the Canadian state manifested in their tuberculosis campaign among the Inuit, where the physical survival of the Inuit were politicized and prioritized over the Inuit's agency and psychosocial needs. The (health)care team, by forcefully separating families and relocating suspected TB patients, caused irreparable harm and trauma, and demonstrated the bleak reality of the state's power over Indigenous bodies. The care was forceful and "bureaucratic"; it did not seek consent or show any regard to the patient's autonomy and identity (Stevenson, 2012). The Farewell, however, represents a model of care different from the centralized, bureaucratic one. The medical professionals and the relatives attempt to care about and for the patient by taking her responses and life realities into consideration when deciding whether to disclose the diagnosis. Regardless of its legitimacy, this form of care—care by deception—arguably perceives the patient as more than just a biological being. At the very least, it treats the patient as a human being with psychological and social needs, even though the patient's autonomy might also have been breached in this process.

Further, the family's model of care also involves communal participation, as it is expressed through sharing the "burden of truth" (Wang, 2019). When Billi challenges her Uncle Haibin, asking if they can tell her grandmother (Nai Nai) the truth, Haibin replies, "you want to tell the truth because you are afraid to take responsibility for her, because it's too big a burden...We're not telling Nai Nai because it's our duty to carry this emotional burden for her" (Wang, 2019, 1:03:06-03:24). In his argument, concealing the truth is equated to sparing the grandmother a significant burden, which is an effort supposedly shared by the entire family and even the extended family and friends—including all those who attended the mock wedding that was meant as a goodbye ceremony. Lochlann Jain (2007) considers cancer as a "communal event" which involves bringing "the private [illness experiences] into the public domain" (p. 516). Jain (2007) envisions alliances of real people, cancer patients, and the wider public, to acknowledge the brutal realities of the disease and to focus on prevention in addition to treatment. In the case of *The Farewell*, the gathering of people, who hail from various parts of the world and are all complicit in the lie, creates a communal event while the patient herself is "blissfully" unaware (Wang, 2019). Unlike what Jain envisions, however, the word cancer is never mentioned in this event of mourning. While the approach is communal, the ugly truth of cancer is still kept under the table—masked by toasts and joyful celebration. Regardless, this wedding provided a space for farewell and remembrance—and a continued fulfilment of the shared duty (of carrying burden) that Uncle Haibin deemed so culturally significant.

This model of communally processing diagnosis and expressing care to the patient sheds light on the potentials of employing alternative ethics. Joseph

Dumit (2010), studying pharmaceuticals in the U.S., states that there is a “new grammar of illness” that disseminates through “authoritative discourses of science and medicine” (p. 38). This new norm leads to “objective self-fashioning,” a process through which one recognizes the self as a patient, and their “new identity appears to have been verified as one’s real and objectively true identity” (Dumit 2010, p. 47). Dumit (2010) claims that western biomedicine (pharmaceutical marketing in particular) is inherently working on, interpellating, and persuading the individual to see oneself as a patient regardless of factual diagnoses. Given this, the non-disclosure approach in the film can be read as a way of resisting a strictly medicalized life—or resisting seeing oneself (or one’s loved ones) purely as a patient of a fatal disease. In the film, the doctor—an authoritative figure—lied to the grandmother about her actual condition; the grandmothers’ caretakers also actively lied about the medication she must take, saying that they are “just vitamins” (Wang, 2019, 0:29:04). This exemplifies a situation where the patient is supposedly spared from viewing herself as a cancer patient, since she is not directly targeted or mobilized into that self-awareness. The healthcare authority does the opposite of labelling the patient: they actively deceive her, convincing her that there is just “some infection” (Wang, 2019, 0:47:42). Nonetheless, the doctor is likely still pushing out medications to the relatives—presumably following the relatives’ will or building a stable, long-term client relationship with the patient-family entity. Though the grandmother’s disease is still medicalized, she avoids self-identification as a cancer patient, which could have subjected her to various behavioral expectations common in the North American context such as “fighting” cancer, seeking treatment, or joining a support group.

A Culturalist Case of Ethics

The Farewell challenges some of the common assumptions in North American healthcare, but it represents a specifically culturalist view that fails to sufficiently address the complexity of the issue. The story in *The Farewell*, based on the director’s real experience, is specific and authentic to its locality. However, the characters often use generalized statements that construct the absolute binary between the “East” and the “West,” which could be misleading if viewed without critical thought (Wang, 2019). The issue of patient nondisclosure might be culturally specific, but it pertains to more than just culture. As a result of the film’s framing, most media reviews interpret the film as a “cultural clash” story (Ide, 2019) without considering the impact of the film on public perception of morality in illness-related scenarios.

When Billi confronts the prominent male figure in the family, Uncle Haibin, Haibin speaks to her with conviction: “you guys moved to the West a long time ago. You think one’s life belongs to oneself. But that’s the difference between the East and the West” (Wang, 2019, 1:02:38-1:02:43). He further explains that “in the East, a person’s life is part of a whole—family, society,” which is opposite to the western norm of “one’s life belongs to oneself” (Wang, 2019, 1:02:45-1:02:58). This speech, which occurs the night before the wedding, is a crucial moment in the film’s narrative. The patriarch Haibin demands that Billi follows his orders by

arguing that Billi is in the wrong, and that she does not understand the cultural norms of “the East” (Wang, 2019). However, by focusing on “cultural difference” alone, this argument is unproductive and coercive: Haibin discredits Billi’s argument based on Billi’s identity as an outsider, not on the validity of her point. A powerful figure in the family, Uncle Haibin uses a scare tactic and otherizes Billi, instead of engaging in meaningful argumentation. The film might portray a realistic scene of family argument here, but this emphasis on cultural binary in this key segment of the film can be misleading. The film is not critical of Haibin’s statement, therefore permitting the idea that cultural differences are concrete, intrinsic, and able to justify potentially problematic actions.

Indeed, American critics commenting on *The Farewell* mostly focus on the “cultural clash” aspect of the film (Ide, 2019). For example, the New York Times critic Brian Chen lists various healthcare-related lies he gathered from interviewing Asian scholars and public figures, with the “liar” being either the doctor, the relatives, or both (Chen, 2019). Chen shows that there are real cultural bases for such ways of indirect communication portrayed in *The Farewell*, arguing for a compassionate understanding of these lies (2019). Similarly, Washington Post editor Marian Liu discusses the perspectives of clinical social workers and psychologists who work with the Chinese community in the U.S., who all see diagnosis non-disclosure as a representation of the culturally-bound, “holistic approach to disease” (Liu, 2019, para. 5). Like the film portrayed, this approach entails emphasizing the connection between emotional and physical health and the preservation of peace within a community, which translates into the common practice of keeping things to oneself to avoid “worry[ing] the other party” (Liu, 2019, para. 4). Many commentators expand the issue into the non-medical sphere of life as well, emphasizing that the differences lie within Chinese cultural norms more generally.

The review articles discussed above seem to follow *The Farewell*’s culturalist narrative in discussing the issue of medical non-disclosure that the film represents. The term culturalism is often used to depict the tendency to attribute health attitudes to “local social patterns and cultural practices” (Fassin, 2001, as cited in Uwgu, 2019, p. 2). Both the film and the public discourse around the behavior of patient deception seem to “overdetermine the role of cultural factors” (Uwgu, 2019, p.2), meaning that they choose to respect this behavior only from a safe distance, without engaging in deeper analysis or considering the ethical significance of such acts independent of the cultural context.

The film’s emphasis on cultural difference could have problematic implications. First of all, this practice of non-disclosure is not commonplace across the Chinese population. The notion of the “East” is abstract: it combines traditional philosophies with modern dogmas, representing itself as a unique, unified, and unquestionable national-cultural identity. Additionally, this ethical dilemma is not only a Chinese one—it is heavily debated by scholars and practitioners, with research being done in various parts of the world including Asia and the Middle East (Yun et al., 2010; Iwai, 2020). Sontag (2001) also discusses how doctors in France and Italy often avoided communicating cancer

diagnoses directly to the patient, while in the U.S., there is more candor, in part because of the fear of malpractice suits. More recently, even in the West where individual autonomy and truth-telling are often prioritized, there are still intricate complexities in medical communications due to individual variance and social contexts (Iwai 2020; Sarafis et al. 2013). The “East vs. West” dichotomy, though having epistemological value, is not ontologically definite; it potentially masks complex cultural and social variance, as well as ethical issues in certain practices. It urges the viewer to accept the cultural explanation of the behaviors of deception without further interrogation.

The film and the public narratives surrounding it mostly stop at the culturalist account, overlooking many ethical problems raised by this case of patient deception. Examples of these neglected aspects include 1) the inability for the patient to consent and 2) the experiential gap between illness experience and disease. First, the grandmother, unaware of her physical condition or her prognosis, is fundamentally unable to consent to any treatment and medication—even though she is cognitively capable, her agency is completely removed and controlled by the relatives (Wang, 2019). Though one might argue that the concept of informed consent is variable in different contexts, this case still demonstrates a violation of the patient’s personhood and will, even though it follows (and reproduces) a specific cultural script. Second, “illness,” in Kleinman (1988), is the “innately human experience of symptoms and suffering” (p.3, 5) while “disease” is interpreted through the doctor’s trained perspective. One often expects to receive a medical diagnosis that mirrors, validates, and explains the illness experience, so failure to receive a valid diagnosis could make the patient feel unseen, causing emotional stress.

These two aspects—lack of consent and the mismatch between experience and diagnosis—do not seem justifiable with the “good lie” argument (Chen, 2019) that the film portrays. Deceiving the patient could cause various kinds of psychological harm, whether the patient realizes the truth or not. These are relevant considerations that the media representation of this issue should include in order to form a coherent, informative account. Instead, the film and related media commentaries mostly reduce these ethical complexities to seemingly unharmed “cultural” differences.

The culturalist account, masking these serious ethical oversights, is dangerous for the public because it could make it easy for people and institutions to embrace and perpetuate norms or practices without critical consideration. Also, the film and the reviewers did not entertain the other side of the argument—that full disclosure, followed by support, could potentially lead to positive emotional wellbeing for terminally ill patients. Lucas (2017), reviewing the BBC documentary *A Time to Live*, argues that terminal diagnosis could open up new possibilities, including allowing individuals to “project manage their own deaths” (p. 1158). The grandmother in *The Farewell*, however, is trapped within a cultural script where her personal autonomy is shifted onto her relatives. Additionally, there are various ways to go about disclosing a terminal diagnosis. Magrane (2018) proposes that it is important for doctors to deliver a terminal diagnosis

without setting a definite timeline on illness progression, which depends on many variables. Offering “a range of possibilities” rather than a single estimate might be helpful to avoid instilling panic (Magrane, 2018, para. 12).

Conclusion

Overall, the issues around delivering medical information in *The Farewell* are relevant in today's healthcare contexts, regardless of cultural background. With more and more parts of China transforming into neoliberal economies, the young, urban population have partially adopted individualism and personal autonomy as behavioral principles, proving that culture is neither static or clearly divided along state or ethnic boundaries. More importantly, the film and the related discourse reflect the current trend of increasing cultural competence in healthcare. According to Gregg and Saha (2006), cultural competence training in medical education often emphasizes boundaries and norms, and could reinforce racial and ethnic stereotypes. As a critically-acclaimed film by an Asian director with an all-Asian cast, *The Farewell* portrays a powerful case of cultural variance in medical communication; but it should be more cautious about what the story implies to its audience, practitioners and the public alike, and whether it creates or reinforces any ethnic stereotypes. The film's lack of critical nuance could lead to further dichotomization of cultural differences and an acquiescence that permits otherwise contentious practices.

Finally, I want to draw on what Iwai (2020) calls “empathic doctoring” as an alternative for following any strict cultural scripts, like the one depicted in the film. Iwai (2020) argues that empathy transcends cultural competency; an empathetic doctor acknowledges that all terminally-ill patients are different individuals situated in complex social and cultural networks. This suggestion prompts practitioners and relatives to examine all possible scenarios and reach an informed decision on what, how, and when to disclose diagnoses in order to serve the patient's best interests. In these communications, case-by-case discretion is essential, and non-disclosure should only be used when essential. More empirical evidence is needed to develop better protocols that protect the agency and wellbeing of terminally ill patients, with consideration of patients' varying personal and health backgrounds.

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How Historical Interventions from the Global North have Facilitated the Overrepresentation of PWID among PLWH Populations in Vietnam

MARY NGO

In 1986, the Vietnamese government implemented the Doi Moi Policy (Chinh sach Doi Moi), which, aided by foreign investments, allowed for a transition towards a market economy and a more industrial mode of production (Do et al., 2012; Giang et al., 2013). As a result, Vietnam experienced very rapid urbanization and growth of their tourism industry. These developmental changes had an immense social impact, increasing the prevalence of sex work, as well as drug use and trafficking. Simultaneously, Vietnam also experienced a rising prevalence of HIV, with the first Vietnamese case reported in 1990 (Do et al., 2012). Do et al. (2012) found the HIV Sentinel Surveillance (HSS) prevalence rate of HIV to be 33.85% in 40 Vietnamese cities and provinces. Today, the Joint United Nations Programme on HIV/AIDS (UNAIDS) (n.d.) estimates that there are approximately 230 000 people currently living with HIV in Vietnam.

The following is an investigation of the population of people who inject drugs (PWID) in Vietnam and their disproportionately high susceptibility to HIV infection. This report will explore the colonial history of drug use and Western intervention in Vietnam, how it impacts present-day drug use policies, and how these policies translate into increased HIV susceptibility for this population. First, Vietnam's history with illicit substances will be presented. This overview will include the Global North's (also referred to as "the West" throughout) intervention in Vietnam via French colonialism, as well as American involvement in the Vietnam War. Then, an analysis of recent drug use policy, legislation and societal perception will be conducted. This analysis will focus on how these factors impact the safety behaviours of PWID, thus contributing to their greater susceptibility to HIV infection.

Colonialism, Western intervention and drug use in Vietnam

Due to its geographic proximity to the Golden Triangle Region—a location of important traffic and trade routes in Southeast Asia—Vietnam has a long-standing history with the production and consumption of opium since its introduction to the country in the seventeenth century (Do et al., 2012; Truong et al., 2020). Opium was originally used for medicinal purposes, but its harm as an addictive substance did not remain unnoticed (Ttruong et al., 2020). Subsequent efforts by the Vietnamese government to limit the spread and usage of opium were hindered, however, by France's occupation of Vietnam (Truong et al., 2020). The French very quickly established a monopoly over the substance, regulating the production and sale of opium in Vietnam to financially support their colonial

rule (Truong et al. 2020). They implemented a tax on opium, which comprised more than half of the colonial state's revenue (Truong et al., 2020). To further ensure its spread, prices for opium were eventually reduced to make it more accessible to low-income Vietnamese people (Truong et al., 2020). Thus, by 1918, there were nearly 5000 dens and shops dispensing opium, and by the 1940s 2% of the Vietnamese population in Vietnam had used opium (Truong et al., 2020). The poppy, from which opium is extracted, became a symbol of French intervention and oppression, as well as financial colonialism (Truong et al., 2020).

As such, following the country's liberation in 1945, President Ho Chi Minh and the new Vietnamese government declared opium a “*te nan xa hoi*,” which translates to “social evil,” prohibiting its consumption and production (Truong et al., 2020). Shortly after, however, heroin, cannabis and amphetamine consumption rose during the ongoing Vietnam War between North Vietnam and the United States of America (USA) (Truong et al., 2020). By the end of it in 1975, there were approximately 300,000 people—both Vietnamese and American—using drugs in South Vietnam (Truong et al., 2020). The post-war Vietnamese government sought to reduce drug usage through the introduction and implementation of new policies (Do et al., 2012). However, the 1986 Doi Moi policy expanded the drug market in Vietnam via a shift towards a market economy funded by foreign investments (Giang et al., 2013). This policy change allowed for a new rise in prevalence of substances like heroin and amphetamine-type stimulants, further complicating the situation of substance use in Vietnam (Giang et al., 2013). The Vietnamese government viewed drugs as an external contaminant from the Global North, based on the role Western countries, like France and the United States, played in the introduction and spread of drug use in Vietnam. Thus, ensuing action was taken to outlaw their usage (Giang et al., 2013; Truong et al., 2020).

On the other hand, Truong et al. (2020), argue that the implemented punitive anti-drug policies created an incredibly outdated narrative of harm around drugs facilitated by contempt for the Global North. As an example, throughout the 1990s, cannabis was mischaracterized as one of the most dangerous drugs in existence, on par with methamphetamine and heroin (Truong et al., 2020). Furthermore, nationalist anti-drug discourse painted Vietnam as a moral counter to the evils of the West, which includes drugs (Truong et al., 2020). While this rhetoric and the aforementioned policies against drug use come from a place of distrust in the Global North, which was well-earned given the harm colonialism and Western intervention have had on the situation of drug use in Vietnam, the framing of drug use as a social evil has created a fearful, criminal, and punitive environment surrounding it (Truong et al., 2020). This extreme characterization of drugs can isolate those who use drugs and/or are struggling with addiction, restricting their access to education, outreach and employment. People who use drugs, as a result, may be hesitant to access health and social services for fear of punitive action being taken against them. An example of this is the instance of individuals not calling for an ambulance during an overdose, worried that, if they do, it will draw attention to their drug use and invite legal repercussions (Truong et al., 2020, para 13).

These policies and laws against drug use stem from the incorrect conflation of drug use with addiction. The social attitude towards drug use in Vietnam

during this period labelled all people who used or had used drugs as addicts in need of treatment at compulsory treatment centres, regardless of the context and frequency of usage (Truong et al., 2020). These centres were established in 1993 to re-educate, punish, and rehabilitate people who use drugs (Giang et al., 2013). These beliefs and the climate surrounding drug use that arose from them stem from a moral model of addiction that supports punitive responses (Truong et al., 2020).

Many of the interventions implemented by the Vietnamese government to remedy addiction acted at the individual level, blaming drug use on the person who uses the drug (Truong et al., 2020). These notions of individual blame were reinforced further by propaganda and the media. Both of them were controlled and used by the government to advance anti-drug sentiment, characterizing drug use as a significantly more serious problem than it actually was while painting drug users as weak and morally corrupt (Tria Kerkvliet, 2018; Truong et al., 2020). Despite the Vietnamese government's efforts to eliminate drug use, Do et al. (2012) reported that Vietnam recently ranked sixth in East and Southeast Asia for total PWID.

Due to the colonial history of drug use, it is met with distrust by the Vietnamese people, which has been leveraged by their government to fuel harmful narratives surrounding drug use that demonize people who use drugs (Truong et al., 2020). As will be discussed, these narratives can have profoundly negative effects on their well-being, especially with regards to injection drugs and their users.

The intersection of HIV and injection drug use in Vietnam

HIV comes with its own array of discrimination (Go et al., 2017). A 2004 study conducted by the United Nations in Vietnam found that 30% of interviewees believed that a person living with HIV should have their employment terminated (Thi et al., 2008, p. 64). Furthermore, 80% believed that, in addition to dismissal, their HIV status should be made public (Thi et al., 2008). Interviewees in another 2004 study revealed that discriminatory behaviours toward people living with HIV (PLWH) were motivated by a fear—an unfounded one, but a fear nonetheless—of transmission through casual contact (Thi et al., 2008).

The stigma associated with illicit substances, including injection drugs, is often connected with other stigmas, most notably HIV. As such, in the early days of the HIV epidemic in Vietnam, HIV and injection drug use were considered “twin epidemics,” compounding each other's associated stigmas (Giang et al., 2013, p. 43; Thi et al., 2008).

Injection drug use plays an incredibly significant role in the Vietnamese HIV epidemic. In 2000, 63.3% of reported HIV cases in Vietnam were attributable to injection drug use (Do et al., 2012). As of 2019, the prevalence of Vietnamese PWID living with HIV is 12.7% of approximately 189,000 total PWID (UNAIDS, n.d.). Despite this reality, HIV treatment access for PWID remains relatively low. PWID were found to have a poorer retention of antiretroviral therapy (ART), with

a rate of 63.3% at 60 months, compared to the rate of 85.7% at 60 months for people who do not inject drugs (Giang et al., 2013).

PWID are made particularly susceptible to HIV infection through unsafe injection practices, primarily through the use of contaminated injection equipment (i.e., needles, syringes, drug solution, rinse water, etc.) (Do et al., 2012). Although Giang et al. (2013) reported that needle sharing has decreased since the 1990s, Do et al. (2012) found that large regional networks of PWID sharing injection equipment were responsible for an increase in yearly HIV infections of at least 20%. More than 50% of PWID respondents in a recent study claimed to inject drugs at least once a day, with the majority of them doing so at shooting galleries or in the streets (Do et al., 2012, p. 480). Drug users will also sometimes have someone else inject them—usually a shooting gallery owner, a drug dealer or a fellow PWID (Do et al., 2012, p. 480).

Sharing injection equipment is unfortunately quite common. Needle sharing among PWID is reported to range anywhere from 14% to 23%, with drug dealers claiming to have used one single syringe on up to 100 individuals (Do et al., 2012, p. 480). Of the PWID who were HIV-positive, 18.9% confirmed that they have borrowed used needles/syringes and 16.4% confirmed that they have shared used needles/syringes (Do et al., 2012, p. 481). When asked about these sharing practices, the individuals revealed that they believed that borrowing syringes was safer than lending out their own (Do et al., 2012, p. 481). This misconception is indicative of a lack of equipment safety education, yet Do et al. (2012) found that the majority of PWID interviewed were quite knowledgeable of the main modes of HIV transmission (p. 481).

There are many reasons beyond lack of awareness that can explain why PWID may find themselves sharing injection equipment, especially needles and syringes, which suscept them to HIV infection. A common practice among PWID in Vietnam is pooling money to purchase a drug, and then sharing the injection, seemingly to divide drug costs (Do et al., 2012). There are several reasons related to the stigma associated with injection drugs (and illicit substances in general) that also facilitate unsafe injection practices. Many PWID, fearing police arrest and legal repercussions due to the government's demonization of injection drugs, will not carry their own needles or syringes, opting to use shooting galleries instead (Do et al., 2012). Given the prevalence of needle sharing, there have been attempts introduce peer educators to these shooting galleries for the provision of needle exchange services. However, many PWID believe that peer educators will attract police and, therefore, avoid visiting when peer educators are present (Do et al., 2012). In this manner, the criminalization of injection drugs and other illicit substances is not only facilitating unsafe practices, but preventing people from accessing safer ones.

Legal repercussions are not the only factor preventing PWID from engaging in safe injection practices. Scholars have identified that due to the growing presence of stigma surrounding illicit substances, PWID avoid needle exchange programs, fearing their participation in these programs will publicly associate them with injection drug use (Lan et al., 2018). Furthermore, much like PLWH, PWID experience discrimination and mistreatment at the hands of healthcare

providers (Do et al., 2012; Thi et al., 2008). In theory, new, clean needles and syringes are easily accessible as they are available to purchase at pharmacies. However, in practice, PWID have revealed in interviews that some pharmacies refuse to sell them needles and syringes (Do et al., 2012). The effects of public perceptions of PWID, manifesting either as fear of judgement or unjust treatment by others, have become a barrier to accessing safe and sterile injection equipment for the prevention of HIV infection. Drug-related stigma can additionally stop PWID from seeking care from their healthcare provider for drug addiction (Lan et al., 2018). Stigma, in this scenario, is hindering PWID's access to the services that could very well put an end to the behaviour that said stigma is associated with.

There are many contributing factors to the barriers faced by PWID which prevent them from engaging in safe injection practices and/or accessing programs promoting these practices, as well as putting them at risk of HIV infection from injection equipment sharing. Whether they manifest in law enforcement or public perceptions, they can all be traced back to the government's punitive approach towards illicit substances as a reaction to the past interventions by the Global North in Vietnam.

Conclusion

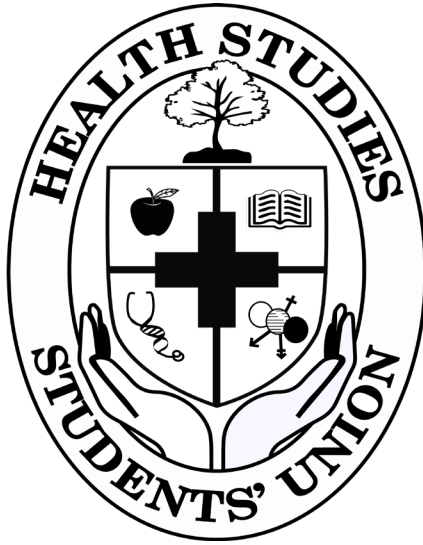
Vietnam has an extensive history with drug and illicit substance use that is not free of colonial and Global North intervention. In light of the French's use of opium to fund and maintain their control over Vietnam and its people, and the introduction of modern drugs to its population via the global market, the Vietnamese government was able to harness distrust of the Global North to advance harmful narratives concerning drug use and addiction. These narratives, and the resulting policies and legislation, have had a negative impact on injection drug users, increasing their susceptibility to HIV and facilitating their disproportionate overrepresentation among the Vietnamese population of PLWH.

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