APORIA

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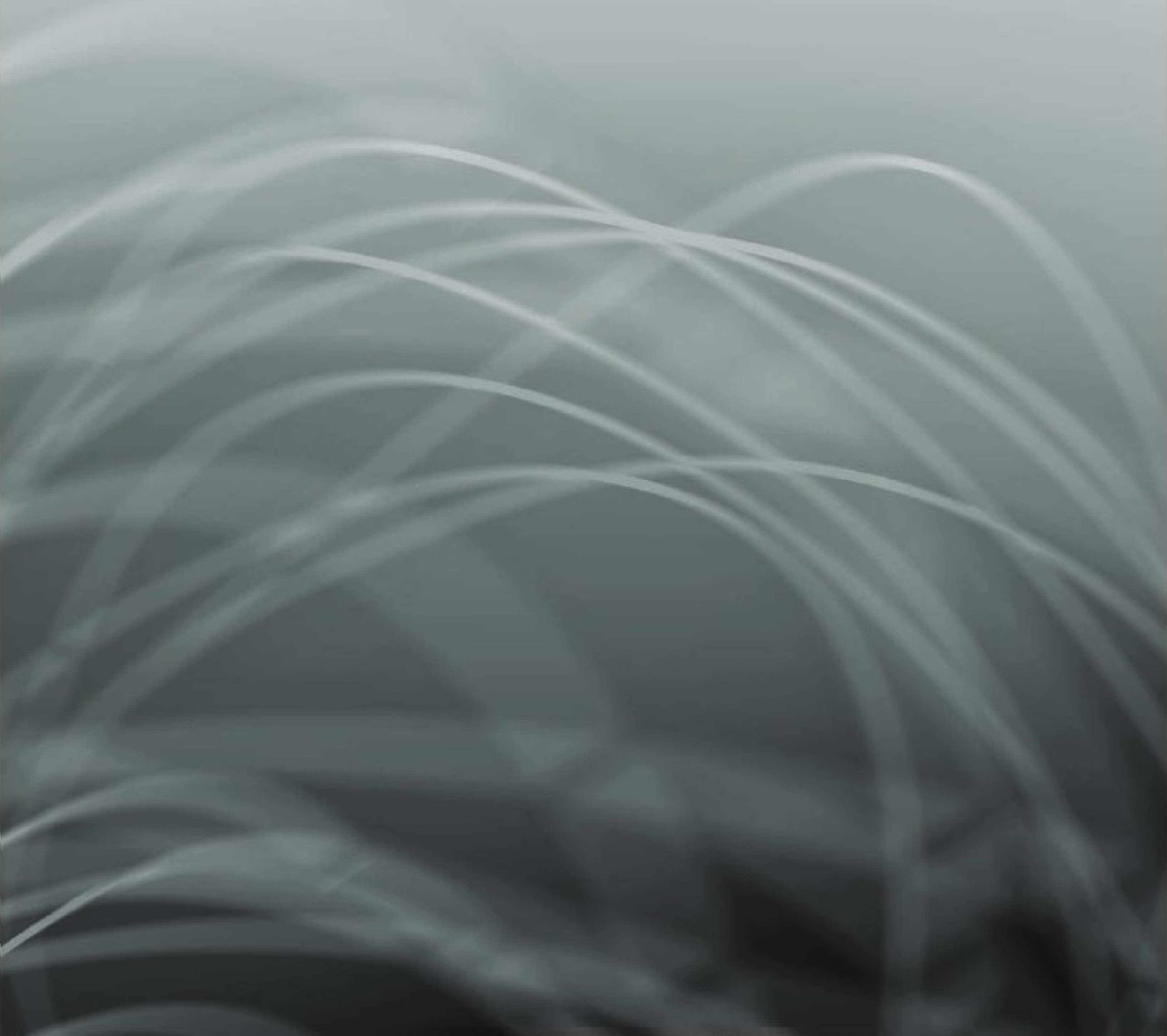

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Sommaire/Content

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Éditorial/Editorial

To the Editor:

We read with great interest the important paper on “Nursing Voices during COVID-19: An Analysis of Canadian Media Coverage”[1] and commend the authors for undertaking this study. It’s an important addition to our understanding of nurses’ voices in news media. As the lead researchers on the Woodhull Revisited Project, we want to share a correction and some additional thoughts.

First, the 2017 replication of the 1997 Woodhull Study of Nurses and the Media did not find that nurses’ representation as sources in health news stories decreased. The difference between the 4% of health news stories including nurses as sources in 1997 and the 2% in 2017 was not statistically significant, so we concluded that there has been no change in 20 years.[2] That, in itself, is astounding given the higher levels of education of nurses and, in the United States, the visibility of the Future of Nursing,[3] a landmark report that is the most downloaded document published by the National Academies of Science, Engineering, and Medicine.

Second, the authors describe the 83 news reports that included nurses’ voices as “extensive media coverage” (p110). While 83 is probably more than what one would find pre-COVID-19, it represents perhaps two instances per week of nurses’ voices being included in news stories between 1 January and 21 May. We suspect that physicians were included in at least one news story every day (and probably much more often) during that same time period in Canada. We have not systematically analyzed nurses’ representation in news media in the United States during that time, but we were impressed with seeing nurses every day in some news outlet, talking about their experiences of caring for people with COVID-19, how to prevent its spread, and the crucial issue of inadequate personal protective equipment (PPE) early on. Now, as the virus wanes in New York and early surge areas in the U.S. while it spreads to more rural areas, one seldom sees a nurse in the national news media. We contend that during pandemics such as Ebola and SARS-CoV-2 that dominate the news for a period of time, journalists compete for stories from all angles. It’s not surprising, then, that we see a bump in nurses’ being included in news stories; but what will happen when the pandemic eases? One of us (DJM) was president of the American Academy of Nursing during the Ebola pandemic and was called upon frequently when American nurse Nina

Phan was diagnosed with the disease, but calls stopped as the spread was stopped in the U.S.

Third, this leads us to encourage all nurses to be proactive in helping journalists to see nurses as experts in health, health care, and health policy, and help them to find the right nurses for their stories. Gagnon and Perron note that the Woodhull Revisited Project found that nurses and nursing organizations need to be more strategic in engaging health journalists. Our qualitative study of health journalists also found that nurses' under-representation as sources in health news was due to bias in newsrooms about women, nurses, and positions of authority in health care.[4] Journalists don't understand what nurses do and how they could inform a news story. We all have a role to play in raising journalists' awareness of the importance of adding this diverse and unique voice to stories. As we have written in a blog to journalists at the Association for Health Care Journalists,[5] we tell journalists, 'if you're not interviewing a nurse, you may be missing the best part of the story.'

The union voices that Gagnon and Perron found to be well represented in their analyses have an important role to play in developing an organized approach to educating journalists about what nurses do, finding the right nurse experts for interviews, and suggesting story ideas. They also can develop nurses' media competencies through continuing education sessions on media training, as Gagnon and Perron suggest. (For more ideas on how to increase nurses' representation in health news stories, go to www.go.GWU.edu/Woodhull.) We have been taking these actions in the U.S. and finding great interest among journalists who are women; but we have longstanding relationships with some national journalists who are men who have welcomed our story ideas that we pass along from the frontlines. We help to find journalists' nurses with the expertise the story needs. We've also coached nurses to be "media-ready" and have written Op Eds and commentaries about nurses' expertise.[6] We want to ensure that nurse experts don't disappear in a post-COVID world.

Finally, we want to applaud Gagnon and Perron for speaking about the war metaphor. We agree that we must break out of this image of nurses as expendable soldiers and replace it with one of nurses as experts in health and healing. We have a long way to go before our voices are truly valued by news media; but concur that we can and must raise the visibility of nurses as true experts in health. This includes school nurses who are so essential during this pandemic, hospice and home care nurses, and public health nurses. And as we told one journalist who said he didn't use nurses as sources because he covered the business of health care, 'Who better to understand the business of health care and it impact on patients, families, and communities than the chief nurse of a hospital who probably is responsible for close to 70% of the hospital's budget?'

It's up to all of us to make sure that the public has access to nurses' views, experiences and advice.

1.https://uottawa.scholarsportal.info/ottawa/index.php/aporia/article/view/4842/3941
2.https://sigmapubs.onlinelibrary.wiley.com/doi/full/10.1111/jnu.12429
3.https://www.nap.edu/download/12956
4.https://journals.lww.com/ajnonline/Fulltext/2018/10000/Original_Research___Journalists__Experiences_with.24.aspx
5.https://healthjournalism.org/blog/author/diana-mason-and-barbara-glickstein/
6.https://www.usatoday.com/story/opinion/2020/06/26/nurses-leaders-medicine-but-overshadowed-media-column/3223242001/

Diana J. Mason, PhD, RN, FAAN
New York, NY, USA

Barbara A. Glickstein, RN, MS, MPH
New York, NY USA

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Abstract

Definitions and understandings of the term “community health” are numerous, but generally orient themselves around an expanded understanding of health exceeding biomedical imperatives. Rethinking the conception of community health through a vitalistic approach with the idea of health, and thus the community, at its core allows for a deeper understanding of health experiences’ complexity and could eventually inspire practice innovations in community health centers. In this paper, we will present this theoretical conception of health and discuss how it can help to understand the innovative interventions approach conducted within community health centres in Canada. Specifically, the practical implications of this theoretical conception will be illustrated through two Canadian community health centres. A new perspective on health could have numerous implications for health professionals with the development of cutting-edge interventions potentially leading to change benefiting the community, but also for teaching and research innovations empowered by a deeper understanding of the wider story behind health issues.

Key Words community health, health, social norms, vitalism

Practical Implications of Understanding Community Health Through Vitalism in Canadian Community Health Centers

ELISABETH BEAUNOYER, VALÉRIE DESGROSEILLIERS, NICOLAS VONARX, & BERNARD ROY

Introduction

Community health is an interdisciplinary field that refers to a wide variety of realities[1] and overlaps with multiple areas related to health sciences, such as public health, medicine, nursing, psychology, and other social science fields. The multiplicity of community health definitions is probably no stranger to the polysemy and the ambiguity of the notion of health. From the WHO definition[2] to the Ottawa Charter’s definition[3] several definitions of health coexist, thereby generating a diversity of applications depending on their area of concern. In an effort to distinguish public and community health, Vonarx and Desgroseilliers[4] propose an epistemological reflection on how we think and construct the idea of health, and contingently the idea of community, by adopting a vitalistic approach drawn upon Georges Canguilhem’s work.[5,6] Specifically, this approach acknowledges that we cannot consider health strictly on the basis of absolute benchmarks because of the normalizing effect they have on living conditions. In vitalistic thought, health is argued not as standard to achieve and maintain, but as a condition of existence that needs to be implemented according to its own subjectivity and with respect to the rules of propriety[7] constrained by the belonging to a *milieu*, understood in the sense of social context or environment. As such, we understand that health is a living condition intimately related to the requirements of the *milieu* on a social, or even community level, and that its definition and implications are constantly disputed by the *milieu*, on the one hand, and its subject, on the other hand. This theoretical conception thus rethinks community health in light of a new conception that allows for ideologies to reach beyond practical and financial imperatives.

This idea of community health can serve as a mean to better understand what characterize the intervention practices within the Community Health Centres (CHC) and could even aid to distinguish them from mainstream healthcare in Canada. Canadian CHCs share several similar characteristics including the status of non-profit organization receiving public funding, the provision of comprehensive and integrated primary health care, and community engagement and participation.[8] Indeed, the concept of health used by health care professionals (HCPs) influences their way of looking, talking, hearing and thinking the human existence in the planning of community health-specific interventions. For this reason, thinking critically about a conception of health that stresses its epistemological and ontological grounds proves to be relevant in order to highlight the differences between a community health-related approach to care and a practice stemming from conventional medical thinking. In the first part of this paper, we will summarize the ideas underlying the vitalistic conception of community health as proposed by Vonarx and Desgroseilliers [4] (see the original book chapter for a more in-depth reflection). In the second part, we will illustrate how this theoretical conception of health applies to community health practices in a more intelligible and potentially more operational way. Although, this theoretical conception could arguably suit multiple health systems, this paper will pursue its illustration within a Canadian health care context, the one in which the initial reflection was developed. For this purpose, a short summary of the historical foundations of the Canadian healthcare system and centres will be presented. Then, we will provide two examples of Canadian centres showing how they integrated, or at least partially integrated, a conception of community health, revisited through vitalism.

Rethinking the idea of community health using a vitalistic approach

In mainstream health care, the biomedical perspective is widely integrated and accepted, according to which health appears to be understood on a binary mode, opposing its presence to the absence of disease. In this paradigm, the benchmarks that identify any pathological sign rest upon norms based on physio-biological and psychic assumptions suggesting a physical and biological body failure expressed in terms of excess or deficiency, or even a quantitative abnormality. Canguilhem introduces this notion of normality as a theoretical unit constructed by the exercise of reason and acting as a reference point in a given space and time.[9] This is what made the assessment of health using measures and variables possible, enabling the documentation of a condition labeled as “normal” or “healthy,” as opposed to “pathological.” Although various studies in social and human sciences showed that health needs to be thought as a phenomenon that also encompasses subjective and social dimensions (see the work of Herzlich).[10,12] it appears that its biomedical conception prevails for HCPs working in health care institutions and that health is almost exclusively assessed by applying objective standards. Standardizing the organism’s biological and physiological aspects supports a vision of health as a state (or multiple states) that needs to be controlled and mastered, or normalized even, by using indicators to measure observable variations and apparent gaps according to objective standards established by medical sciences. Hence, the idea of both control and determinism is fundamental to a biomedical paradigm.

At the turn of the 1960s, a certain idea of community health emerges inside a critical thinking movement about society’s medicalization, notably driven by thoughts developed by Ivan Illich in his work *Medical Nemesis: The Expropriation of Health.*[11] Questioning the biomedical paradigm is at the core of this movement, challenging the fact that health has become – according to the rules of capitalism – market value or goods to be consumed and managed for anyone willing to function within society. As such, Illich emphasizes that health essentially falls under the authority of an overspecialized medical infrastructure organized around technical services and care that strictly target the alleviation of symptoms, and therefore fails to identify the root causes of diseases, and neglects at the same time the influence of human vulnerability.[11] Illich clearly highlights the role of the various social, environmental, and political determinants on people’s health while stressing that medicine, as a factor, is far from assuming the lifesaving role it claims to have, not to mention it has been occasionally counterproductive. In the wake of these reflections, further studies highlighted the enhanced role and significative nature of multiple factors impacting health, be it family life, work and housing conditions, lifestyles, social cohesion, socio-economic status, etc. [12].

Canguilhem also articulated thoughts about health, arguing that health is not reducible to an ensemble of measurable and controllable objective factors for it touches upon more than just physiology and biology. Consequentially, the idea of health cannot be comprehended through “a continuum spanning […] from a complete state of well-being up to death and going through all possible forms of diseases and disabilities [free translation]”.[13 p87] For Vonarx and Desgroseilliers,[4] casting our eyes beyond a biomedical conception of life involves recognizing and accepting a certain freedom and free will in a subject for whom health is not defined by predetermined biomedical norms. In this context, the vitalistic approach presents itself as an opportunity to understand health differently, in part because it recognizes that forces of life produce instability, and likewise ups and downs change the way we respond to situations. Through the lens of vitalism, health is thus understood as a normative ability and, because of that, as a dynamic and subjective resource as well, or, in other terms, as a condition of life managed by a subject constrained by a milieu.[14]

Normativity

In community health, the vitalistic ideas that guide the conception of health, as presented by Vonarx and Desgroseilliers.[4] build on the work of Canguilhem and his concept of normativity. This concept suggests that health is not defined by its alignment with the norms, but rather by the individual's normative ability to establish new ones based on the situations they experience and the requirements their living milieu imposes upon them, including how they relate to the people "that matter to them." This existential mode adopted by a living being constrained by their milieu is called an "allure de vie." According to Canguilhem[6], health and disease are inseparable but do not oppose one another, which means that disease is not the absence of health and health is not the absence of disease. Instead, the latter should be understood as an event for it disrupts the existence of a living being. A subjective assessment acts as a barometer of how a given condition is or remains vital for the individual or their community and therefore nourishes their "allure de vie". Pathology arises when a disruption of the "allure de vie" brings about a reduction in their ability to create their own new vital values, norms or *milieu*, which raise a feeling of being unable to face the movement, and echoes a lack of flexibility and freedom. The idea of vitality (biological life) is thus eminently subjective, resting on qualitative thinking. Therefore, we understand that health can no longer be assessed strictly through the lens of physio-clinical objectivity and that subjectivity, both on the individual and community level, appears to be the sole voice through which feelings about life can be understood.

Health as a Dynamic and Subjective Resource

According to Vonarx and Desgroseilliers[4], the concern to think health outside of the biomedical spectrum leads us, in the light of Canguilhem's vitalistic thought, to consider health as a dynamic and subjective resource. As such, health is no longer relegated to a condition one can have but is rather understood as a resource that is constantly acquired and that makes sense solely for the individual and their living environment. It allows people to move forward in life with a plan reflecting aspirations that are, above all, personal,[14] and negotiated depending on their social belongings. Everyone has their own conception of health and illness, which results in a paradoxical, complex, and contextual concept that is inseparable from the individual, living and interacting within their milieu.[13] Here, the actor lies at the centre of the equation and their experience of health necessarily becomes subjective, as opposed to the biomedical perspective.

Implicit in the above, conceptualizing health as a normative ability, as well as a dynamic and subjective resource, requires casting our eyes beyond the individual. Indeed, their world is built collectively, within a group, the community or the society to which they belong. The idea of health is constructed upon the relationships we forge with others through negotiation, questioning and intersubjectivity. Health and milieu are not fixed as autonomous notions where the subject acts as a mid-point on an occasional basis, health rather results from the interaction between the subject and their surroundings. Thus, health shall be regarded as an ability that allows any subject to establish new standards for themselves in a complex and dynamic social living environment, by taking into account what makes sense to them, considering that everyone is continually entangled in a network of meanings – a context of existence regulated by rules of propriety enabling the symbolic management of social actors' public appearances while they interact in their living environment.

Community

Based on the above, thinking the concept of health through the lens of vitalism necessarily involves reconsidering the idea of community. Health, as per the vitalistic approach, is experienced and transformed by the dialogue based on reflexivity and negotiations between the individuals' life plan and their *milieu*.[4] Therefore, health is undoubtedly related to the social context of emergence, i.e., the community. It constitutes an essential dimension of everyone's existence because everyone is necessarily part of a world, or even several worlds. The community provides rules of propriety and brings forth semantic contents for people to use in their existence. The propriety, as proposed by Mayol[7],

> is simultaneously the manner in which one is perceived and the means constraining one to remain submitted to it; fundamentally, it requires the avoidance of

> all dissonance in the game of behaviours and all qualitative disruption in the perception of the social environment (p. 17).

The rules of propriety provide the community with an implied and unwritten form of collective agreement, which is understandable to all individuals through language and behaviour, to which any submission or transgression is necessarily noticeable.[7] The community shares a common will and it is sustained by identity markers that qualify the existential context of living together.[4]

The community carries a unique life experience where universalism and generalization do not have their place. Therefore, the intervention within a community follows a process adapted to the local context that leaves room for creativity and almost always combines sanitary and social issues.[15] This subjectivity implies instability in the responses to interventions approaches that prevents the appropriate prediction and monitoring of the results and that might have unintended effects. In order to work on a normality gap within a community, it is important to understand the norms of propriety in the milieu, which are often very stringent and impactful on the behaviours. That explains why great value is given to listening to the Other in community health, in order to ensure their participation not only in identifying the needs but more importantly, in the transformation process to express this "normativity" both from a personal and collective perspective. Indeed, giving a voice to the social actors must allow the interventions' alignment to the needs expressed by the subjects. We are thus mobilizing "the knowledge, the experiences, the expertise of the concerned actors and citizens by a given reality of health [free translation]" through a shared project producing a normative activity which aims to go beyond the discomforts of existence that are felt, experienced, and believed.[4 p19] The exercise of this normativity is inseparable from a participation that calls for the implementation of conditions that will facilitate empowerment and in which suffering has more to do with a reduced power to act, possibly even its destruction, than physical or mental pain.[16]

Rethinking the idea of community health using a vitalistic approach helps to grasp health as a condition of life that deserves to be understood according to the people's life experiences as living and interacting subjects within complex social relationships.[4] Laying out the theoretical benchmarks raises the issue of whether this perspective is applicable to health care settings or not. This conception of community health could provide a starting point and appropriate tools to identify what characterizes care practices in Canadian CHCs. It is worth noting that while this idea of health and, therefore, of community health, results from a purely theoretical approach, health care practices in CHCs might be influenced by certain political, pragmatic, financial and ideological factors.[4] Therefore, integrating such a community health approach within CHCs presents many challenges, mainly due to the paradigmatic orientation that currently dominates the Canadian healthcare system.

Illustrations of the community health vitalistic approach

Emergence of community health centers in Canada

The theoretical benchmarks introduced at the beginning of this chapter provide tools to comprehend the current community health practice in Canadian CHCs. Aligned with a legacy of dominance exerted by a growing medical authority over several centuries,[17] the Canada Health Act passed in 1984 greatly contributed to establish the biomedicine predominance in the Canadian health care system, which was essentially built around a hospital-based clinical service offer. Indeed, while the language used in the act's title expresses the idea of health, the terminology used in body of the text rather refers to the medical profession: "to ensure that all eligible residents of Canadian provinces and territories have reasonable access to *medically necessary* hospital and *physician services* on a prepaid basis"[18 p7] We see in this medical mission that the regulating forces immediately associate health to medicine, at the risk of confusing these two terms with one another. The genesis for the community health approach would result in part from "community demands in order to get the best care and [...] services [free translation]",[18 p173] which have foster the emergence of particular organizational structures that apply a health conception that transcends the biomedical perspective and which constitute local front-line service reorganization initiatives.[19] As a result of a critique of the medico-centered model and its inability to respond to the needs of vulnerable populations, the *Clinique communautaire de Pointe-St-Charles (CCPSC)* – one of the first citizens' initiatives of free clinic – emerged in the fall of 1967 in one of Montreal's most disadvantaged neighbourhoods.[20] As the citizens faced a lack of access to primary health care in their neighbourhood, they decided to develop by themselves the medical and illness prevention services they needed, rather than waiting on a system change initiated by the government.[21] In the 1960s, other clinics emerged with similar aspirations, proposing, in a sense, to deploy normativity individually, of course, but more so communally, in order to transform living environments in accordance with the citizens' well-being aspirations. This period marks the birth of a community clinic model governed by the community, one that will set trend in Quebec.

The "local community health services" (CLSCs) were introduced in the 1970s following the recommendations of the Castonguay-Nepveu Commission and found their sources of inspiration in clinics like those of Pointe-Saint-Charles and

Hochelaga-Maisonneuve in Montreal. However, as soon as they were implemented, the CLSCs' mission was hampered by the physicians' corporations which refused that their members be bound by a wage agreement and, most importantly, to lose control over the medical institutions. In order to counter the deployment of CLSCs on the Quebec territory, the physicians' corporation encouraged its members to disaffiliate from the CLSCs and to create in their vicinity private polyclinics fully controlled by physicians. Consequently, the development of community health care throughout Quebec has been deeply compromised. Today, community action is no longer mentioned in the CLSCs' mission statement and they are not sovereign institutions managed by their own boards of directors.[22] Nonetheless, initiatives going by different names and emerging in a few locations reveal, on the one hand, the vitality of the community health paradigm and, on the other, the resurgence and increase of social inequalities.

In the next section, we will present an illustration of a Quebec CHC, the *Coopérative de solidarité SABSA*, that partially integrate a community health vitalistic approach, with the deployment of individual and community normativity. A second example can push further forward the reflection by illustrating a partially integrated community health vitalistic approach in a centre outside of the mainstream healthcare. This example is the *Maison Michel-Sarrazin*, which, from where we sit, illustrates a health care practice that accepts the unique and normative nature of health in the end-of-life experience. The following analysis is not meant to be exhaustive or a perfect illustration of the vitalistic approach, but rather an illustration of the key points in each of these examples.

Individual & community normativity: The example of the coopérative de solidarité SABSA

The *Coopérative de solidarité SABSA*, created in 2011, is another non-profit organization example that has emerged from a critique of both the medical body and the marketing of health. This initiative originates from an awareness on the magnitude of the HCV and HIV/AIDS epidemic among vulnerable populations,[23] and indignation over the response offered by the mainstream healthcare organization[24]. From the start, it has endorsed the mandate to provide services to a vulnerable clientele, whose lack of health care stands out as a health priority, using a "holistic response-centered approach to the global needs of the people integrating physical health, mental health and psychosocial dimension".[24 p7, free translation] The services provided at the clinic are varied (see the website for an exhaustive description [in French only]; www.coop-sabsa.com) including the prescription of diagnostic examinations and drugs, health education programs, as well as expertise in hepatitis C, and other psychosocial services related to the person's health journey (for instance, taking care of someone's cat(s) while they are hospitalized). The main territory serviced by the cooperative comprises of Saint-Roch and Saint-Sauveur neighbourhoods in Quebec City's Lower Town. However, the SABSA team agrees to provide care to people who live outside these strict geographic boundaries. Although just over half of the visitors in 2017 live in central neighbourhoods of Quebec City, many reside in the suburbs, in other cities of the province or are homeless.[25] The community relates here not only to a local context, but also to an experiential context, in the sense that SABSA's clientele includes relatively unaffiliated people that share common conditions of existence, for instance a more "disadvantaged" living environment or issues with mental health, addiction or chronic diseases.[25] The cooperative solidarity program allows full autonomy to the SABSA workers regarding the priorities, the process and the services provided. However, this autonomy is constrained by limited funding. SABSA, which advocates for the development of a provision of accessible and free health care, does not charge any fee to create a file nor costs for the consultations. If the person does not have a health insurance card, they will be welcomed and treated at SABSA all the same.

In Quebec, this model is innovative because caregiving relies on specialized nurse practitioners who are practising in full autonomy without physicians present on-site. Physicians still partake in the trajectory of care and nurses can refer to them if needed. The team also consists of one psychosocial support worker, nurse clinicians, and other HCPs.[23,26] A specialized nurse practitioner on the front line carries out the prescription for diagnostic examinations and drugs, take care of common health issues (such as otitis, urinary tract infections or pneumonia) as well as chronic disease and pregnancy. In this clinical practice framework, the physician's expertise is neither dominant nor exclusive, unlike mainstream healthcare framework (as evidenced by the necessity to transit by them to access other professional services). This transfer of power underlies a particular political resonance. These conditions can help to detach from the biomedical perspective, in order to adopt a humanistic and pragmatic philosophy of care.

Normative nature of the health path

The humanistic and pragmatic philosophy adopted by the SABSA cooperative fosters management by the individuals. The humanistic approach articulates care around the priorities as well as the concerns expressed by the person. The workers or volunteers will act as a guide or an advisor to develop an intervention plan together that will best meet the person's needs. In this sense, we believe that the SABSA cooperative caregivers are part of the normative approach of the person in a vulnerable situation. Rather than judging them against moral values involving bending the individual's will within the frameworks of the socially prescribed normality, the people at SABSA, through an ethical position that demands to listen to the person's story, supports them in their life path, and in the interstices of their social bonds. The pragmatic approach implies to accept deviations from the prescribed, moral or social norm and to listen to the norm(s) corresponding to the milieu they belong to. The focus is similar to an approach of harm reduction used outside the scope of public health which aims to protect the population. The primary objective is to respect the trajectory of the person who suffers and to act with concern and respect for the subject's life path. In other words, there is no persuasive speech held about a behavioural change (e.g., smoking cessation). The intervention rather aims to support the person in their choice by recognizing their decision-making power, which is necessarily rooted in the social or prescribed norms of the *milieu* they belong to. The psychosocial support worker, for example, is integrated into the people's living milieu in order to mobilize the meaning from their singular experience so to match the care provided with the needs expressed. These needs can include to organize material possessions, to take care of the person's pets or to find a new housing.[25] The SABSA cooperative has the flexibility to adapt to the variety of life experiences and provide services tailored to the reality of its members.

Deployment of normativity in a community

Two elements foster the deployment of normativity in a community. First, and similarly to the CCPSC, the cooperative solidarity program allows citizens and caregivers to play a significant role in the organization by giving them a voice in terms of direction and decision making concerning the provision of health care and services.[25] This implies recognition of the subject's autonomy: each individual going through their ordeal knows best what is important to them. The place attributed to citizens and caregivers thus takes on a particular political resonance that translates into a transfer of power to the individuals regarding the determination of not only what defines health in the community, but also the therapeutic approaches they need to improve health of the community. Second, the desire to provide services to a vulnerable clientele – for which we agree that the root causes of their health problems reside in their living conditions[20] – implies a recognition of the milieu's impact on health. Since the citizen is part of one or several world(s), their health is inseparable from their context of emergence, from the community – this dynamic space where various influences meet, mingle and merge.

A thoughtful analysis has led us to think that such a conception of health is also investing other health care spaces. In the following section, we present this care space and emphasize how in this particular case, the political dimension of the living underlying the community health vitalistic perspective, can also address an ethical concern.

Health's unique and subjective nature: The example of the Maison Michel-Sarrazin

The Maison Michel-Sarrazin (MMS) is an end-of-life care centre founded in 1985 and located in Quebec City, where caregivers support people with cancer in the last stage of their lives.[27] The services provided are free of charge and dispensed equitably to those who meet the admission criteria (based on diagnosis and place of residence). The MMS health care team consists of HCPs from various disciplines, including physicians, pharmacists, nurses, social workers, one psychologist, one occupational therapist, one physiotherapist, and one nutritionist. Volunteers complement the health care team by assisting "the nursing staff in providing care and a comforting presence for patients and family members [free translation]".[27] In addition to its mission to deliver end-of-life care to patients and their family members, the MMS operates a day centre that welcomes patients and their loved ones on a daily basis. The day centre provides services and offers a variety of activities including professional services and complementary therapies (e.g., individual or group psychosocial support, massage therapy, and artistic expression) as well as various events animated by volunteers (e.g., listening and practice of music, discussions, meals, and relaxation). As opposed to the prior example, the *Maison Michel-Sarrazin* is not a CHC according to the CACHC's description,[8] but is instead a not-for-profit private hospital centre, which activities are funded in part by public funding, but more importantly by charitable donations from the community.[28] Nevertheless, its philosophy of care, comprehensive and humanistic, presents several common points with a vitalistic approach to community health, as to the unique and normative nature of health experienced in an end-of-life context.

The uniqueness of the lived experience

At the MMS, the types of care provided focus on the uniqueness of experience lived by both the people in end-of-life and their family members. Health is understood as an entirely subjective and unique phenomenon, by the recognition of the uniqueness and the specific identity of each person. Death is not a failure at life or the result of an undefeated pathology, but rather the ultimate experience of life, a state of transformation. Believing in the uniqueness of each person also means to believe in their potential as a human being to *evolve* up until the end and in their ability to decide in which living conditions they want to end their life, whenever accommodating is possible.[29] The end-of-life experience can give rise to various emotional, behavioural, and social responses that are difficult to predict from one individual to another. The experience of grief also varies from person to person and from time to time and comprises several elements unique to each individual and to the context surrounding the loved one's death.[30] Time is also playing a role to the extent that every single day brings forth different needs, which translate into different types of care for each patient-caregiver dyad. Demands and aspirations regarding life change and evolve according to the intersubjective and mediated dialogue between sick people, family members and caregivers. Besides, individuals with cancer are not described as patients or sick people per se, but rather as house guests ("*invités de la Maison*"). This attention paid to the terminology demonstrates this concern to consider the individual as a whole, beyond the medical condition they are presenting. The word Maison, French for "house," also emphasizes the importance of welcoming people in their last "home."

Deployment of a normative ability

Here, Canguilhem's[6] words claiming that disease is not the absence of health and health is not the absence of disease take on their full meaning. Cancer represents a deviation from the accepted biological and social norm but does not necessarily mean poor health. End-of-life is thought of as a stage of life, death, as a natural process, and this perspective acts as a guiding principle for the delivery of care.[31] End-of-life stage is essentially a new living condition during which the person and their family members can exert their ability to adapt to new norms while remaining rooted to their living *milieu*. Considering the uniqueness of the lived experience, this can translate differently for everyone. For instance, the house guests can smoke, as long as they remain outside, and to bring their pet(s) with them. Also, they are free to choose what they eat, their varying tastes and wishes are taken into consideration. Adult grief groups offered by the MMS explore themes such as family and social life reorganization, among other things. Hence, a wife can seek to cope with the identity change that arises from the death of her husband (status changing from married to widow) in order to feel more at ease with her new reality and while interacting with her social circle. While MMS's caregivers deliver care and interventions that aim to promote adaptation among the guests and their family members, they do not act solely as outside witnesses. Because they play an active role in this dynamic and in their social milieu, they become a part of the normative activity deployed and may possibly end up questioning their own conception of health due to its influence.

The example of the MMS illustrates how a health vitalistic approach allows us to think outside the biomedicine prescriptive framework while not confining community health to a particular organizational and institutional context. Although the community is not formally involved in the governance of this centre, the MMS general philosophy allows space to welcome the subjectivity in the lived experience of the individuals and conceive death as a normative experience of life.

Conclusion

An epistemological and ontological reflection on how the idea of community health is constructed appears helpful to illustrate what characterizes health care practices in CHCs. Community health revisited through Georges Canguilhem's perspective allows us to go beyond the dominant biomedical model in health care services within health institutions, and to possibly consider innovative ones. Indeed, this reflexive process highlights the necessity for community HCPs to reframe the concept of "care" outside its strictly curative intents. CHCs contribute to health by acknowledging the individual's unique relationship with their milieu and the rules of propriety, as a biological, social, cultural and economic entity, that allows them to fit within the one or several communities they belong to. The vitalistic approach to health recognizes the impact on health of the social and cultural conditions, that are also fundamentally political.[32,33] This perspective can also apply in contexts where the vulnerability is expressed differently, as is the case at the MMS. Thus, community health initiatives can affect different unaffiliated populations, whose needs are not met by the mainstream healthcare systems. The centres provided as examples in this chapter illustrate how this idea of community health can express itself in multiple ways according to different organizational contexts. Interestingly, these sites are operating in the margins of Quebec's health system, one as a non-profit organization, and the other as a private hospital centre. This exclusion from the system could foster the adoption of a perspective going beyond biomedical aspects, but not without contingencies. Among others, limited financial resources can be particularly restrictive due to reduced operational effectiveness, the inability to compensate the professionals for their work and, most importantly, the limited number of patients who can benefit from care and services. Beyond the difficulties the development of such an approach could encounter, this paper is mostly intended as an invitation to all students, practitioners, decision makers, as well as managers, to consider the idea of health differently and to think about practical implications of such an analysis. When thinking about the best way to improve health in the community, the first question to ask could be which “health” are we talking about. A community health vitalistic approach could have multiple implications in the field in terms of practice – as we discussed at length in this paper –, but also in terms of teaching and research. This perspective could serve as a milestone for field definition and theoretical development as well as for the designation of research objects and methodology that truly embrace the complexity that underlies health situations.

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To contact the authors:
Elisabeth Beaunoyer M.A., Ph.D.(c)
Université Laval
Faculté des sciences infirmières
1050 Avenue de la Médecine
Québec, Québec, G1V 0A6
Canada
E-mail: elisabeth.beaunoyer.1@ulaval.ca

Valérie Desgroseilliers, M.A., Ph.D.(c)
Université Laval
Faculté des sciences infirmières

Nicolas Vonarx Ph.D.
Université Laval
Faculté des sciences infirmières

Bernard Roy Ph.D.
Université Laval
Faculté des sciences infirmières

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Abstract
Recent events such as the COVID 19 pandemic and racist police violence have contributed to a heightened awareness about the nature and origin of health care disparities. Nurses are portrayed as heroes while expected to work with no equipment, and nursing organizations release antiracist statements, while little is done to address the underlying conditions that cause disparities. In this paper, we engage with ideas from The Invisible Committee and other theorists to suggest that nursing needs to develop new ways of thinking about both its past and its present politics if any chance of a radical new future is possible.

Key Words COVID-19, critical theory, destituent power, insurrection, nursing resistance

Tomorrow is cancelled: Rethinking nursing resistance as insurrection

KYLIE M. SMITH & THOMAS FOTH

> “To limit oneself to denouncing discrimination, oppressions and injustices, and expect to harvest the fruits of that, is to get ones epoch wrong” - The Invisible Committee

Introduction

We began this paper in mid 2019 in preparation for the International Philosophy of Nursing Society/Philosophy in the Nurses World conference in Victoria, Canada. The theme of the conference was “Thinking about ideas in nursing” and we had some thoughts about the way that critical theory could be combined with critical history to address the racist thinking that was embedded in psychiatric practice, for example. As we began to write our paper for publication, we were constantly outrun by events around us: first the COVID 19 situation and the re-opening of the global economy and then the street fights as resistance to racist police killings in the US and elsewhere. We adapted our paper to attempt to address some of these issues but we could not deal with all of them in depth. In the process, we also realized that our framework for understanding these events and for explicating the role of nurses needed new tools. At the same time, we read The Invisible Committee’s new work, Now, and realized that it had several important implications for thinking about how nursing power can be understood in the context of current social upheavals. In the paper that follows, we engage with certain key principles from the Invisible Collective’s work and consider how this kind of theorizing can open new ways of thinking about the role of nursing in social justice.

In their Now manifesto, the anonymous philosophers behind The Invisible Committee write “all the reasons for making a revolution are there. Not one is lacking. The shipwreck of politics, the arrogance of the powerful, the reign of falsehood, the vulgarity of the wealthy, the cataclysms of industry, galloping misery, naked exploitation, ecological apocalypse – we are spared nothing”.[1] If this was true in 2017 when Now was published, it is even more so today in the context of the COVID-19 crisis and a surge in racist police violence, which has placed health care and nursing front and center in the everyday struggle between life and death. These events have combined to lay bare disparities and inequities in health care that reflect the racist foundation of western societies more broadly. At the same time, nurses are proclaimed heroes in this “war” with “the invisible enemy”, yet they are expected to go to work with inadequate protective equipment, paying the ultimate price with their lives, while leaders from nursing professional organizations willingly appear in White House photos bullied out of wearing protective masks.[2] These tensions represent a crisis in nursing, which has not been able to mount any substantial co-ordinated response to the situation for their own welfare, nor for the welfare of their patients.

Nursing theorists and philosophers have written critically about the way that nursing is embedded in systems of bio-political surveillance and governmentality through technologies and discourses of biomedicine and evidence-based practice.[3] They have also encouraged us to think less along lines of hierarchy and to embrace critical theory and thinking for an understanding of nursing’s role in systems of oppression.[4] In their recent article “We have never been nurses” authors Dillard-Wright, Walsh and Brown lay out the way nursing is implicated in hetero-patriarchal, neoliberal and colonizing systems that stifle nursing’s emancipatory potential.[5] Rather than posit a solution, they encourage us to engage in a discussion about the future of nursing in a post-human world. We take up their challenge in this paper, arguing that in order to realise this future of nursing, we must step outside what currently exists. We engage with the work of The Invisible Committee to argue that nursing cannot make “the system” better because the system does not want to be better, and that attempts to work with the system as it is serves only to intensify the inequity and injustice, especially in a time of crisis.

Before we move on, we want to pause to consider this use of the word crisis. Already adopting the language of “crisis” is covering up what really led us to the situation we are confronting right now. The term “crisis” is extensively used in public discourse and in the media, whether in the context of the “migration crisis,” the “economic crisis,” or “humanitarian crisis,” etc. Rosi Braidotti[6] points out the inflationary use of the term that has come to mean everything and nothing. Over the course of centuries “crisis” has had very diverse connotations in legal, military, social, economic and cultural contexts. According to Gorgio Agamben, “[i]n the medical tradition, crisis means the moment in which the doctor has to judge, to decide if the patient will die or survive. The day or the days in which this decision is taken are called crisimoi, the decisive days”.[7] The idea of crisis also possesses an organic or processual character in medical catastrophic situations, suggesting “a natural process, a surge, a wave”- like process “as if by a violent natural force”.[8] In theology, “crisis is the Last Judgment pronounced by Christ at the end of times”.[7] In the late 19th century, economists developed a crisis theory and in the early 20th century, theories emerged around what were perceived as crises of cultures. It is because of the ability of the term to be combined with other words and “the implicit slippage between them that the term “crisis” has been able to become such a powerful trope, gaining traction in the most diverse domains and discourses”.[9] However, with, or perhaps despite, its inflationary use, the term “crisis” has taken on an important function in the governing of our societies.

Invoking the term crisis means to prepare for the imposition of exceptional measures that are justified by the urgency or the emergency of the situation – as in the case of COVID-19 – and these “crisis” situations often call for the immediate suspension of rights and freedoms and democratic practices, often on a “semi-permanent basis”.[9] By emphasizing that a situation is a crisis, measures can be implemented that would normally not be accepted by the general public. “A crisis situation is often an “opportunity” to introduce far-reaching mechanisms of control, cutbacks, or practices of large-scale extraction of resources, such as in the kinds of “crisis management” following natural disasters like earthquakes”[9] or a pandemic like we are currently experiencing. Thus, these situations allow democratic decision-making processes or public debates to be circumvented. Agamben emphasized that the role of crisis in the governance of current societies touches on every aspect of our life and coincides with normality – crisis has become a tool of governmentality. But a society ruled in this mode of governance is a society in which democracy is abended, “because in it political life has become impossible, while democracy means precisely the possibility of a political life.” Government has put itself into a permanent state of emergency and a “destituent power, in so far as it deposes once and for all the law”.[7] It was Agamben who clearly highlighted the dangers that come with the declaration of a public health emergency and the implementation of a global state of exception in the context of the pandemic.

But it is also possible to use the term crisis differently. Jean-Luc Nancy[10] reminds us that “a crisis is a period where something is revealed,” symptoms appear and reveal something about us and it is this “moment of revelation that allows us to judge and to heal",[10] and Joseph Vogl[8] contends that "crisis" and "critique" are complementary. Seen from this perspective, if a crisis is claimed, a struggle evolves around the interpretation of the situation. Questions can be asked as to what concepts should be used, or what problems should be foreseen. Whereas the notion of crisis is often used to foreclose the possibility of assessing a situation differently or of finding different solutions, it could also be used to resist or contest even the descriptions of the situation. As DeCauwer suggests, "[o]ther questions should be formulated and different projections of the future should be proposed". Not only is "another future possible," but so are other assessments of a "crisis situation"[10] and this is an important struggle if the Left wants to regain the traction it seems to have lost. A ""crisis situation" is an invitation to sharpen our capacity for judging a situation, to propose different concepts, theories, and narratives, and to invent alternative solutions to the attempts to manipulate the anxieties, uncertainty, and suffering of the people by different political fractions".[9] This paper is one step in contesting the commonly accepted definition of the COVID-19 crisis.

As we face the reality of a "crisis" in which some patients are chosen to die through deliberate government negligence and nurses themselves are forced (and accept) to work without proper protection, an appropriate question to ask is how did we get here, which is necessarily a historical question. In a world now decimated by COVID-19, where Black lives obviously do not matter, we can not simply wait for a return to the normal, or even to settle for a new-normal. Rather we must interrogate the normal we did have. For the writers of The Invisible Committee this equates to "tearing a hole in things from the inside"[1] and facing the multiple deferrals from the past that have led to this present. The next section of this paper surveys the current situation and the state of nursing activism in the face of COVID19 and the renewed Black Lives Matter movement. We then explore some of the concepts used by The Invisible Committee and the philosophical and theoretical threads they pull on to consider what it might mean to imagine a new "politics" of nursing for social justice.

The current situation

The COVID19 pandemic has exposed the social and racial inequalities, the precarious living conditions of workers, the disastrous consequences of the neoliberal transformations of healthcare systems and social services, the link between infectious diseases and climate change as well as the consequences of the ruthless exploitation of resources, the consequences of pharmaceutical corporations solely interested in profits, the disastrous effects of the continuous systematic dismantling of public goods and austerity measures.[11] Combined with the impact of police violence, the COVID-19 crisis has made visible and exaggerated the already existing inequalities of our neoliberal societies,[12] yet nursing has presented few answers to the question of how to deal with this pandemic and its consequences in the future. 2020 has exposed multiple social disasters but there are no models for how to arrive at a better and more just world. Historian Joan Scott described this as one of the failures of our epoch, namely the difficulty of imagining a world different to the one we live in today.[13] Historian François Hartog called this failure "presentism".[14] With this term, Hartog tries to grasp the fact that a "corporeal discipline" of the pandemic has been imposed without us having the time to reflect on the consequences of this new regime. Pressured by the notion of a public health emergency, this "regime of presentism" is perceived as a sudden onset of chaos that can only be counteracted by the medical gaze that introduces a temporality of medicine – we live in the medical prognostics of the crisis and our lives are structured by the rhythm of the "crisis" and its expected peaks or waves.

However, the pandemic also exposed a global vulnerability. Everyone is vulnerable to the virus either through direct interactions with other human beings or by touching contaminated surfaces. At this level, vulnerability describes the way our bodies and our social lives are interconnected and interdependent. At another level, the public health response to the virus has been to identify "vulnerable groups" that include Black, Brown and Indigenous communities deprived of adequate healthcare throughout their lifetimes and through the long history of colonialism, exacerbated by structural racism and police violence. Thus, the pandemic highlights that for some vulnerability to COVID-19 is exponentially heightened. As Judith Butler has written, "Perhaps there are at least two lessons about vulnerability that follow: it describes a shared condition of social life, of interdependency, exposure and porosity; it names the greater likelihood of dying, understood as the fatal consequence of a pervasive social inequality".[15,16]

One interesting aspect of current developments is that multiple forms of resistances are emerging: general strikes and continuous wildcat strikes by low paid workers at Amazon, Meat-packing facilities, rent strikes, social media campaigns etc.[17] Mainstream media rarely report about these new forms of resistance and nursing associations are often not involved in these protests. Rather, they promote an image of the nurse as hero visualized in the celebration of frontline workers every evening and push for the nursing voice to be strengthened at “the policy table”. These campaigns not only obscure the fact that it is a political decision to increase the precarity of nurses and other low paid workers and to expose them to an increased risk of dying, but what is more problematic is that nurses themselves often disseminate the image of the nurse as a hero. Despite the fact that some nurses (and even more physicians) exposed the lack of PPEs and the deplorable conditions in hospitals (it is noteworthy that the deadly conditions in long-term facilities have rarely been made public by nurses) seldom nurses speak-up in support of the movements for a radical change, a change that is actually needed if we want to live in a liveable world. It seems as if many nurses are pleased to be perceived as (dying) heroes and see this discourse as a sign for a societal recognition of nurses. But by not actively supporting and advancing more radical changes nurses become once again “complicit” in the perpetuation of this unequal condition by promoting a view of going back to “normal” – a normal that will be built on the death of what neoliberalism considers superfluous people. There are numerous ways that nursing actions can be seen to perpetuate these problems.

a. Nursing the pandemic

Early on in the pandemic, nurses began to campaign for people “self-isolating” at home. Pictures of nurses holding signs like “Stay Home For Us” mushroomed on social media.[18] These moralizing images promoted what the majority of governments decided as a response to the coronavirus: “saving lives was more important than anything else.” As Didier Fassin[19] emphasized, this “anything” implies a lot. “It is not only the interruption of social and economic activities with all that we can foresee in terms of recession, unemployment, and pauperization, but it is also the suspension of civil liberties and fundamental rights-the possibility of circulating, of meeting, of protesting, of going to work or to school. Moreover, in many countries, the declaration of a state of emergency has altered the checks and balances in government”.[20] This seemingly humanitarian discourse promoted “saving lives” as the ultimate reason for state mandated lockdowns but what this discourse did not question was who in our current societies is excluded from being considered as a life worthy of being saved and whose lives will be lost as the consequence of the confinement. Early on in the pandemic, Judith Butler observed the unequal consequences of the “lockdown” for those whose loss of lives did not count because they had been abandoned by society long before the onset of the COVID. These superfluous human beings comprise the homeless, the unemployed, the racialized low-paid “frontline” workers, the people confined in overcrowded prisons, migrants, refugees and asylum seekers who are retained in camps under terrible conditions, the “sans-papiers” in many countries who are afraid of going to a doctor, etc. All these categories of people have not been included in the humanitarian politics of saving lives and nurses, by repeating the mantra of “stay at home” and uncritically supporting confinement and state of exceptions, once again unwittingly promoted a politics of (racist) exclusion. Furthermore, the unequal value of lives will play out after the “reopening” of the economy. What we will see are the devastating effects of the measures taken during the pandemic, particularly in regard to impoverishment, food insecurity, unemployment and health. Already before the pandemic, neoliberal capitalism in the US (but a similar trend seems to emerge in Canada) (21) has led to what economists Anne Case and Angus Deaton called “death of despair” meaning the decline of life expectancy for people between 25 and 50 years of age from the poor and lower middle class (22). Most of these deaths are due to suicide, drug overdose and the consequences of alcoholism. It can be expected that this trend will fortify in the years to come. These deaths are not grievable because they are not publicly acknowledged (23). Butler contented that certain deaths are ungrievable deaths because these are deaths of lives that were never recognized as lives in the first place (24). When these lives are lost nothing is lost because these lives were never considered lives. This is particularly evident in the movement for Black Lives Matter.

b. Nursing and Black Lives Matter

Nursing organizations have suddenly realized that anti-racism should be one of the foundations of nursing caring attitudes in the midst of the uprisings following the police murders in the US. Both the American Nurses Association and the American Association of Colleges of Nursing released statements deploring the killings and stating their support for the Black Lives Matter movement. However, what these associations rarely recognize is the fact that “the state-sanctioned murder of Black people continues on other fronts as well, including public health and economic injustice”.[12] Neoliberalism paired with colonialism and white supremacy systematically abandoned Black communities and Indigenous people long ago, thus increasing their vulnerabilities and risk of premature death.[25-27] At the very moment we write this, new allegations about the racism of health-care staff in emergency rooms in the Canadian province of British Columbia have been made public. Health-care staff, including nurses, were playing a 'game' they called "The Price is Right" to guess the blood alcohol-level of incoming patients they presumed to be Indigenous as closely as they could, without going over. This example highlights once again how deeply racism is entrenched in healthcare in all Western/ Northern countries.[28] As with the COVID-19 pandemic, the pandemic of racist violence cannot be separated from the violence imposed by neoliberal capitalism. Neoliberalism produces massive misery and plunders the public sector. The coronavirus pandemic and the pandemic of racist violence are both the consequences of the neoliberal societies we live in. The paramilitary police forces attacking peaceful demonstrators are another aspect of neoliberal capitalism that systematically dismantles liberal-democratic institutions and makes resistance a life-threatening undertaking.[29-31]

What nursing organizations do not provide is an in-depth analysis of the roots of racism and the role nurses are playing in sustaining a colonial society that is founded on racism. For example, nurses rarely reflect on their role in sustaining the inequalities in health services and in our societies at large.[32] This needs to change. Instead of insisting on their benevolent caring attitudes, nurses must confront their complicity with the history of colonialism, racism, healthcare disparities, etc.

c. I can't breathe

Actually, this sentence is much more than the last words of George Floyd before he was lynched by police officers. What we are confronting today is the collapse of our world in which even the right to breathe is not a universal right. What we experienced with COVID-19 is what Latour called a dress rehearsal for what will come in the near future.[33] This means that the ruthless exploitation of the earth, the extraction of resources and the systematic and ongoing dispossession of Indigenous unceded territories and land will lead to a crisis that will amplify the disastrous consequences we encountered during the pandemic.[26] In a blog entitled The Universal Right to Breathe, Achille Mbembe points to a need for a post-human understanding of the convergence of the virus with the consequences of colonialism and globalization. "We must answer here and now for our life on Earth with others (including viruses) and our shared fate. Such is the injunction this pathogenic period addresses to humankind. It is pathogenic, but also the catabolic period par excellence, with the decomposition of bodies, the sorting and expulsion of all sorts of human waste – the "great separation" and great confinement caused by the stunning spread of the virus – and along with it, the widespread digitization of the world".[34]

Nursing organizations' inability to critically self-reflect during the COVID19 pandemic is symptomatic of nurses' self-image today, which we see as a continuation of how nurses construed themselves in history. Instead of trying to maximally manage a healthcare crisis that is the result of the continuous neoliberal attacks on healthcare and social services, nurses should wake up and boycott a system that continuously jeopardizes their lives and the lives of the many they care for (19, 35). We need to abolish this healthcare system (and the way we live and exploit this world) and come to a different understanding of what it means to live together, including non-human inhabitants of the earth (36).

Tomorrow is cancelled and destituent power

The idea of abolishing systems as they currently exist is central to the work of The Invisible Committee, who have spelled out their approach to insurrection in numerous works since the uprisings across Europe, the so called Arab Spring and the many anti-racist insurrections all over the world beginning in the early 2000s.[37,38] In Now, they argue that this project can not be delayed any further. When they state that "Tomorrow is Cancelled" they are stating that waiting for the right time or the right conditions is not possible or ethical anymore, that the time for change is Now.[1] There will be no tomorrow otherwise. They also argue that politics as usual will not bring the required depth or nature of change that the world needs. Instead they argue that we are living in societies in which politics is a spectacle and at the same time politics is in the process of decomposition. Over the course of the COVID crisis, the spectacle of politics is probably once again best represented by Trump and his COVID press conferences. But Trump is not alone. On a global scale, politicians use the "crises" to stage a form of politics that systematically negates the way politics had been understood up till now. The armed storming of the Michigan state house and the many racist and right-wing demonstrations against the lockdowns globally shows what is meant by decomposition of politics.[39-41]

We live in a "fog of commentaries" that makes it increasingly difficult to actually see the world how it is. Politicians like Trump, Netanyahu, Bolsonaro, Modi, Putin or European rightist governments in Poland, Hungary, etc. but also Johnson, Merkel or Macron can no longer be criticized because they are the personification of the caricature of politics and they are proud of it. The political condition we live in today no longer tries to hide authoritarian forms of domination and has abandoned the pretence of liberalism. This new age disseminates an "illusion of unity"[1] that hides the fact that we are living in an increasingly fragmented reality that has been pushed even further through "social distancing" measures. The Committee writes: "We live in a world that has established itself beyond any justification".[1] This is the reason why criticism no longer works. It is merely absorbed and passed over, like a discarded protest sign in a tear-gassed street. We are living in the "cage of counterrevolution"[1] that makes it increasingly difficult to achieve radical change. The only way is to invent a critical praxis that is built around action which is not understood as a way to achieve a goal but rather as a value in and of itself. In order to make a new world, action is an end in itself and only through action will we be able to construct a world that is radically different.

If the COVID pandemic has achieved one thing it is that it unveiled the world we live in, which is built on inequalities, racism, blunt disregard of social justice, etc. There can not be a "back to normal" in whatever way that may be imagined because trying to get back to normal would rebuild the power relations that need to be abolished. Instead the Invisible Committee calls for an instant insurrection and communalist living. We see this call to insurrection as wake-up call to nurses to become involved in insurrectional practices instead of trying to make the health care system "better." Nurses must realize that they are once again being used as "cannon fodder" in a war they never chose and that this is the result of a neoliberal, racist political rationale.

This idea of insurrection goes probably against the grain of how nurses often understand their "caring" attitudes. The Invisible Committee rejects the idea of constituent power and calls instead for destitution, meaning rather than trying to make existing institutions better they call for destroying political institutions in their traditionally understood forms. The problem of trying to ameliorate the system is that we will always be caught in a vicious cycle. History shows that political activists often end up in governments and oppositional leaders often end up as ministers, making them part of the system they can no longer critique. One example from the area of health and nursing is the history of Medicine Sans Frontiers (MSF) and other humanitarian NGOs. Former presidents of MSF like Bernard Kouchner became ministers in socialist and conservative governments in France. This is a characteristic of what the Committee calls the counterrevolutionary regime we live in - it reintegrates revolutionary movements by reconstituting the power relations these movements attacked in the first place. The only way to escape this circle is destituent insurrections, which means to disengage with authority, institutions, governments, and the system at large. "...[W]here the 'constituents' place themselves in a dialectical relation of struggle with the ruling authority in order to take possession of it, destituent logic obeys the vital need to disengage from it. It doesn't abandon the struggle; it fastens on to the struggles positively. It doesn't adjust itself to the movements of the adversary but to what is required for the increase of its own potential. So, it has little use for criticizing".[1] When nurses continually call for nursing voice or a seat at the policy table, they are asking to be closer to the power that already exists and not fundamentally reject or transform it.

It is in these street struggles (and not in academic critique) that the Committee sees an experience of what they call communism. In these fights the combatants experience what living and fighting together really implies. United in a (violent) fight suspends the fragmentation of our lives and instills a true sense of being together. It's a coming community. A critical part of this way of living is the Committee's notion of becoming ungovernable as the way to resist. Becoming ungovernable means that institutions need to be neutralized and emptied of their substance through an active undermining of their political legitimacy. Only the ungovernable cannot be reintegrated into the counterrevolutionary regime. What is meant by ungovernability was visible in the protests against Trump's inauguration in January 2017 when the slogan "become ungovernable" gained traction on social media and the huge demonstrations in different big cities in the US. As Nikita Shepard notes, "[e]ven Chris Hedges, a left-wing author notorious for his attacks on anarchists and other social rebels, adopted this anarchist and autonomist rhetoric within weeks of Trump's inauguration: "We have the power to make the country ungovernable. But we do not have much time...Now is the time NOT to cooperate. Now is the time to shut down the system of power. Now is the time to resist".[42] The same became true for the recent Indigenous protests against the construction of the Coastal GasLink Pipeline in Canada when railways and bridges were blocked for weeks and brought the economy to a halt in solidarity with the Wet'suwet'en fight for the protection of their unceded land.[43] And particularly Black and Indigenous autonomists have taken up the language of ungovernability and used it in practical actions of resistance.[44-46]

The Invisible Committee provides some concrete examples of sites they believe should be destituted of power, all of which have implications for nursing. In relation to the academy, they argue that "to destitute the university is to establish, at a distance, the places of research, of education and thought, that are more vibrant and more demanding than it is - which would not be hard - and to greet the arrival of the last vigorous minds who are tired of frequenting the academic zombies, and only then to administer its death blow".[1] For nursing, this means a deep questioning of the very foundations of knowledge, of what "health" means and who it privileges, and to take an account of the racist history and consequences of biomedicine and evidence-based practice which have become so unquestionable in nursing discourse. The uncritical invocation of "science" means that nursing seeks only to bring itself further into the systems of discrimination of oppression and therefore robs itself of a language of critique.

This is also true where nursing is complicit with systems of incarceration, from jails through to immigrant detention camps. If we were to learn anything from nursing's history then these should be an anathema to nursing organizations and are sites where nurses could actively refuse to be participants. Rather, nursing could argue for other ways of thinking about issues of public safety and public health. "To destitute the juridicial system is to learn to settle our disputes ourselves, applying some methods to this, paralyzing its faculty of judgement and driving its henchmen from our lives".[1] To defund the police would open up space for abolishing the conditions that cause "crime" in the first place: poverty, trauma, inequity, disenfranchisement, racism. Black Lives Matter "call for a national defunding of police. We demand investment in our communities and the resources to ensure Black people not only survive, but thrive".[47] One current example for how destitution could work in praxis is the Capitol Hill Autonomous Zone (CHAZ) in Seattle, an area taken over by protesters after the police withdrew on June 7, 2020 during the protests against the systematic killing of black people by the police.[48] Autonomous zones are nothing new and exist in many countries, like the Zone To Defend (ZAD) in Notre-Dame-des-Landes in France against the construction of a new airport,[49] the occupation of the Hambacher Forst in Germany against the deforestation for brown coal extraction,[50] Standing Rock and the occupation of railways in Canada against pipeline projects.[51]

When the Invisible Committee writes that "to destitute the government is to make ourselves ungovernable. Who said anything about winning? Overcoming is everything"[1] they speak to the respectability politics that is at the core of nursing hierarchy and leadership. The very real fear of becoming unemployable keeps nurses governable, and it also limits their ability to critique the policies and systems that cause oppression in the first place. Policing the discipline in terms of appearance and language while allowing racism to flourish undercuts nursing's claims to any kind of radical reimagining.

The most obvious call to arms from The Invisible Committee is their call to destitute medicine. Even though the Committee refers to biomedicine here, their message applies to nursing too, because it operates within the same system of technologies of biopower, discipline and surveillance of people's bodies. The Invisible Committee argues that "to destitute medicine is to know what is good for us and what makes us sick, to rescue from the institution the passionate knowledge that survive there out of view, and never again find oneself alone at the hospital, with one's body handed over to the artistic sovereignty of a disdainful surgeon".[1] Nurses and nursing scholars emphasize a caring attitude as a central characteristic of nursing and try to distance themselves from the biomedical discourse in healthcare. However, by adopting post-positivistic discourses and methodologies like Evidence-Based Nursing, rational decision making, quality and LEAN management, to name just a few, nurses actually promoted the neoliberal transformations of healthcare and converged with the biopolitical perspective of medicine. Thus, in regard to healthcare, we think that we must destitute medicine and nursing by developing our own knowledge about what constitutes health and wellness and to truly emancipate both future nurses and our patients from the biopolitical regime of surveillance and the discipline of compliant bodies. Health is not a moral choice that people as individuals make, rather it is shaped by the circumstances over which people have no say, and is therefore something that people negotiate to the best of their ability according to their own measures.

To destitute medicine and nursing also means that we should re-discover a knowledge that has been suppressed but still exists in the underground. This knowledge might be Indigenous knowledge or the knowledge that has been violently erased through witch hunts, professional midwifery etc. We, and nurses in particular, should cultivate this knowledge because we must realize that how the healthcare system is organized now is not beneficial to our health. COVID has shown that the healthcare crisis was not just because states were not prepared, but rather something is fundamentally wrong with our healthcare, otherwise the mass dying in long-term care facilities or refugee camps, prisons and of racialized groups could not have occurred. Instead of merely protesting to get more PPE, nurses should be at the forefront in the fight for different ways of providing care. Instead, nurses try to compensate for the consequences of the murderous state health policies even if it means that they pay with their own lives or health. When, if not now, is the moment that nurses must engage in the struggles that emerge globally in the form of general strikes, rent strikes, upheaval against racialized treatment of people, prison riots, etc. to destitute the world. Instead of going to work as usual and waiting for injured bodies to be delivered into the system as it is, and charged for the pleasure, nurses could be in the street providing mobile health care, refusing to be sidelined, and taking a stand at the same time. If nurses and other healthcare workers would become ungovernable on a global scale, we oddly might be on the way to build a medicine and nursing that is good for us. CHAZ is an opportunity to live another form of being together and to develop an actual form of solidarity by contributing our knowledge and ideas for the development of this community. This is much more than the defunding of the police and rather a way to build something new. But the precondition would be to break down the failed system and only from the ruins and rubbles of the current healthcare system that has failed the majority of people can something new develop. It is not by attacking institutions, but rather by letting them die that change will come. "The destituent gesture does not oppose the institution. It doesn't even mount a frontal fight, it neutralizes it, empties it of substance, then steps to the side and watches it expire. It reduces it down to the incoherent ensemble of its practices and makes decisions about them".[1]

Black studies scholars Stefano Harney and Fred Morton[44] used the term undercommons to try to describe a similar approach. The undercommons is a kind of subversive power that unites all those people who are generally excluded.[44] If we unite and act together with those who are excluded from the healthcare system, we are able to infiltrate these institutions in a way that neutralizes them and undermines their function. It is something that happens beneath the surface and builds up an uncontrollable power that eventually leads to demise of the institution. This is necessary because "the purpose of the medical institution is not to care for people's health but to produce the patients that justify its existence and a corresponding definition of health".[1] Is this what nursing wants for itself?

Thus, it is not about trying to make institutions better or trying to influence the political system but rather to destroy them. We currently see that all the promises made during the lockdowns, like the promise to increase funding for healthcare, to make healthcare more inclusive, to strengthen public health and hospitals against privatization and profit orientation are end up in smoke. France is probably the most impressive example. French president Manuel Macron pledged "massive investments in healthcare"[52] during the COVID-19 implementation of a state of emergency that led many healthcare workers to believe that they would have a say in "correcting" the faults of the past, these healthcare workers now realize that the government will not change the course of its neoliberal transformations. Healthcare workers participated in what the French government called "Ségur de la santé", where nurses, physicians, paramedics, technicians, rehab, etc., compiled a list of demands including better recognition of healthcare workers, better remuneration, new forms of healthcare funding and particularly a critique of pay for performance schemes, new policies for investments in hospitals and health, inclusion of users of services in the planning of these healthcare services, but realized after only three weeks of so-called consultations that their proposals were dismissed.[53]

What would it mean to "destitute" these kinds of processes? The Committee defines two dimensions of destituent power. Going back to the Latin root of the word, the Committee understands destitutere as "to place standing separate, raise up in isolation; to abandon; put aside, let drop, knock down; to let down, deceive".[1] The second dimension of destituent power is destruction as a necessary way to build something completely new. Harcourt explains this two-dimensional understanding as "[t]he first represents the secessionist and separatist removal to the commune, apart from capitalism and liberal society; the second, the attack on capitalism, on private property, on consumption, on 'the world of capital'… The first is a 'communal ideal' and the second is a 'violent anarchist action'".[54] But there is too much invested by nursing, in its politics of respectability and desire for comfort, that works against this kind of radical and uncomfortable change. We are advocating for practical action from nurses, for getting involved and engaged with actual ongoing struggles and for a kind of anarchy in thinking – a complete rejection of what we think we know and have been told in order to imagine the seemingly impossible.

Conclusion

Based on our theoretical discussion, we see the actual task of a nurses' insurrection in the practical support of the ongoing street fights. If nurses would provide care to those wounded in these struggles, nursing would become something very different to what it is right now. For us, the invitation to destitute nursing and to invent new forms of care would mean that we care for the ones fighting for another way of living together and by doing so, we will find new ways of what it means to really care for each other and for the world we live in. There is no easy answer here and we do not pretend to know what it is, but we know that the articulation of a new way of thinking, a new set of ideas, is required. If we want to be part of a movement, not merely a moment, if nursing wants to be part of a future in which Black lives truly matter, then it can not continue on the path it is on. A call to singular values, vapid anti-racist statements, a reiteration of nursing's mandate to care, the demand for a seat at the policy table or for recognition of the contribution of nurses during this pandemic, merely serves to shore up nursing's place within the system that is itself the problem. So too, the rhetoric that nursing uses through adopting a neoliberal managerial approach which reifies biomedicine, technologies of surveillance, and white supremacy, makes nursing incapable of imagining any other way of being in the world. A critical philosophy that seeks to destitute racist medicine and nursing's complicity with systems of neoliberalism is what is required. We can not afford to wait, the insurrection is coming, the insurrection is now.

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To contact the authors:
Kylie M. Smith B.A. Ph.D
Associate Professor
Emory University
Mellon Faculty Fellow for Nursing & the Humanities
Nell Hodgson Woodruff School of Nursing
1520 Clifton Rd NE Room 354
Atlanta GA 30322
United States
email: Kylie.m.smith@emory.edu

Thomas Foth, RN, PhD
Associate Professor
University of Ottawa
Faculty of Health sciences
School of Nursing

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Abstract
Poststructuralism, with its critical interpretations of knowledge, discourse, truth, and power, offers a set of compelling analytic tools for disentangling and deconstructing the ways in which health-related phenomena exist and are understood. This paper adopts a poststructuralist stance to outline the impacts of medical hegemony on the lives of people who use drugs, as well as responses to the harms experienced by this population. This analysis reveals how structuralist projects have narrowed the scope and impact of harm reduction through processes of medicalization, neoliberal responsibilitization, and medical co-opting and depoliticization. Nomadic thinking is then introduced as a means for health policy makers and practitioners to transform the boundaries of dominant approaches to harm reduction – particularly, in ways that (re)politicize harm reduction through forms of equity-promoting and social justice-oriented action. Implications for (re)politicized, community-engaged, and structurally responsive approaches to harm reduction in health policy and practice are then discussed.

Key words discourse, harm reduction, medicalization, people who use drugs, poststructuralism

(Re)politicizing harm reduction: Poststructuralist thinking to challenge the medicalization of harms among people who use drugs

TREVOR GOODYEAR

Introduction

The rise of evidence-based practice agendas across Western healthcare and academic settings has distinctly shaped knowledge development and application in healthcare.[1] Within this evolving context, empirically driven ideologies and discourses have manipulated philosophical, disciplinary, and practical orientations to health to be highly medicalized and individualistic.[2,3] For people who use drugs (PWUD), medical hegemony has distinctly contributed to the pathologizing of substance use through the disease model of addiction – a framework for understanding substance use that is limited in scope and that ignores the wider context in which both substance use and substance use-related harms are situated.[4,5] Further still, the advancement of empiricism has had substantial implications for the development and implementation of strategies to support PWUD and promote safer substance use. For instance, although harm reduction has been inclusively conceptualized as "policies, programmes and practices that aim to minimise negative health, social and legal impacts associated with drug use, drug policies and drug laws",[6] it has largely been taken up as a biomedical intervention that is reliant on individual behaviours and the use of technical supports (i.e., healthcare services) to mitigate potential health-related harms (e.g., overdose, infections). The conceptual tension about what constitutes harm reduction – and even what is considered to be harms – has led to ongoing philosophical debate concerning the nature and scope of harm reduction.[7] This debate has direct implications for PWUD, as well as for clinical and public health responses to substance use and substance use-related harms. Indeed, while medicalized approaches to harm reduction have been greatly effective in mitigating the potential health-related harms associated with substance use,[8-10] this orientation to harm reduction does little to address the broader historical, socio-cultural, and political forces that create and sustain the conditions in which PWUD experience profound health and social inequities.

In Canada and internationally, marginalizing social and structural conditions (e.g., violence, trauma, poverty, lack of quality housing) are well-known determinants of substance use and also create and exacerbate harms among PWUD.[11,12] At the same time, the widespread social stigma and prejudice surrounding substance use have served to further marginalize and “other” populations of PWUD.[13] Processes of social exclusion such as these have also been formalized into practice and worsened by penal drug policies and laws (e.g., the criminalization of substance use, mandatory minimum penalties for drug offences, zero-tolerance substance use policies), which serve to maintain and exacerbate negative societal judgments associated with the presumed moral worth of PWUD.[14-16] Even within healthcare settings, it has been widely recognized that PWUD tend to face stigmatization and violence when interacting with service providers,[17,18] which often prompts PWUD to delay or altogether not access health and social services – including those falling under the umbrella of harm reduction.[19] Across all of these contexts, the health and experiences of PWUD are structurally embedded within systems of domination and oppression (e.g., colonialism, racism, cisheteropatriarchy, classism, poverty) that operate across multiple axes of social location to shape individual experiences (including harms) in continuous and intersecting ways.[11,20] Taken as a whole, the myriad of harms and inequities faced by PWUD represent a near global crisis – one that will require concerted and equity-oriented public health and clinical responses. Within this context, it has aptly been argued that narrowly focused and empirically motivated healthcare orientations to harm reduction have limited potential for meaningfully improving the health and wellbeing of PWUD over the long term.[11]

Given the limitations in highly medicalized approaches to harm reduction, there is need for knowledge about how harm-reduction theory and praxis can be advanced to more equitably and more comprehensively support the health of PWUD. To achieve this will require challenging the hegemony of science and grappling with competing notions of knowledge, truth, and action – particularly as they pertain to experiences of human health and illness.[21,22] Thus, in an era of highly medicalized approaches to substance use and harm reduction, this paper seeks to address the following philosophical question: What are the implications of a poststructuralist and nomadic orientation to harm-reduction policy and practice? In doing so, this paper critically analyzes how harm-reduction philosophy and practice have been developed within overarching contexts of medicalization and neoliberalism. The aim of this paper is not to disparage the contributions of empirically driven knowledge in the field of harm reduction, but, rather, to elevate forms of inquiry and action that – although marginalized in practice – have significant potential to critically advance harm reduction in ways that more justly and more comprehensively support the health of PWUD. To do so, this paper first provides an overview of the origins and contributions of poststructuralism as a philosophical perspective in the context of health scholarship. A poststructuralist lens is then applied to the topic of harm reduction and implications for knowledge, discourse, and practice in this substantive area are discussed. Next, this paper highlights the potential of nomadic thinking as a means to challenge and resist the empiricist status quo that has appropriated and medicalized harm reduction. Finally, this paper argues that adopting a poststructuralist and nomadic orientation to harm reduction elucidates the demand for (re) politicizing the state of harm reduction such that health policy makers and practitioners better attend to the marginalizing socio-structural conditions and broader oppressive contexts in which inequities for PWUD are created and reproduced.

Poststructualism: Truth, subversive analyses, and critique

Poststructuralism is a philosophical perspective that focuses on and interrogates notions of knowledge, discourse, truth, and power, as well as how these notions produce and shape individual identities and subjectivities.[23] In drawing on the works of Mackenzie,[24] Williams,[25] and other prominent poststructuralist figures (e.g., Foucault, Deleuze, Guattari), Holmes and Gagnon[23] argue that the three philosophical assumptions underlying poststructuralism are primarily concerned with truth, subversive analyses, and critique. First, with regard to truth, poststructuralism is concerned with structuralist projects (e.g., empiricism) that attempt to create a rigid and generalizable understanding of the reality or truth of given phenomena.[23] In contrast to the empiricist notion that understandings of phenomena are based on absolute truths, poststructuralism argues that how phenomena are interpreted is a matter of perspective – and that individual perspectives are shaped by structurally imposed societal norms. Poststructuralism draws particular attention to how entrenched systems and structures enact power to shape the types of knowledge that are produced, disseminated, and privileged in society, while simultaneously directing the ways in which these sources of knowledge are codified into societal norms and understandings of reality.

Second, poststructuralism calls for subversive analyses about how particular phenomena occur and are understood, thereby prompting consideration of alternative ways of knowing and being that could exist if one were to think differently about a given phenomenon or the world more generally – that is to say, if one were to think beyond structurally imposed understandings of reality.[23] In this way, poststructuralism catalyzes the questioning and reconsideration of structured understandings, rigid assumptions, and dominant perceptions related to what is generally deemed to be good or bad, true or false, expected or unexpected The subversive effects of poststructuralism thereby facilitate the disentanglement and deconstruction of how systems of hegemony shape the ways in which phenomena exist and are understood.[25]

This deconstruction is closely linked with poststructuralism's third principle – critique – which necessitates the critical appraisal of preconceived ways of being and knowing, including, in particular, through "a robust approach and account for the continuous interplay between knowledge and power".[23] In a societal context where multiple structures influence and attempt to govern individual behaviours and attitudes, critique facilitates exposure of the underlying workings through which various forces – be they academic, legal, biomedical, or other – contribute to the subjugation and othering of bodies, knowledge, and practices.[23,26] As argued by Holmes and Gagnon,[23] critique is thus highly politicized and intimately linked with resistance to governmentality and social control, as, according to Foucault, "the art of not being governed or better, the art of not being governed like that and that cost [is the] very first definition of critique".[27] Partnered with subversive analyses, critique serves as a powerful tool for uncovering and pushing back against the inner workings behind empiricist knowledge structures, thereby freeing opportunities for improving social conditions through processes of resistance, resurgence, and counterhegemony.

Poststructualism and harm reduction: knowledge, discourse, and practice

Poststructuralism facilitates the critical examination of health-related knowledge development and application – namely, by exposing how power relations and social realities direct what is observed, considered, and privileged with respect to health and wellbeing.[28] While structuralist projects have shaped health and healthcare in a variety of contexts, the impacts of medicalization on the experiences and realities of PWUD are particularly pronounced. In applying a poststructuralist lens to the specific context of substance use, one begins to see the ways in which harm reduction has been taken up and influenced by medical hegemony. Although the consequences of this co-opting are broad in scope, empirically driven structures and processes have largely manipulated harm reduction such that it tends to be operationalized as a form of "population governance" for PWUD.[13] What follows is a poststructuralist analysis of the ways in which medical hegemony has governed and shaped three key facets of harm reduction: knowledge, discourse, and practice.

Biomedical knowledge and the medicalization of harm reduction

From an epistemological standpoint, structuralist projects have fashioned an empirically driven hierarchization of harm reduction-related knowledge production and application. In exploring the limits and implications of this privileging of medicalized knowledge, poststructuralism draws attention to underlying mechanisms of "how this knowledge is produced and in what context; how scientific claims are made, by whom, and to what end; who the objects and subjects of these forms of knowledge are; and, finally, how these forms of knowledge and the systems that generate them can be destabilized".[23] Within the context of medical hegemony, practices commonly deemed as falling under the umbrella of harm reduction are largely biomedical in nature, and, for instance, include technically oriented interventions and practices, such as opioid agonist therapy, needle and syringe distribution programs, safer drug administration practices, naloxone kit distribution and utilization, sexually transmitted and blood-borne infection treatment and services, and so on.[29,30] These technical approaches to harm reduction are undoubtedly effective in reducing the physiological harms associated with substance use, and they also have had tremendous – even life-saving – impacts on the lives of PWUD.[7] Further, given the clinical challenges posed by the substance use-related health problems many PWUD experience (e.g., complex overdoses, antibiotic-resistant infections, lack of effective pharmacological interventions for methamphetamine dependence), medicalized approaches to harm reduction have a pivotal role to play in advancing substance use care and outcomes for PWUD. Nevertheless, narrowly medicalized approaches to harm reduction emphasize the inherent role, knowledge, and power of service providers in making decisions about and taking ownership of harm reduction.

Indeed, despite PWUD being the end-users of harm-reduction services, medical hegemony has situated biomedically driven knowledge sources and practitioners to be privileged as the "experts" – and, in many cases, the gatekeepers – of harm reduction-related information and interventions.[7,31] For instance, despite widespread acknowledgment that the provision of injectable opioid agonist treatment (i.e., prescription hydromorphone or diacetylmorphine) has significant health and social benefits for many people who inject drugs, its availability and accessibility is restricted by an array of clinical and regulatory barriers, including lack of specialist healthcare infrastructure and providers, strict eligibility requirements for treatment initiation (e.g., age, ability to self-administer the medication, DSM-V diagnostic criteria), and approval through regional health-related regulatory bodies (e.g., the Government of Canada's *Special Access Programme and List of Drugs for an Urgent Public Health Need*).[32] Within the context of this example and other substance use-related intervention landscapes, the service-related barriers experienced by PWUD are further exacerbated by challenging patient-provider power dynamics and widespread experiences of stigma that negatively influence health care access and utilization.[29,33] Through these interrelated processes of medical paternalism and marginalization, healthcare institutions and broader sources of state control effectively dictate which harm-reduction services are available to PWUD, how and when they can be accessed, and to what extent and under which circumstances harm-reduction knowledge and tools are provided. This institutionalized and "one-size-fits-all" healthcare model of harm reduction is grossly inadequate for PWUD,[29] and represents a pervasive source of control and governmentality. To deconstruct and challenge this medicalized model, poststructuralism reveals and critiques how knowledge and information pertaining to harm reduction are both produced and applied to shape and govern the experiences of PWUD.

Medicalized discourses of responsibilitization

Poststructuralism is concerned with how knowledge interacts with language to shape societal thoughts, assumptions, and practices, thereby facilitating the critique of how dominant discourses enact power to "structure societal life and regulate populations and individuals, while also legitimizing or condemning particular practices".[23] In this way, language and discourse become sites for political resistance against structuralist ideologies that attempt to define individual and social realities.[23,34] For PWUD and health systems and service providers, medical hegemony – despite its assumed intent to promote healthy populations – has profoundly and problematically influenced the discourse surrounding harm reduction to be overly individualistic. Dominant medicalized approaches to harm reduction tend to be laden with neoliberal ideology, which asserts that individuals are freely responsible for their own health and wellbeing, and, further, that suboptimal life conditions or poorer health status are largely due to a lack of effort or agency.[35] For instance, in the context of increasingly fentanyl-adulterated illegal drug supplies and opioid overdose crises internationally, emerging public health responses have called for PWUD to reduce overdose risk by agentively taking up drug-checking technologies to screen their substances for the presence of fentanyl and other synthetic analogues (i.e., highly potent opioids).[36] Responses such as these reflect neoliberal discourses of "responsibilitization",[29,37,38] which have largely positioned the burden of mitigating substance use-related harms with PWUD themselves, thereby diffusing and redirecting state responsibility for taking action to promote safer substance use, such as by providing a safe and regulated drug supply. The products of this discourse constitute a highly decontextualized and narrow conceptualization of harm reduction, which emphasizes the role of resiliency-based processes of self-care and self-management for PWUD to mitigate harms, and which does not take into account the many socio-structural barriers (e.g., stigma, criminalization) that restrict opportunities for PWUD to use substances more safely and to access harm-reduction services.[7,39,40]

The discourse surrounding harm reduction is closely intertwined with medicalized notions of surveillance – notions that are formally structured into reality via epidemiological tools and methods. As argued by Jiao,[7] the medicalization of harm reduction has been primarily driven by knowledge stemming from epidemiology,[39] which is a field that privileges scientific claims related to concepts of disease, risk factors, and at-risk subjects,[41] and that is concerned with generalizable, combinable, and comparable constructions of risk[42]. The epidemiological focus of harm reduction is evident in the widespread and structured monitoring of substance use-related adverse outcomes (e.g., drug-induced psychosis, incarceration [due to the criminalization of substance use], overdose, and the transmission of blood-borne infections,). While knowledge obtained through these risk-focused epidemiological means certainly has a role to play in informing harm-reduction policy efforts and priorities, data of this sort often lack sufficient attention to the impacts of broader socio-contextual influences on the health of PWUD,[7] such as laws and policies, social and structural determinants of health, and intersecting systems of power and oppression. Given this lack of accounting for contextual influences on substance use and health, epidemiology has been criticized as "serv[ing] as an extension of surveillance medicine through the vehicle of governmentality",[43] as surveillance and the wider medicalization of harm reduction unjustly exert "bio-power"[44] to structure societal life and regulate and govern the lived realities of PWUD.[13,45] Indeed, the rhetoric surrounding medicalized harm reduction largely has privileged the concept of "risk management" for PWUD – thereby operationalizing surveillance discourse through notions of governance and control over populations, their behaviours and practices, and the corresponding risks that populations both create and to which they are subjected.[43,46] This epidemiologically driven labelling of individuals and populations as "risky" exacerbates the marginalization of PWUD and invokes processes of internalised self-surveillance,[47] as "this labelling encourages self-regulatory neo-liberal strategies that capitulate to state power".[13] Poststructuralism draws attention to the ways in which societal norms, expectations, and practices related to substance use and harm reduction stem from and reinforce a variety of social institutions – including medical hegemony and neoliberalism. Structuralist projects such as these exert power in ways that influence the construction of understandings of health, risk, responsibility, the self, and;[23,34] in the context of substance use, dominant discourses embedded within these institutions have distinctly shaped harm reduction in ways that are individualistic, context-stripped, and often detrimental to the health and wellbeing of PWUD.

Medical hegemony and the depoliticization of harm reduction

Along with its vast influences on knowledge and discourse, medical hegemony also has depoliticized harm-reduction policy and practice. Here, poststructuralism draws attention to the ways in which structuralist projects influence and govern harm reduction, and, as a counteraction, identifies opportunities for political processes of critique and resistance.[23] Historically, harm reduction originated from informal – and, at the time, "radical" – grassroots practices led by PWUD and allies, including the then-illegal distribution of sterile injection equipment.[48,49] Despite its politicized and community-based origins, however, harm reduction largely grew in prominence and was formally codified into healthcare practice after it was taken up by epidemiological and public health stakeholders – specifically, to reduce HIV transmission during the height of the crisis.[29] This scale-up and institutionalization of harm reduction across medicalized structures and contexts was greatly advantageous for communities of PWUD, as it facilitated efforts to bolster the harm-reduction movement and further promote health care and outcomes PWUD;[29] however, it has also "washed out" and marginalized the grassroots experiences and efforts of people with lived experience of substance use. This co-opting has sanitized the oppositional political origins of harm reduction as a "platform for broader and more structural social change".[50] In commandeering the harm-reduction movement toward one focused on risk reduction and individual strategies and interventions for mitigating substance use-related harms, medical hegemony has both disrupted community agency and solidarity in taking up harm reduction as a fundamentally "anarchist-inspired form for practice".[48] In doing so, control and authority over harm-reduction services largely have been removed from the communities who access, experience, and are most impacted by them.[29] Here, poststructuralism resists totalizing processes of medicalization and depoliticization to identify avenues for (re)politicizing the future of harm reduction in ways that more critically and equitably support the health and wellbeing of PWUD.

Nomadic harm reduction: Alternative and more comprehensive paths forward

Poststructuralist approaches to health-related scholarship and practice support resistance to and deterritorialization from empirically driven, rigid, and medicalized orientations to human health.[23] From a poststructuralist standpoint, nomadic thinking offers a distinctly political method for understanding the ways in which certain types of knowledge and priorities are devalued within overarching healthcare contexts, and, in doing so, of disrupting dominant ways of thinking and doing health policy and practice.[51] In effect, nomadic thinking refers to freeing oneself from codification and stratification (i.e., thinking beyond structurally imposed understandings and realities), while also theorizing opportunities for resistance and subversive action.[23] Although there is no one proclaimed, structured, formulaic way of engaging in nomadic thinking – due, in part, because of its evolution and growth according to diverse environments, contexts, and relationships – engaging in this sort of thinking privileges notions of openness, creativity, and subversion that are required to reorient and transform dominant approaches to knowledge and practice.[52] Given the extent to which empirically driven ideologies direct health policy and practice agendas,[1-3] including those related to substance use and harm reduction,[4,6] and given that overly medicalized approaches are inadequate for addressing the structurally embedded harms facing PWUD, the need for concerted political thought and action in pertinent healthcare contexts is paramount. Here, nomadic thinking facilitates the expansion of medicalized approaches to harm reduction and, in doing so, (re)directs healthcare system and stakeholder attention toward the highly political foundations underpinning the harm-reduction movement. For health researchers, policy makers, and practitioners, embracing this nomadic school has critical implications related to the ways in which harm reduction is conceptualized and mobilized into action. As outlined in detail below, nomadic thinking in healthcare contexts can serve to better center harm reduction toward the experiences of its service users, broaden the focus and aims of harm reduction to include socio-structural considerations, and reorient harm reduction to be taken up as a platform for social change.

Centering the experiences of PWUD

Nomadic thinking offers a grassroot means for revolutionizing the boundaries of prevailing orientations to harm reduction. Nomad science is unmistakably political in that it is subversive in intent and, further, is aptly responsive and oriented toward the emerging needs of its service users[28,53] – in this case, PWUD and allies at the forefront of harm-reduction practice. For health policy decision-makers, the recognition of service users as nomadic and transformational subjects is urgently needed to disrupt the narrow reliance on medicalized approaches to harm reduction. Indeed, despite facing historic and ongoing political scapegoating, stigmatization, and repression by marginalizing socio-structural forces,[13] PWUD remain steadfast in their ability to organize and champion change in order to protect themselves and their communities from harms.[48] For example, in response to the opioid overdose crisis and limited access to spaces in which substances can be used safely (e.g., wherein overdose events can be appropriately responded to), communities of PWUD across Canada have rallied together to implement much-needed overdose prevention sites. Largely operating outside of governmental approval processes and requirements (e.g., related to: staffing, operational models), overdose prevention sites are often peer-led and designed to offer low-threshold and accessible services. While a testament to the community strength and resiliency of PWUD, overdose prevention sites also reveal critical limitations to the state-sanctioned response to the overdose crisis, including the lack of infrastructure for healthcare system-implemented safer consumption sites, as well as inadequate public backing for (or, some contexts, stark opposition to) community-driven overdose crisis response efforts.[13,31] Here and in other intervention contexts, the harm-reduction efforts of PWUD regularly operate independently of or without significant support from health policy actors and associated resources (e.g., funding) – due, in large part, to continued, negative societal judgments and dominant norms (e.g., punitive control, stigma, social exclusion) toward PWUD.[13,54] Within this context, nomadic thinking challenges the ways in which dominant discourses continue to marginalize and sideline the experiences of PWUD, while simultaneously thwarting the development and expansion of community-informed harm-reduction efforts.

For healthcare providers and institutions, the subversive intentions underpinning nomadic thinking serve to disrupt the status quo of medicalized approaches to harm reduction, thereby freeing opportunities for (re)centering harm reduction toward the diverse needs and experiences of its service users. Consider, for example, that hospitals in many settings, including in Canada, have paternalistic and abstinence-oriented drug policies that expect PWUD to use only a prescribed dose of a substance, to alter the route of substance administration, or to abstain from substance use while in hospital.[17,18,55] Such policies restrict opportunities for safer substance use (e.g., by denying access to certain harm-reduction services, such as sterile injection supplies and safer consumption sites within hospital settings), and also structure hospitals as risk-environments in which PWUD experience a series of adverse outcomes, including experiences of leaving hospitals "against medical advice," high hospital re-admission rates, and increases in morbidity and mortality – often due to nontreatment or undertreatment of the health conditions for which they were originally hospitalized.[56] Within the context of this example and others, nomadic thinking privileges marginal experiences and perspectives and, in doing so, draws attention to opportunities to more equitably support PWUD. This may include, for example, hospital policies that are grounded in harm reduction, as well as clinician approaches that are, relational, nonjudgmental, responsive to power imbalances, and respectful of the agency and subjective and situational needs and experiences of PWUD. Nomadic thinking in healthcare therefore expands conceptualizations of harm reduction in ways that more fulsomely attend to the practices, supports, and needs which PWUD themselves are bested suited to determine are the most helpful and most urgently warranted.[29] In doing so, nomadic thinking provides the foundation for collaborative action as a means for grassroots harm-reduction work across pertinent health policy and systems-level contexts.

Broadening the scope of harm reduction

In applying a nomadic and poststructuralist lens to harm reduction, clinicians working alongside PWUD can facilitate opportunities for broadening the scope of harm reduction beyond medicalized knowledge and physiological harms. While institutionalized and depoliticized approaches to harm reduction largely have taken after biomedical models that locate health at the static and context-stripped intersection of substance use and the individual,[48] nomadic thinking privileges knowledge and action that exist outside of medical hegemony and that tend to be pushed to the margins.[28,57] For example, within a healthcare context where PWUD are often positioned as passive recipients of care who are acted upon in their "best interests" by "expert professionals," such as clinicians and policy makers,[58] nomadic thinking – with its careful deliberation about subjectivity and multiplicity in points of view – departs from "top-down" and medicalized ways of thinking by broadening the scope of factors considered in harm-reduction practice. In effect, nomadic approaches to harm reduction in clinical contexts more fully consider the interplay of alternative sources of knowing, such as experiential and contextual knowledge (e.g., stemming from constructivist and critical theory paradigms, respectively).[7,13] This broader and more pluralistic epistemological stance supports greater heterogeneity and nuance in clinician approaches to harm reduction, which is of critical importance in addressing the socially and structurally embedded harms faced by PWUD. For instance, in accounting for non-medicalized sources of knowledge within healthcare encounters, space is created for expanded conceptualizations of harm reduction that consider both physiological and social harms (e.g., stigma, criminalization, poverty). Knowledge gained through these means draws attention to how susceptibility to harms (both physiological and other), as well as the capacity for PWUD to take up harm-reduction strategies and attend to their own health and wellbeing, are situated within broader social, economic, political, and structural contexts.[7] This expanded approach to harm reduction prompts greater clinician awareness of the common problems and barriers to safer substance use faced by PWUD, and thus creates opportunities for tailoring harm reduction efforts to more effectively support PWUD. Indeed, through deeper consideration of diverse sources and types of knowledge, nomadic thinking begins to distil some of the ways in which harm-reduction policy and practice can metamorphosize to be more comprehensive and responsive to social contexts of PWUD's lives.

Harm reduction as a platform for social change

In broadening the scope of harm reduction, opportunities for further articulating its underlying intentions and goals are also revealed. Poststructuralist critique serves as a tool for examining the extent to which harm-reduction efforts have been subdued by ideological systems of beliefs – namely, prevailing discourses of medicalization and neoliberalism. Relatedly, nomadic thinking, with its acknowledgment and promotion of multiple discourses, offers a unique avenue for expanding and politicizing harm-reduction policy. Specifically, nomadic thinking supports the dismantling of individualistic, egalitarian, and context-stripped neoliberal discourses – discourses that stand in opposition to the democratic decision-making and collective grassroots action bases upon which harm reduction was originally founded.[7] With its inherent resistance to "being confined within political and ideological systems of totality",[53] nomadic thinking resists conforming exclusively to existing medicalized and depoliticized discourses and, instead, privileges alternative and marginal discourses. This commissioning of marginal (i.e., nomadic) discourses, such as social justice discourses, is needed for health-related policy makers to reorient philosophical and pragmatic orientations to harm reduction toward the structural drivers of inequities facing PWUD.[7,12] In adopting a social democratic orientation to harm reduction, the assumed responsibility in preventing and addressing harms faced by PWID is shifted – specifically, from lying with the individual to more justly being a moral obligation of society and the state. Given the contested history and ongoing nature of the state-sanctioned war on drugs, those who use them, and those who sell them,[48] however, specificity with regard to what should constitute this societal response is warranted.

Critically oriented and equity-promoting harm reduction.

From a systems-level and structural standpoint, nomadic thinking in the context of harm-reduction policy prompts a critical reconsideration of the causes of harms for PWUD. Extending upon the political nature of nomad science and social democratic beliefs that it is a social responsibility to address harms faced by PWUD, a nomadic reading of harm reduction accounts for the ways in which socio-political influences both create harms and constrain opportunities for reducing harms. In close alignment with the anarchistic and action-oriented roots upon which harm reduction was founded.[48] nomadic thinking offers a critical method for disrupting the rigid, individualistic, and narrowly structured orientations to harm reduction that tend to be imposed by medical hegemony.[53] With its subversive intent, nomad science precipitates an expansion beyond the medicalized view that PWUD themselves create harms (e.g., due to lack of agency, effort, and/or willingness), and instead directs attention to the ways in which socio-structural conditions cause and exacerbate harms for PWUD. This a prudent and urgently needed shift in health practice and philosophy, as the status quo of medicalized and depoliticized approaches to harm reduction are insufficient for addressing the structural drivers of inequities faced by PWUD.[12] Within pertinent health and social policy arenas, nomadic thinking – beyond its many other advantages – is perhaps most conducive to (re)politicizing harm reduction such that it places social factors, human rights, and equity more firmly in the foreground of approaches to supporting PWUD. Through this lens, harm-reduction approaches and interventions become more strongly integrated within a broader social justice framework – explicitly, one that adopts a primary health care orientation and that seeks to improve the social determinants of health for PWUD.[12]

Harm reduction, reconceptualized through perspectives of poststructuralism and nomadic thinking, is thus presented as a more structurally responsive approach than the existing and limited-in-scope medicalized state of affairs. While harm reduction is not a panacea in that it alone is expected to address all of the social oppressions experienced by PWUD,[11] it does provide a critical lens for illuminating and addressing the harmful social conditions in which the lives and experiences of PWUD are situated. In this way, opportunities are revealed for expanding the scope and impact of harm reduction, including, in particular, by strengthening the demand for social justice-oriented and equity-promoting political action. As argued elsewhere,[11-13,59] there is a critical need for clinicians and policy makers engaged in harm-reduction efforts to be attuned to and responsive toward the intersecting systems of power and oppression that impose structural violence and harm against PWUD. Here, a nomadic and (re)politicized orientation to harm reduction demands a critical examination of all levels of social determinants and policies (e.g., penal, housing, welfare, health) that influence opportunities for health and wellbeing for PWUD.[11,12] In this way, the primary focus of harm reduction becomes neither substance use nor individual; instead, this (re)politicized reading of harm reduction is more critically oriented toward the myriad of other contextual influences that give rise to and sustain inequities facing PWUD.

Conclusion

Although empirically driven and medicalized approaches to harm reduction have led to pronounced reductions in the occurrence of physiological harms among PWUD, these approaches also have inadvertently narrowed the scope of harm reduction through processes of medicalization, neoliberal responsibilitization, and depoliticization. As a counterbalance to this hegemony, poststructuralism provides a critical analytic framework for exposing and critiquing the many unanticipated consequences of medicalization on the lives of PWUD. Moreover, nomadic thinking offers a means for disrupting and transforming the boundaries of dominant approaches to harm reduction. Specifically, nomadic thinking in healthcare contexts can strengthen opportunities to center harm reduction toward the experiences of its service users, broaden its focus and aims to include socio-structural considerations, and catalyze opportunities for equity-oriented social change. Conceptualized in these ways, tactics for health policy and practice stakeholders to (re)politicize the state of harm reduction are illuminated. Now, the challenge will be to take up these calls and diverge from the status quo of harm reduction. Given inequities faced and given that concerted political action and long-term structural changes are required to promote the health of PWUD in equitable and meaningful ways, the need to (re)politicize harm reduction in healthcare is paramount.

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To contact the author:
Trevor Goodyear, RN, MSN, MPH
University of British Columbia
School of Nursing
T201-2211 Westbrook Mall
Vancouver, BC, VT6 2B5
Canada
Email: trevor.goodyear@ubc.ca

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Abstract

Consensual non-monogamous parenting couples are at increased risk for health inequities, especially during the transition to parenthood. This article presents partial results of a more extensive mixed-methods study exploring the conciliation of these couples' parenting role and their sexual lifestyle, more specifically, their perceptions of health care providers including nurses. Semi-structured interviews and online questionnaires were completed with a total of 6 participants. Positive and negative issues were identified that were clients- and health care providers-based. The Expanding the Movement for Empowerment and Reproductive Justice lens was used to discuss the positive and negative consequences. Nurses need to develop, implement and evaluate a different clinical approach with these couples, who are aware of the health risks associated with their lifestyle, yet they always put their families first. Nurse administrators need to assess their institutional policies that are based on hetero-mononormative assumptions.

Key words consensual non-monogamy, couples, health care professionals, parenthood, nurses

Consensual Non-Monogamous Parenting Couples' Perceptions of Healthcare Providers during the Transition to Parenthood

JACQUELINE AVANTHAY STRUS
& VIOLA POLOMENO

Introduction

Consensual non-monogamous couples (CNMCs), having made a conscious decision to have more than one sexual partner,[1] identify as swingers, polyamorous or being in open relationships. One in five Americans have engaged in consensual non-monogamy (CNM) at one point in their lives;[2] Canadians also follow this tendency.[3] People identifying as CNM are more likely to be gay, lesbian, or bisexual,[4] while those considered as swingers are more associated with heteronormative sexuality[5]. Certain studies have looked more closely at societal attitudes in regard to CNMCs[1,6]: CNMCs are viewed less favourably than the general population, with swingers being viewed the least favourably of all of them. For those who practice polyamory, another concern involves the stigma that may extend to their offspring.[7]

Sexual minorities including CNMCs appear to experience more health disparities than the rest of the population. This can be attributed to minority stress,[8] which can increase with discrimination encountered in their daily lives as well as during health care encounters[9]. This population can experience higher levels of mental health issues, and higher rates of tobacco, alcohol, and substance use.[8] The findings from the study conducted by O'Byrne and Watts[5] on CNMCs and their sexual practices indicate that CNMCs may be at greater risk for sexually transmitted infections (STIs), and may delay or refrain from seeking health care for their sexual health. Women in this study were at greater risk of developing

STIs compared to men.

There is a dearth of studies that have considered CNMCs' perceptions with health care providers (HCPs), especially those involving nurses.[10,11] CNMCs have revealed that they have had both positive and negative experiences while engaging with health care providers and the health care system.[5,10] The ever-changing fabric of Canadian society, including CNMCs, combined with the health inequities encountered by sexual minorities, reinforces the need for nurses to be more comfortable with and well-versed in human sexuality and sexual diversity.[11] Yet, nurses have demonstrated a lack of knowledge and discomfort when addressing issues related to human sexuality and sexual diversity.[12] This can be partially attributed to nursing education programmes that do not include sexuality in their curricula, and the approach used in the teaching of sexuality in these programmes is 'haphazard at best'.[13]

This article reports partial findings from a larger study that investigated consensual non-monogamous parenting couples' (CNMPCs) conciliation of their parenting role and their sexual lifestyle during the transition to parenthood,[11] more specifically, the findings that pertain to CNMPCs' perceptions of health care providers including nurses. The underlying conceptual framework that was used is the Reproductive Justice Framework.[14] The Expanding the Movement for Empowerment and Reproductive Justice (EMERJ)[14] lens is a concrete way of integrating the Reproductive Justice Framework both research-wise and clinically, especially when engaging with CNMPCs.

Methods

Study design, sampling, and recruitment

The original study[11] was a mixed methods study using the triangulation design convergence model[15] as part of the first author's master's thesis research study.

Purposive sampling utilizing key informants and the snowball technique[16] were used to obtain a sample of CNMPCs living in Winnipeg, Canada and who identified as consensual non-monogamistes during the transition to parenthood. The methods of recruitment included the use of the Fetlife platform, and sending invitations to the local swinging clubs and hangouts of CNMCs in Winnipeg. A total of eight participants were recruited, but only six of them completed both the online questionnaire and the interview. The two participants who chose not to continue with the study did so for personal reasons. Three interviews were conducted before the initial data analysis. Interviews were then added in groups of three until no new themes emerged, and when data saturation had been obtained.[17,18] Informed consent was obtained by all subjects prior to the start of the study.

Data collection and analysis

To follow Plano Clark and Creswell's[15] triangulation design convergence model, both quantitative and qualitative data were collected at the same time. The qualitative data were first analyzed, followed by the quantitative data. Once all of the data had been analyzed, they were then converged.

The quantitative data were collected using an online questionnaire that contained 24 questions regarding sociodemographic, relational, and parenting characteristics. This same questionnaire also included the following scales: the Parenting Sence of Competence Scale (PSCS);[19] the Personal Assessment of Intimacy in Relationship Inventory (PAIR);[20] as well as the Parenting Role-Sexual Role Conciliation Scale (PRSRCS) which was created for this study.[11] The online questionnaire took the participants between 15 and 20 minutes to complete. The obtained quantitative data were analyzed using descriptive statistics (mean, SD). SPSS Statistics version 24[21] was applied for this part of the analysis.

The qualitative data were collected using a semi-structured interview guide.[16] This guide was developed incorporating the themes from the EMERJ lens,[14] Cowan and Cowan's Ecological Model,[22] as well as the various themes that emerged from the literature review. The interview guide contained 32 questions divided into four different sections. The first section explored the participants' perceptions of their transition to parenthood. The second part focused on their particular sexual style. The third part delved into the conciliation of their parental role and their sexual lifestyle. The final section assessed CNMPCs and their experiences with healthcare professionals including nurses and the health care system. Participants were given the option of conducting the interview in person, over the phone, or via Skype. The interviews were audiorecorded and took between one and two hours to complete. The Schreir approach[23] for qualitiative data analysis was applied for this part of the data analysis.

Results

This article presents partial results from the larger study. The participants' profile will first be presented, followed by the qualitative results in regard to CNMPCs' perceptions of health care providers including nurses during their transition to parenthood.

Participants' profile

There were four female and two male participants who were part of the sample. The participants' ages ranged from 31 to 45 years (M = 37.67 years, SD = 6.37). Five participants identified as bisexual or pansexual and the other one as heterosexual. At the beginning of the transition to parenthood, four participants identified as swingers, one was in an open relationship, and the last one was polyamorous. At the time of data collection, four participants identified as being polyamorous and two others as swingers. Four participants were married, one was common-law, and the last one was separated. The number of children for each participant ranged from 1 to 3, with an average age of 10.63 years at the time of the interviews. Their incomes ranged from $19 000 to over $60 000. All participants were Canadian born.

Qualitative data results

Several themes were identified during the general qualitative data analysis, however for this article, only the 'Relationships with Health Care Providers' theme is presented. This theme contains four categories: fear of judgment, health risk awareness, health care providers' lack of training, and factors facilitating and hindering this relationship. Eight subcategories were identified.

Fear of judgment

The first category, 'Fear of Judgment', contained three subcategories: 'Heteronormative Assumptions', 'Perceived Judgment', and 'Fear of Repercussions of Lifestyle on Parenting'.

For the first subcategory of 'Heteronormative Assumptions', five out of the six participants indicated that their healthcare providers (HCPs) demonstrated heteronormative assumptions, meaning that the HCPs assumed that the participants were in a heterosexual monogamous relationship. The HCPs questioned the paticipants' need for STBBI testing in two circumstances because their clients were married (Participants P1 and P4). One participant (P1) chose to disclose her lifestyle which she later regretted, and the other (P4) chose to instead lie about her situation, claiming that she thought that her husband was cheating on her. Another participant (P3) delayed seeking care for her postpartum depression after the birth of her second child due to the heteromononormative assumptions demonstrated by her Public Health Nurse, which eventually led to postpartum psychosis.

The second subcategory, 'Perceived Judgment', was expressed by four participants. This influenced whether or not the participants were disclosing their lifestyle to their HCPs. They believed it was on a more 'need to know basis' (Participant P2). Perceived judgment was demonstrated when one of the participants (Participant P4) sought out an abortion after a pregnancy that occurred after a swinging encounter:

> ...it was met with, you know, almost a, well you know, this was a decision that you made to do and this kind of the consequence of your decisions and it's like, well, you know it was an accident just like it would have been between a normal couple but I don't think they would have come at us with that sort of mentality, if it was just my partner and I going in and saying, you know: "We're young, we're in school, this is an accident, and you know this is not what we are looking for" vs. "I am might be pregnant with my husband's best friend's kid." (Participant P4)

The third subcategory, 'Fear of Repercussions of their Lifestyle on Parenting', was demonstrated by all participants in that they did not want their lifestyle choices to affect their offspring. This fear was demonstrated by one of the participants (Participant P4) when the Child and Family Services initiated an investigation into her lifestyle. This investigation was halted, and apologies were made after the participant informed the worker's supervisor, reinforcing the fact that her sexual lifestyle had no bearing on her ability to parent.

Health risk awareness

Two subcategories: 'Informed Consumer' and 'Pregnancy and STI Prevention', are included in the second category of 'Health Risk Awareness'. The first subcategory, 'Informed Consumer', highlights that all participants were well aware of how their sexual lifestyle could affect their health. They went for regular STBBI screenings and chose to inform others before engaging in the sexual lifestyle. Participant P4 highlighted the need for advocacy because HCPs lacked education when it came to sexual minorities and sexuality in general, stating that participants had "the need to have a voice".

When it comes to pregnancy and STBBI prevention, all participants chose to be more careful while trying to conceive and during their pregnancies. Five out of the six participants decided to be monogamous while trying to conceive in order to ensure the paternity of their child. Participant 1 expressed it in the following way:

> during the trying phase, during the pregnancy, during the postpartum experience as well there was no sexual ah contact with anybody outside of umm.. my husband for myself and for when my husband did have ummm...a couple of encounters during the pregnancy, it was done extremely safely and just... I mean that's part of the lifestyle that we live and the you know the making sure that we were being safer for our family. (Participant P1)

All participants expressed concerns for people who participate in CNM and are not aware of the risks associated with it due to the HCPs' lack of knowledge.

HCPs' lack of training with CNM

This section on the third category of 'HCPs' Lack of Training with CNM' contains two subcategories: 'Lack of Sexual Education in Schools' and 'Providers' Lack of Training during the Prenatal Period'.

Participant P6 expressed her concern with the training that HCPs receive during the prelicensure programs to which the rest of the participants alluded to. She did not believe that HCPs received enough training when it came to sexuality and sexual minorities. However well-intentioned they are, HCPs did not always provide the support she needed for her particular sexual health concerns. She partially attributed this to the HCPs' lack of knowledge about the use of the correct terminology:

> …they are interested, but they don't know what it means. So then you have to get into, delve into an explanation um, and with the lifestyle, there always needs to be a definition anyways, because my definition of a full swap might not be the same thing as what someone else might consider a full swap is in the lifestyle. But you do need to know what the basic terminology means. What is the risk, what does it refer to and that doesn't seem to be the case. (Participant P6)

This lack of training appeared to be even more problematic during the prenatal period. Only one of the six participants attended prenatal classes, two used a doula, and the other three preferred not to take prenatal classes because they felt these classes were "rudimentary at best" (Participant P2). All participants claimed that the prenatal classes, reference books as well as the doulas did not have or give very much information about sexuality during the transition to parenthood. They all felt that more information is needed to be given about sexuality in prenatal classes and after childbirth, and that resources should be developed for different levels of education.

Factors facilitating and hindering the relationship

This last category focuses on the factors that facilitate the relationship between HCPs and their clients followed by those that hinder it.

There are three facilitating factors. The first facilitating factor for CNMPCs appears to be the inclusion of all parenting partners when care is provided during the transition to parenthood. The second facilitating factor is when HCPs including nurses are able to understand that CNMPCs put their families first. Participants took their safety and that of their children very seriously. Participants wanted reassurance from HCPs that the participants' lifestyle would not have repercussions on their children's health and wellbeing, and that they could live a complete and rewarding life free of discrimination.

The third facilitating factor revolved around relationship building using the following six strategies. Participants believed that the first strategy for relationship building should start at the intake interview with a questionnaire:

> …verifying if the person leads an alternative sexual lifestyle of some form, would probably help open a conversation, without actually asking, just questionnaires would open doors for them. (Participant P5).

The second strategy involves using language that is neither heteronormative nor mononormative; this would normalize sexuality and lead to more clients disclosing their lifestyle to their primary care providers. The third strategy mentioned by five out of six participants was using a harm reduction approach, starting with assessing their knowledge about STBBIs or other risks associated with their lifestyle. The fourth strategy would be for HCPs to give care without judgment and to work with this sexual minority. The fifth strategy involves HCPs working in partnership with their clients, and recognizing their clinical limitations, as stated by Participant P6:

> Don't just sit there and wait for me to disclose my life story. It's not going to happen… When they go to the doctor's they're sick, and they want to know what's wrong. They're not going to bring in all kinds of things which might have been factors in what's happened to them, but if you're not disclosing that you are open to ah… hearing what might happen and truly find a solution to what's happened um that's appropriate and fitting to their lifestyle and their sexuality, then, that makes it complicated… You know your partner happens to be infected, so that could have happened. (Participant P6)

The last strategy that would help these particular parents would be to have HCPs specialize in sexual minorities along with being well versed in human sexuality.

Participants mentioned that when the facilitating factors were not present, their relationship with the HCPs could be adversely affected, meaning that the faciltators became obstacles. Another hindering factor mentioned by the participants was when HCPs assumed that they were a homogenous group. All participants explained that there are many differences among CNMPCs which could be problematic when HCPs assume that they are the same. This was expressed by Participant P4:

> Every non-monogamous relationship is different… whether there is an extra partner or not… or however the dynamic is, ask questions respectfully…. So that you know… who

> to address and how to address. How they play a role in… Cause I mean I believe now, very holistically, that everything in your life has to work together. So it… my biggest advice would ask respectful questions. And don't be afraid to… If they're sharing that they are in a non-monogamous relationship with you, they have already opened up to you. (Participant P4)

Discussion

There were both positive and negative issues that affected the participants' relationships with their health care providers. Some of these issues stemmed from the clients themselves, while others were HCP-based. Using the EMERJ lens,[14] the consequences of these issues for the relationship between the participants and the HCPs were both positive and negative.

The positive issues that emerged from the findings related to the clients are based on resilience. Young and her collaborators[24] conducted a scoping review on the application of resilience theories in the transition to parenthood. According to these authors, resilience is a useful concept for synthesizing information about the transition to parenthood. Although the authors do not present a definition of resilience in their article, they do indicate that resilience theories gather around two critical components. The first component is the presence of a significant threat or challenge, while the second component is the positive adaptation despite the stressor.[24] Young and her colleagues[24] consider the transition to parenthood as enough of a challenge due to the vulnerability associated with it that it requires a resilient response. CNMPCs, in the present study, demonstrated this resilience by being health-focused during their transition to parenthood. They did this at three levels involving their relationship, their children, and with their HCPs. At the relationship level, all of the participants had a great awareness of their sexual lifestyle and its potential consequences on their health. They demonstrated this by going for regular STBBI testing, informing potential lifestyle partners of their health status before sexual encounters, and having a more holistic view of health (physical, mental, emotional, and sexual). At the level of their children, the participants became protective of them by returning to monogamy during conception, pregnancy, and in the first few months after birthing in order to better control their situations and to prevent any risks occurring to their health and that of their unborn and born children. At the level of HCPs, the participants were actively involved in their health care, sought health care services when mental health and sexual health concerns had to be addressed, and tried to find HCPs who were caring, non-judgemental, and more aware of the reproductive justice approach to care. The participants were very well aware of the health risks associated with their lifestyle during the transition to parenthood.

The findings that have just been highlighted are compared to those reported in the literature in terms of those that are similar, the ones that are contrary, and the others that are distinct. A part of these findings in the present study in which the participants were found to be health-focused is supported by those published in the Jenks study (25). The participants in the Jenks study[25] did seek out mental health care and counselling services when needed. However, the other findings reported here are different from those presented by Fernandes[26] and by O'Byrne and Watts[5]. In these latter two studies, the participants who were CNMCs would delay seeking preventative and sexual health care, which is contrary to the findings revealed in the present study, as the participants did seek health services. Lastly, the findings presented here are distinct in that they contribute to a beginning understanding of those individuals who are parents and engage in the 'lifestyle' during the transition to parenthood. There is a dearth of studies that have focused on this unique sexual minority regarding their health and their health behaviours during a period of vulnerability involving the perinatal period from conception to life with baby. It would appear that the participants in this study demonstrated resilience through their focus on health: it is this health consciousness that appears to underlie their resilience during the transition to parenthood.

Although there were positive client-based issues based on resilience, there were negative issues based on fears, particularly two fears related to disclosure of their sexual lifestyle and stigmatization of their children. The participants expressed the fear of having to disclose their lifestyle, especially when they had prior negative experiences. Also, for those participants who identified as swingers, they valued non-disclosure as a priority. These findings in regard to this first fear are supported from the literature, in that sexual minorities tend to not disclose their sexual lifestyle due to HCPs' judgemental attitude.[27] The participants also expressed a second fear involving the stigmatization of their children, more so for the participants who identified as being polyamorous. This fear is similar to that reported by other researchers.[7,25,28] The findings that were published by these three studies[7,25,28] indicate that their respondents did not want their children to be treated differently in school, have their lifestyle negatively affect their various sexual opportunities, and have their children taken away as they did not abide by heteromononormativity. HCPs need to be aware that this sexual minority has these two particular fears. Other fears may be present that may not have been identified by this study.

There were both positive and negative issues that emerged from the findings in regard to the HCPs themselves. Two positive issues were connected to the HCPs but from the perspective of the participants. All six participants revealed how some of their HCPs demonstrated respect toward them by being supportive of them and their children, and of their sexual lifestyle. The HCPs also had a non-judgemental attitude toward them. When participants perceived this, they were more open and willing to discuss issues regarding their health and chosen sexual lifestyle, even when they perceived that their HCPs lacked knowledge and training in human sexuality. This respect likely stems from HCPs being more aware of the emerging family structures in Canada. According to Leonardi-Warren et al.,[29] when HCPs are more aware of the role they play in building relationships with clients and emerging family structures, they are more likely to use inclusive language and question institutional policies that do not support the inclusion of all families in their care. Nurses can do this by being conscious of the importance of building a therapeutic relationship built on trust.[9] Pallota-Chiarolli[7] indicates how this can be done by including all family members in the care provided by HCPs during the transition to parenthood; however, it also includes stressing the importance of recognizing CNMPCs' strengths as families, all while acknowledging their differences.

On the other hand, the findings from the present study seem to indicate that HCPs who are open and non-judgemental are the exception and not the norm. The majority of participants expressed how they had received care from HCPs who held heteromononormative assumptions. This highlights two negative issues that were revealed by the participants, namely, that the HCPs lacked both knowledge and training in human sexuality. The lack of knowledge and training frustrated participants at times, which led them to try to find HCPs who were more knowledgeable about sexual minoirties. The participants also delayed seeking care, or seeking care without disclosing their lifestyle. These findings support previous literature[12,29-33] that highlights that HCPs receive very little education and training in sexuality in their undergraduate programmes, and even less about alternative sexual lifestyles.[34] This lack of education leads to HCPs being uncomfortable discussing sexuality, regardless of the health care setting.[12,29] The findings from this present study indicate that, although sexuality is a crucial aspect during the prenatal period, the participants received little or no education in this area during this particular phase of the transition to parenthood. Education for sexuality should be available throughout this transition.

When HCPs are uncomfortable discussing sexuality, it can be advanced that it is more difficult for them to move beyond society's heteronormative assumptions. The HCPs' discomfort and their lack of education in sexuality translate into starting discussions about sexuality with their clients with underlying heteronormative assumptions. The findings suggest that these assumptions can lead to non-disclosure on the part of the clients, which can be especially problematic during the transition to parenthood. On the other hand, no published study could be found that corroborates these findings. Therefore, it can be posited that similar to Landry and Kensler's study,[9] miscommunication can ensue, especially when the HCPs do not understand the terminology being used when discussing their clients' lifestyle, or they can present themselves as being curious without having the appropriate tools to help their clients.

So far, the discussion has been considered in light of the positive and negative issues that are clients-based and HCPs-based. However, the consequences of these issues on the relationship between clients and HCPs need to be discussed in terms of the positive relationship between them and of the negative one. In order to accomplish this, this discussion needs to be put into a greater context by its integration with the Reproductive Justice Framework which is represented by the EMERJ[14] lens. The three arenas of the Reproductive Justice Framework that are crucial to this integration are family, health and safety, and access and opportunity. For the Family arena, it is important to identify the ways in which parents maintain their family unit. For the Health and Safety arena, this involves how health and safety are promoted and save-guarded. For the last arena of Access and Opportunity, opportunities must be put in place so that sexual minority parents' gender, body and sexuality are respected as well as they having access to HCPs including nurses and healthcare services.

For a positive relationship to be present between clients and HCPs, while considering the three arenas of Family, Health and Safety, and Access and Opportunity, this means that this particular sexual minority follows the philosophy of 'Family First, Lifestyle Second' (Family arena), while being supported by an underlying resilience and health consciousness on their part (Health and Safety arena), which is also accompanied by HCPs who have both sexual minority knowledge and training (Access and Opportunity arena). On the other hand, the negative relationship between clients and HCPs may occur in the following way when involving the three arenas. Although the participants do put 'Family First' (Family arena), they are still worried about the repercussions of their lifestyle on their children and the stigmatisation that they may face. In the arena of Health and Safety, CNMPCs may decide not to divulge their lifestyle to their HCPs. They may also be more likely to encounter greater health risk, especially in the initial exploration phase of consensual non monogamy, as they do not necessarily have the tools to be able to say 'no' to unwanted sexual contact. Lastly, regarding the Access and Opportunity arena, CNMPCs have very limited access to HCPs who are well versed in human sexuality and sexuality minorities.

Strengths and limitations

The first strength of this study is that it was able to identify factors that facilitate and hinder the relationship between this particular type of sexual minority clients and HCPs. Secondly, this study was able to look more closely at the CNMPCs' conciliation of the parenting role and their sexual lifestyle during the transition to parenthood. These two strengths are especially important for nurses as frontline workers, as they will be better equipped to understand this subgroup of parenting couples.

On the other hand, the first limitation involves the small sample size, yet it appears to be adequate enough,[35] as the findings paint a rich contextual picture of CNMPCs and their perceptions of HCPs. The few studies that have been conducted on sexual minorities used similar sample sizes.[35] The second limitation is that the study concentrated on a small geographical area within the province of Manitoba, so it may be difficult to generalize the findings to other parts of this province, to the rest of Canada, and elsewhere. As this is one of the first studies of its kind, it can lead to further research on this sexuality minority in a parenting context that is underrepresented in both research and health care.

Implications for nursing practice and health and social care policy

The findings from this study lead to a number of implications for nursing in all areas of nursing practice such as nursing education, practice, administration and research, as well as health and social care policy.

Nursing education

Prelicensure nursing programs need to include content on sexuality and sexual diversity. Nurse educators need to be taught how to deliver patient education using a sex-positive approach, defined as "respecting the wide range of human sexuality. It involves talking with your clients openly and without judgement about their sexuality",[36 p1] and how to transfer this knowledge to undergraduate students These educators would also need to learn to take special considerations for dialogue using clarification and a common language.[36] Once these students graduate, they can transfer their new knowledge and skills to the workplace. Such frontline nurses would apply them (knowledge and skills) in sexual-cultural safety environments.[37] Knowledge and training about sexuality and sexual minorities can help address health inequities through the lens of cultural safety, as nurses must "acknowledge that we are all bearers of culture, expose the social, political and historical contexts of health care",[37 p2] and look at "difficult concepts such as racism, discrimination, and prejudice"[37 p2].

Nursing practice

Nurses who do not receive prelicensure training in human sexuality and sexual minorities must be given the opportunity to attend this type of continuing education training. The onus of responsibility is on both the nurses and their administrations as such training will help them to improve their clinical practice. Through cultural safety, frontline nurses and other HCPs will not make assumptions about their clients based on sex, sexual orientation and sexual practices, age, gender, race, relationship status, ability, socioeconomic status, and other aspects.[36] For example, during health visits, nurses can ask questions pertinent to what the visits are for, including those relating to sexuality, thus promoting the relationship between nurses and their clients. Also, nurses can be encouraged to have an open and honest, inclusive intake interview when seeing new clients that does not use heteromononormative language[9] Nurses need to develop, implement and evaluate a different clinical approach with CNMPCs who are a particular type of sexual minority, who are well aware of the health risks involved with their lifestyle, and who put their families first, yet they do not let their sexual lifestyle interfere with their ability to parent their children.

Administration and advanced nursing practice

Nurse adminstrators need to assess their institutional policies that govern health care based on hetero-mononormative assumptions.[38] They also need to be more aware of newly emerging family structures, and how political and societal institutions that are grounded in mononormativity can negatively affect CNMCs and their families.[11] Taking on a more leadership role through their advanced practice, nurse administrators and managers can emulate behaviours that frontline staff can adopt, and promote continuing education workshops that allow for a greater representation of sexual minorities.[9]

Research

Researchers should be encouraged to be more aware of their biases and the pervasive heteromononormative assumptions in nursing research.[39] They can get around these issues by adopting critical theory, queer theory, and intersectionality theory, and integrating them into their research studies. By adopting such theories, they can better recognize how structures including academia inherently perpetuate hetermononormative assumptions. By doing so, the responsibility lies not only on the oppressed, but also on the oppressor, who can change the status quo. Promoting participatory action research will set the stage for their voices to be heard and to be at the forefront of such change.[40]

Health and Public Policy

There has been an increased focus on nurses' advocacy role being combined with changes to Canadian legislation and code of ethics, leading to a politization of nurses.[38] They have a responsibility to use their emancipatory, sociopolitical platform to inform health and public policy for this particular group of parents. Nurses can advocate for changes to structural policies that limit access and opportunities for sexual minorities such as CNMPCs, thereby decreasing health inequities that are often associated with such groups.[38]

Conclusion

Sexual minorities including CNMPCs continue to be underrepresented and underserved in nursing practice and research, and in health and public policies, potentially leading to health inequities for them. The CNMPCs in this study have demonstrated a certain resilience in navigating the health care system. Nurses and other HCPs need to increase their capacity to better serve this sexuality minority during their transition to parenthood by basing it on respect that includes their clients' sexual diversity, and meeting them where they are at on their life's journey. For this group of parents, family is always first.

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To contact the authors:
Jacqueline Avanthay Strus, R.N., M.Sc.N.
Professor
Université de Saint-Boniface
École des sciences infirmières et des études de la santé
200 ave de la Cathédrale
Winnipeg, Manitoba R2H 0H7
Canada
Email: javanthaystrus@ustboniface.ca

Viola Polomeno, R.N., Ph.D.
Adjunct Professor
University of Ottawa
Faculty of Health Sciences
School of Nursing

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Abstract
This article proposes two premises that underlie biomedical health care delivery provided through medical missions to Madiha (Kulina) Indigenous Amazonian people living in forest villages. First, that health care is implemented through a set of detached transferable goods and services. Second, that health is a condition that requires the importation of knowledge and resources. The premises were induced through qualitative research on the Brazilian government's medical missions that provide biomedical care to Madiha (Kulina) in the southwestern Amazon as part of the national health care system. Despite policy rhetoric, delivery practices disregard embedding health and health care in local infrastructure and cultural conditions. There is little or no collaboration with Indigenous healers, capacity building of the local (Indigenous) health care system, education of resident lay health monitors, or extensive and lasting infrastructural development. The article recommends reorientation of delivery to prioritize local health care infrastructure development.

Key words Amazonia, health care, Kulina, Madiha, medical missions

Underlying premises in medical mission trips for Madiha (Kulina) Indigenous people in the Brazilian Amazon

CHRISTIAN FRENOPOULO

Introduction

This article proposes that the delivery model of the medical mission is one conspicuous reason why the Brazilian government's health care system is not able to meet patient and health care staff expectations for improving the health of Indigenous Amazonians living in forest villages. Although it has morphed over the decades, the traveling medical mission is still the core of biomedical health care delivery in these villages. The consequence is that biomedical self-sufficiency and independence has never been successfully achieved there.

The mission trips described in this article are a government service of the national health care system in Brazil and, as such, they implement an iterated non-specific model of delivery that responds to universal health care targets established by the government authorities.[1] Despite policy and political rhetoric that intends to present them as part of a coherent and cohesive primary health care organization specially designed for Indigenous populations,[2] the research presented here shows that their actions mirror Short Term Medical Missions (STMM) and other types of medical missions, and for that reason, can justifiably be considered in the context of the literature and research on medical missions. Dependency on medical missions to supply health care in remote areas, insufficient local infrastructure, and culturally insensitive and decontextualized interventions are issues that have been examined many times in the literature [e.g., 3,4,5,6,7,8]. The specific locality discussed here is representative of this type of problem.

The contribution of the article is its analysis approach, drawing on the literature of medical missions to interpret government-funded interventions. The intention is to show how a national health care system can provide a service that may be just as neocolonial as Short Term Medical Missions (STMM) funded and staffed by expatriates.

Medical mission trips, regardless of their funding or staffing, share some core characteristics that are summarized in this article as two basic premises. Firstly, medical mission delivery treats health care practice as a set of transferable goods and services. Secondly, health is managed as a condition that requires imported knowledge and resources. In the trips observed in this research, these premises appear to go unrecognized by most actors. The few staff members who do perceive them, do not consider them problematic. On the contrary, these premises are integral to the narrative of heroism that pervades their work,[9 p347] being used as arguments to convey the relevance of the trips.

These premises need to be made explicit because they are potential contributors to certain problems that staff persistently complain about, but do not see as outcomes of mission delivery. Specifically, there is a chronic perception among the workers that there are insufficient staff and resources, and also that there are enduring cultural barriers that obstruct patient adherence. The workers seem to think of these problems as self-sustaining and unrelated to the delivery format.

This article notes that health workers do not see these issues as intertwined with delivery. Instead, they consider the delivery model intrinsically beneficial. Staff believe that the problems are due to defective and insufficient implementation. They tend to think that the solution for deficient health care is to intensify the delivery format and to further its implementation. In contrast, this article highlights a fundamental flaw in the approach itself.

It is important to clarify that the problem is not mission delivery per se, which can offer valuable support to deal with certain types of health concerns. Rather, the issue is the reliance on a model that is implemented in tandem with a disregard for developing the local health care infrastructure, thus perpetuating dependency on external resources and actors.

The research shows that where these missions are carried out, there is almost no concurrent investment in the improvement of the local health care infrastructure, and above all, its independence. For example, there is virtually no strategy to reduce disease prevalence and incidence by targeting local structural factors. There is very little attempt to improve the population's living conditions. There is scant attention to the education of the population and resident village lay health monitors. There is no engagement with the Indigenous medical system and no significant attention to Indigenous understandings of health and disease. Although there have been attempts to improve drinking water supply and waste management, these have been short-lived investments.

In short, biomedical health care provided through the format of the medical mission in Amazonian villages does not express a public health approach of attempting to promote long-term improvements in health status by addressing local structural changes. Instead, the medical mission format localizes disease as a problem limited to individuals, detected and treated in the fleeting clinical encounter. Most of the nursing work is certainly oriented towards prevention and screening, such as universal immunization and prenatal care. However, actions are limited and mostly focused on individuals, not on generating health care infrastructure.

This article presents data obtained through qualitative research of the medical missions that provide health care for Madiha (also known as Kulina) living in the Upper Purus River region in the southwestern Brazilian Amazon, mostly during 2009-2010. The data shows that there is little verifiable improvement in health indicators, that there is low patient adherence to professionals' directives, and that staff share a persistent perception of insufficient resources and staffing. The article shows that these recurrent problems are attributable, to some extent, to the medical mission delivery format.

This argument is intended to be very straightforward and understandable to a broad readership. Yet, since biomedical delivery in remote or rural areas of the Amazon has long applied the medical mission model for decades, it is apposite to continue to analyze this type of health care delivery.

The article is relevant for nurses, among other health professionals and administrators, because it tries to expose underlying conceptual assumptions of a particular delivery format that is taken for granted as unproblematic. The conceptual basis of nursing and health care education and practice often loses ground to a narrow focus on procedural and technical skills.[10,11] Nurses working with remote populations or with populations that are culturally very distinct could benefit from this article by questioning the conceptual basis of their work, asking themselves if they consider that health is something that is "taken" to a location and otherwise unavailable locally, and if their work genuinely supports local health care infrastructure and autonomy or if, instead, it perpetuates dependency.

The article concludes by proposing that these medical missions should be redesigned as supports for the development of local health care infrastructure. Medical missions should become elements of a multilayered process oriented towards long-term capacity-building at the local level. This delivery formant should apply resources and actions to providing long-term benefits for the local health care system, and should respond to planning that is based on local health priorities.

Despite funding stability[12] and administrative reorganizations[13] over the past decades, the delivery of biomedical care for Indigenous Amazonians living in forest villages in the region of this research has been broadly inefficient to significantly improve community health.

Epidemiological indicators do not demonstrate notable declines in disease incidence and prevalence for endemic diseases between 2004 and 2009.[12,14,15,16,17,18,19]. In terms of patient utilization, the population was generally reluctant to use services and found them discomforting. Patients avoided diagnostic analyses and often did not adhere to treatments. In terms of staffing quantity and quality, there was a constant turnover of health care workers. Difficulties in recruitment and retention of professionals persistently occurred. The researcher personally observed these occurrences from trip to trip, and heard them repeatedly recounted in interviews and conversations with staff and other professionals. Concurrently, the same types of issues have also been documented for Indigenous health care in other regions of Brazil [e.g., 20].

Supplementary interviews in 2020 obtained updated information that revealed a persistence of the model and its underpinnings. A permanent health post was recently built in one of the villages in 2017, which is an important step in the direction of infrastructure development. However, it is only open when the traveling team is present. Otherwise, the general delivery format is the same, especially for the remaining villages.

Theoretical background: Medical mission delivery

In this article, the term “medical mission” is used as an analytical category for a particular health care delivery format involving traveling health care teams. It is applied here to the government-funded medical and nursing trips to remote forest villages in Brazil that are part of the national health care system.

Government-funded medical missions in Brazil

The medical mission delivery format has always been a staple of the Brazilian government’s health care services for its Indigenous population, despite a succession of evolving bureaucratic structures intended to supersede it. Government-funded health care, which began in the early twentieth century, variously consisted of combining the actions of traveling medical teams, attempts to epidemiologically isolate Indigenous lands and populations, the permanent (or semi-permanent) residence of a nursing professional (or team) in or very close to select key villages, and sometimes outsourcing medical and sanitary services to NGOs or other organizations with their respective traveling teams.[2,21,23]

Specifically, in the 1950s, the Aerial Sanitary Units Service (Serviço de Unidades Sanitárias Aéreas) would fly to offer basic services to remote villages, such as immunization, dentistry, and tuberculosis control.[2 p7] Later, they were replaced by the Traveling Health Teams (Equipes Volantes de Saúde) in 1967, also traveling sporadically to offer care to Indigenous communities.[2 p7] As funding decreased, NGOs and the Catholic Church began to offer services in the absence of government teams, also relying on traveling teams.[1 p121-126 p133-136,22,23,24,25] In the 1980s and early 1990s several meetings proposed reorganizing delivery on the basis of local districts, to rationalize administration of resources, which eventually evolved into the current system.[2 p8]

The current delivery model began in the 1990s. In the current model, traveling health teams visit the villages to offer basic medical and prevention services, and conduct epidemiological surveillance. They travel to the villages with variable regularity depending on the region and environmental conditions.[2 p14] The teams are called Multidisciplinary Indigenous Health Teams (Equipes Multidisciplinares de Saúde Indígena).[2,26] In principle they should be comprised of a physician, a nurse, a dentist, and a nutritionist, each with an assistant, and some other technicians and specialists.[2 p14, 26 p46] In practice, they are never so complete, as numerous professionals are consistently lacking [e.g., see 20].

Each village also, ideally, has a permanent resident lay health monitor (usually barely trained and equipped with a minimal set of basic over-the-counter medications) and a lay sanitation monitor, who are theoretically also part of the team but in practice not always significantly included.[2 p14] Care that entails more than basic medical or nursing services requires transport out of the village to hospitals or clinics in the nearest towns or in major cities.[2 p14] The current organization intends to complement the traveling health teams with other supplementary structures (e.g., Indigenous representatives in administration and supervisory boards, attempts to introduce water and waste sanitation infrastructure, etc.), but the core frontline of medical, nursing and prevention services for the villages is still the traveling team.[2,26]

There is an established health care policy for Indigenous populations since 2002.[2] It mandates the implementation of a differentiated delivery that encompasses the “cultural, epidemiological and operational specificities of those populations”,[2 p6] and which must develop and implement “appropriate technologies based on the modification of conventional Western service delivery”[2 p6] as well as the “formation of staff for work in intercultural contexts”.[2 p13]

Successive studies of the Indigenous population’s health care system over these past decades have reiterated the lack of achievement of these policy objectives. Langdon and Garnelo[1] confirm the gap between the legal guarantees and cultural rights of the Indigenous populations, and actual objective results. They explain that the policy recognizes the legitimacy of Indigenous knowledge and practices, and mandates an approach that integrates Indigenous medicine with biomedicine. Biomedicine is assigned a role of complementary medicine.[1] Yet, in practice, there has been little impact in that direction. There is a disconnection between the policy and the actual “therapeutic practices of the multiprofessional teams that provide primary care in Indigenous villages”.[1]

In practice, biomedical health care personnel conceive of Indigenous medicine and culture in essentialist terms, and do not recognize Indigenous agency or the recreation and reinvention of tradition [e.g., 27,28]. Indigenous peoples and their views are “negated or ignored by an official health system that limits itself to a vague ordering of administrative health routines” that is “marked by a high degree of standardization of rigid prescriptive technical norms, whose biomedical character makes them impervious to local contexts and singularities” [e.g., 1,27,29,30,31]. Attempts to build intercultural or intermedical health care have mostly originated from Indigenous actors, and administrators and providers of biomedical care have been uninterested in this integration, consistently dismissing or segregating Indigenous medical knowledge and practices.[20 p179]

Specifically regarding nurses working in Indigenous health care, a recent study by Calvacante[20] in the state of Pará (northern Brazilian Amazon), showed that the nurses were focused on technical and biological aspects of delivery, and did not have sufficient cultural competencies.[20 p200] The nurses confirmed that their actions in the villages were focused on fulfilling technical procedures and bureaucratic duties, following the administration’s calendar, which, they acknowledged, did not match the context or calendar of the Indigenous communities.[20 p170]

In their interviews with Calvacante, the nurses recognized Indigenous cultural practices, but only as anecdotal narratives of cultural contact, not as genuine care and medical practice. She asserts that the nurses sustained the hegemonic interventionist and technocratic biomedical approach, independent of the social and cultural context of the patient population.[20 p177] In self-assessed questionnaires, the nurses recognized that they had some knowledge of the population’s dietary or social norms, but had less knowledge of the belief system regarding life, death and illness, as well as treatments and rituals. That is, the nurses knew less about Indigenous care approaches and practices than about other aspects of the population’s culture.[20 p176]

Scholars have characterized this relationship between the Indigenous patient population and the Brazilian state in the health care system as a “postcolonial assymmetry” that involves the “legal and moral subalternization of the Indigenous peoples”.[1] This assymmetry is translated “at the technical level in the hegemony of the primary health care model developed in a mechanical and standardized form on Indigenous reserves”.[1]

Indeed, government services for Indigenous populations often establish and reinforce colonial types of inter-societal relationships, sometimes called “internal colonisation”.[32,33,34] From the Indigenous population’s perspective, national citizens who attempt to occupy Indigenous lands, such as ranchers or gold miners, are labelled as “invaders” [e.g., 35]. National citizens are, to Indigenous peoples, cultural and ethnic foreigners who bring imported (i.e., locally unavailable) goods and services into their communities [e.g., 36].

This type of technical procedural delivery of health care services to Indigenous populations has also been characterized as a form of “structural violence”.[21,38] “Structural violence is perceived as a subjectless and blameless systematic violence which transcends those immediately involved in relations of care (health professionals and patients), thus placing constraints on the possibility of action” [21]. Structural violence is a form of “violence exerted systematically--that is, indirectly--by everyone who belongs to a certain social order”.[38 p307] The point about structural violence is that it presents itself to the subjects involved as “nobody’s fault”,[38 p307] since individual actors are not individually responsible for the oppressive structure.

Identifying this type of violence and neocolonial relations embedded in the health care delivery structure is relevant for nurses in the Brazilian Amazon, as they are at the frontline of service delivery in this context. Calvacante's[20 p169 p171] research confirms the pattern that the nurses are decisive members of the medical mission teams, due to the constant lack of physicians. Thus, in addition to their nursing duties, the nurses frequently have to make clinical decisions, evaluate cases and take on the functions of other professionals.[20 p171] They are also required to maintain bureaucratic and administrative records.[20 p170]

The majority of the nurses in Calvacante's study had no prior experience of working with Indigenous patients. They frequently used the metaphor of feeling like they had "dropped in a parachute" into the field, highlighting their unpreparedness for its unique characteristics.[20] In self-assessment questionnaires, the majority recognized that they never or rarely made decisions or carried out actions in conjunction with the Indigenous healers (shamans) and/or midwives.[20 p142] They never or rarely self-examined their own cultural background, never or rarely recognized the risk of cultural imposition, and rarely accepted different perspectives on health, illness and care between patients and biomedicine.[20 p128-9]

"Medical missions" as an analytical model

This article interprets the government's traveling Multidisciplinary Indigenous Health Teams as "medical missions", due to their strong resemblance with other types of traveling medical teams.

The archetypal medical mission would be the Short Term Medical Mission (STMM). Typically, such enterprises are composed of voluntary labor and address health crises.[3] They often attract young medical practitioners, and have become a common training experience globally.[4] Habitually, the health care staff, administration and organization are external agents (often expatriate foreigners), without a personal long-term investment in the delivery location.[4]

A generic model of the "medical mission" can be proposed on the basis of STMMs and other types of traveling medical teams. Namely, a medical mission is a delivery model that consists of a group of traveling health care professionals who provide services to a distant population in the population's location of residence. The goal of a medical mission is to provide care to a population who suffer from a considerable problem of access. Medical missions typically operate obliquely to existing local health care systems, superimposing a divergent delivery model.[39 p1450] They are isolated efforts to provide health care in specific locations for a limited period of time. In contrast to local health care systems, medical missions usually tend to focus on relief and remedial care.[39 p1450]

As a delivery structure, medical missions have some particular characteristics that distinguish them from the delivery of biomedicine in stationary urban clinics, hospitals or doctor's offices. This is partly due to their mobility and to their typically short time demarcations. For instance, medical missions typically focus their scope of intervention on a limited select number of procedures and diseases. They have limited supplies of materials, and the professionals may have limited or no access to ancillary services, such as imaging technology or laboratory tests. Thus, medical missions have limited diagnostic and therapeutic scopes [40]. Also, stationary clinics can also usually redirect their patients further along the health care network with less duress and discomfort for complex or specialized diagnostic or therapeutic needs, compared to mobile clinics [41,42].

Globally, there is also often a high rate of turnover of professionals between trips. There may be little or no opportunities for follow-up encounters with patients. Often, the professionals have little or no prior acquaintance with the patient population. There may be significant ethnic, cultural and linguistic differences between patients and professionals. The work often requires enduring spartan conditions, long hours and intense schedules.[4]

In terms of their efficacy, it is not sufficiently demonstrated that medical missions have lasting impact on the health of communities.[5 p336,43 p424] There is also persisting concern that they may have deleterious effects.[43 p424] As in this article, some recurrent critiques attribute their shortcomings to the delivery format itself. Namely, that medical missions typically focus on treatment of individual problems and rarely engage in prevention or address the health needs of the community as a whole.[6] Mission workers are usually unfamiliar with the local health needs and endemic diseases, the strengths and limitations of the local health care system, and standards of care.[6,7 p339] There are often scant relations with the local health care system.[6] Care is provided under conditions of short amount of time, large numbers of patients, lack of follow up, and limited medications and technology.[6,7 p339] They may provide only temporary therapies that do not address root causes, leave behind waste, and impose burdens on local health facilities.[8 p317] In addition, the care offered may be culturally irrelevant or inappropriate.[8 p317] Medical mission workers are often unaware of the local cultural health belief systems,[5 p335-336], are frequently unacquainted with the local culture, and may confront language barriers.[6,7 p339]

As a consequence, their practices may entrench paternalism, inequitable relationships, and appear ignorant of underlying power and privilege issues relevant to the context.[44 p163] This kind of delivery entails dependency on outside resources and personnel.[5 p338]

Montgomery[5] identified four major assumptions underlying the medical mission delivery model. Firstly, there is an assumption that no localized knowledge is needed and that participants do not require awareness and training regarding the population's medical systems, beliefs and practices. Medical mission workers may remain ignorant of possible conflicts regarding health beliefs and practices, miscommunication and non-compliance. Secondly, there is a naïve realism that assumes that approaches suitable in one setting may be applied intact in another location. This is related to the third assumption, which is a technique or formulaic approach. Mission planners apply a generic design that is essentially identical for all settings, and do not seem to think that special planning or the design of locally appropriate projects is necessary. The fourth characteristic is the assumption that a short-term, quick-fix project is sufficient or satisfactory. Consequently, a longer-term preventive approach is precluded.

As expressed by Dohn and Dohn,[43] the consequence is a delivery model in which the focus is on a technologically oriented program, based on facility resources and the authority of trained specialists who control the health agenda.

A fifth assumption may be added here to Montgomery's list, in view of the frequent lack of evaluation and regulation of medical missions.[8,45] It would seem that planners perceive medical missions as inherently beneficial, such that deliberations regarding their practices and design are unnecessary. In preparation for this article, it was found that there is a paucity of published discussions regarding their ethics, design, and implementation. In a review of articles published in English between 1985 and 2009, the majority (78%) of articles were descriptive of specific mission trips and only 5% had theoretical or conceptual analysis.[6] Very few discussed the ethics, policies, standards or evaluations of short-term medical missions.[6]

Thus, when compared with stationary delivery in urban centers, medical mission delivery may appear volatile, precarious, and restricted. Delivery is not implemented in a way that seamlessly emerges from the unique characteristics of the location and population. Instead, it is usually enacted upon the population as a beneficent foreign practice that is transported without modification from its location of origin.

This type of critique is also developed by Fassin in his analysis of humanitarianism. Fassin argues that humanitarianism reduces aid to the biological lives and biological survival of recipients, oversimplifying recipients' histories, complex realities of suffering and injustice, and subjectivities.[46] Fassin is critical of humanitarianism's "self-congratulatory ethic of rescue". In his view, the medical model of "rescue" is a distraction from how to achieve long-term change and should be replaced by practices that consider structural elements, since humanitarianism does not substitute or resolve systematic oppression or inequality.[47] Due to the focus on the individual, as opposed to community conditions, social processes are translated into the clinical language of individual suffering.[48]

Analytically, "humanitarian" action can be contrasted to "development", which aims for long-term lasting improvements.[49 p1] As such, suggestions to redirect and reorganize medical missions place emphasis on achieving more congruence with the local conditions and culture, and as supports for long-term improvements [e.g., 4]. Melby et al.[4] call for a "paradigm shift" regarding medical missions grounded on four factors: 1) cross-cultural effectiveness and competence, 2) bidirectional relationships, 3) local capacity building, and 4) long-term sustainability.[4] The intention would be to contribute to local infrastructure and human resource development in order to avoid dependence on a repetitive and disjointed cycle of traveling medical teams.[4]

Generally speaking, medical missions must become elements that contribute to local development.[43 p424] They should provide support to local organizations and individuals.[5 p337] They should help with the training of local providers and patients' access to local care.[5 p338,8] Medical missions should supplement local services.[5 p340]

The recipient population, not the mission workers, should be the ones who define the needs to be met.[5 p340,16] All efforts should be coordinated with existing health services and location-specific projects, instead of applying general formulas.[5 p340] The emphasis should be on supporting the local system with skill and equipment assistance, instead of targeting patient volume.[5 p340] The effects of the missions must be assessed in terms of their contribution to the local delivery system.[5 p340] Periodic evaluation should be conducted to improve design and implementation.[8]

Thus, medical missions should move towards community-based health and preventive programs.[43 p424,16] The mission team should help improve local capacity for health care, and address systemic problems related to poor health, such as poverty, hygiene, and illiteracy.[43 p424] Medical missions should move away from a disease and relief orientation towards prevention and local development.[43 p424]

Additionally, mission workers should be trained in cultural awareness and cross-cultural communication, acquire proficiency in the native language, and receive training on the contextual realities of the mission sites.[6,50 p379] Mission planners should promote consciousness-raising among the workers and long-term relationship building with the community.[44 p163]

Broadly speaking, this article contends that the characteristics of the medical mission as an analytical category would apply to the Brazilian government's Multidisciplinary Indigenous Health Teams. These teams are mostly staffed by Brazilian nationals, funded by the state as part of the national health care system, and intended to provide care with some reliable regularity. However, their strategies, practices, and logistical implementation follow the medical mission model. For instance, there are strong cultural differences with the recipient population and the Indigenous medical and health system is neglected or segregated. There is a high turnover of professionals, little coordination with infrastructure development, and a formulaic procedural approach to intervention. Finally, there is little involvement of Indigenous participants in planning and execution.

Other scholars of the government's health care system for Indigenous populations in Indigenous territories in Brazil have not explicitly used the "medical mission" model or the STMM literature to interpret the implementation model and its problems [e.g., 1,20,21,27,28,29,30,31]. Such use is an innovation of this article.

This article advocates that understanding these traveling teams as medical missions could contribute to a inform a "paradigm shift"[4] in their design and implementation, in order to reorient their organization and practices towards local health care infrastructure development that could contribute to an increased ability to resolve and prevent health problems in the villages.

Research methods

Qualitative approach

A qualitative approach guided the research. Specifically, the goal of this article is to uncover conceptual assumptions that underlie a set of practices and behaviors. The article intends to unearth the unspoken notions about health and health care that orient medical mission delivery design and actions. These notions are not quantifiable nor objectively empirical elements, but conceptual assumptions about the nature of health and care [e.g., see 51].

Additionally, the research sought to obtain data from a naturalistic setting, without imposing a controlled and artificial manipulation of variables, and allowing for sufficient flexibility and adaptability for unforseen and unpredictable events that could emerge during interactions with participants and other situations. Generally speaking, qualitative approaches tend to provide researchers with sufficient elasticity to work under such conditions [e.g., see 52].

In terms of positionality [e.g., 51,53,54,55], the researcher is neither Indigenous nor a Brazilian national, and therefore is not a cultural native in the research settings. The researcher would be classed as "White" (branco) by the participants, which is term that is broadly applied in this region (by the Indigenous and by Brazilian nationals) to people with an urban industrial middle class culture. The researcher's status as a foreigner was not evident to participants, and sometimes came as a surprise revelation. This is possibly because the researcher had traveled to Brazil many times before, including this region, and was fluent in Portuguese and comfortable with cultural immersion. The researcher was also quite adaptable to the austere and particular living and travel conditions that characterize the lifestyle of the Brazilian nationals in this region [e.g., see 55]. The researcher did not feel any significant culture shock [e.g., see 56].

As an adult male with a university background, and perceived as "White" (branco), it is possible that the researcher was able to have unfettered access to a number of physical locations. For instance, it may have allowed him to travel alone, to explore locations with independence, and to establish his own routine, thus facilitating passive observations [eg., see 55]. As a male, he may have been expected to accept physical discomforts and spartan conditions. It also may have facilitated social integration with the other male members of the health team and the male boat crew. His positioning may have also potentially implied some degree of assumed authority in interviews, especially with the administrative staff and health care workers. This may have facilitated access issues, including to their grey literature and internal records, and may have implied some degrees of impression management on behalf of some interviewees. Conversely, the researcher did not integrate much with Madiha villagers, and had almost no direct contact with Madiha women or children. He also did not engage in recreational activities with Madiha individuals.

In terms of research gaze and interests, the researcher was mostly focused on the way interethnic relations were carried out in health care interactions, exclusively for academic purposes.

The researcher's individual personality may have stood out, as he is a generally reserved and quiet person, prone to observe and listen. This type of reserved behavior was also a research strategy, to avoid participants feeling invaded and to avoid any demeanor of foreign expert or academic superiority. He was hesitant to participate in some male leisure activities, such as soccer [e.g., see 55 p264].

The researcher assumes that his composure and his blending in with the culture of Brazilian nationals, coupled with the hospitality of the research participants, may have contributed to the rapid formation of comfortable rapport and interactions. It is expected that most of the behaviors observed during research and the information provided in conversations and interviews are naturalistic, representative, and would have occurred in the same way regardless of the researcher's presence [e.g., see 55].

In terms of reliability, as the results of the research echo and reiterate similar findings about comparable settings and programs, it seems reasonable to assume that the results are reliable [e.g., see 57]. In terms of validity, the methods produced data that was coherent with the objectives and the data replicated itself as observations progressed. It seems reasonable to assume that the research and analysis were not significantly impaired by any methodological or personal biases of the researcher or context limitations [e.g., see 57,58].

The researcher recognizes that the opinions and interpretations of the Madiha patient population were not researched systematically, and that some of the information about them was obtained indirectly through the health workers. It is possible that future research that engages the patients' interpretations and experience in a direct manner may qualify or refine the interpretations presented here.

Research population

The core research population considered in this article were the health workers that traveled to Madiha villages to provide biomedical health procedures. The workers formed part of a team of varied professionals. When complete, the team consisted of a physician, nurse and dentist, each with an assistant, and support staff (boat crew and cook).

For this particular location, the team was traveling with some reliable regularity to the villages, ideally once every month. Depending on the size of each village, the team stayed in them for one or two days, sometimes less than a full day.[9] The team lived on the boat during the trip, sharing the living space and all activities. The space was very cramped, and things were constantly being moved around to make space for changing activities. Most of the team members also worked together in an office in the town of Manoel Urbano, where they carried out bureaucratic and organizational duties, and also voluntarily helped any Madiha villagers who were in town to deal with circumstantial needs.[9]

The cooks, boat crew and assistants were residents from the town of Manoel Urbano, except for the dental assistant who was from the nearest town Sena Madureira. One nurse, and the physicians and dentists were from other cities. The nurse had taken up permanent residence in Manoel Urbano, but the physicians and dentists would come specifically for the boat trips and would stay in a hotel if they had to linger in Manoel Urbano. Except for one of the cooks, the workers were quite young, either unmarried or with small children.[9]

The health workers are Brazilian nationals and the language of research was Portuguese. The researcher is fluent in Portuguese. Any conversations or brief interviews with Madiha were also in Portuguese, as the researcher does not speak Madiha. This limited the number of Madiha who could be spoken with directly, mostly adult men. The research did not focus in detail on how the health care actions were received or interpreted by the patient population, which is a very valuable concern to investigate, but was excluded for logistic and legal reasons. Much of the information about the receptivity of the patient population is derived from the opinion of the health workers.[9]

Research location and setting

The researcher accompanied three trips between 2009 and 2010. Each trip took about twenty or more days. The boat traveled from Manoel Urbano along the Upper Purus River and into the Chandless River, located in the state of Acre in the southwestern Brazilian Amazon, not far from the border with Peru. There were six Madiha villages on the team's route, which varied in size from just over one hundred to less than forty people. All the villages had a constant traffic of canoes throughout the day, with villagers visiting one another's village. There were also some nuclear families living in temporary camps along the river.[9]

At each village, the health team unloaded the equipment and carried it up to the village. They set up the equipment in the school house or if there was no school (as in the small villages), on somebody's front porch. Most health actions took place in that single location. For some cases, staff visited individuals in their homes.[9]

The Madiha villages mentioned in this article are located in the municipality of Manoel Urbano, in the state of Acre. The municipality has only one small town. The rest of the municipality is more than 90% tropical forest, with Indigenous villages and mestizo riverine farm homesteads sprinkled along the banks of the river. The Purus River is an affluent of the Amazon River. It runs south to north, starting just across the border in Peru.[71]

As the researcher observed, and as described in the literature, Madiha are hunters and manioc farmers, and they also fish with nets. They live in villages that range in size from just over one hundred people to about thirty or less. Headmen are usually prestigious hunters, and always males. Villagers are usually interrelated as family members.[67,72,73,74] Many Madiha do not speak Portuguese. They are primarily monolingual, and their language is not mutually comprehensible with that of any other Indigenous group in Acre. Their language belongs to the Arawan stock.[74,75,76] As the researcher observed, Madiha shun interactions with other ethnic groups. They do not interact very much with the neighboring Huni Kuin (Kaxinawá) Indigenous people. They also do not interact very much with the riverine farmers. Madiha also rarely visit the town.[9]

The Madiha medical and healing system thrives in the villages. The researcher did not observe Madiha healing and did not research it first-hand. The following brief descriptions of the Madiha medical system are taken from published ethnographic sources. Shamans are males, but the women play an important role in choral singing during ceremonies.[67] Midwives are elderly women. Sorcery is a primary diagnosis for internal illnesses. An enemy, who is usually assumed to be a Madiha male in another village, magically introjects a caustic masculine substance, called dori, into the victim. The dori hardens into a stone, and may eventually cause death. Shamanic treatment attempts to remove the stone. Dori is also what makes men brave and "wild", as opposed to women who are "tame" and nurturing.[67,77] Illnesses on the skin or other external illnesses may be caused by physical contact with a harmful object or animal, such as a cut or an insect bite. In this case, rubbing the location with strong smelling plants or strong smelling industrial products is a standard treatment.[67] Small children are particularly prone to epetuka'i illness, which is caused by parental violation of taboos, such as food taboos.[67]

As observed by the researcher, there is a resident lay health monitor in every village, who is always male and receives a modest government salary. The monitors have little to no training in biomedicine and, according to the medical mission workers, are not always called upon by villagers in cases of illness. The monitor is equipped with some basic over-the-counter medications and a small supply of gasoline to transport patients to the town if necessary. Pregnancy and childbirth are the domain of women and the midwives, thus the monitors do not participate.

Research ethics

The main research was conducted for a doctoral dissertation in medical anthropology at the University of Pittsburgh.[9] The doctoral research was declared "exempt" by the Institutional Review Board of the University of Pittsburgh, reviewer: Nicholas Landolina, IRB # PRO08120207 [e.g., see 65].

In addition, informed consent was obtained in written form from the regional Indigenous Health Care administration. At the time, this was Mr. José Carlos Pereira Lira, FUNASA regional coordinator for Acre, and from nurse Neiva da Silva e Silva, administrator of Pólo Base de Saúde Indígena de Manoel Urbano.

The researcher also obtained informed consent verbally from individual interviewees prior to interviews, and by the villagers at village meetings prior to observations [e.g., 51, 66]. Participants are not named in this article [e.g., 51].

The behaviors observed for this article were all public behaviors. The observed health procedures were carried out in a public space with a large number of onlookers, that included villagers, staff and boat crew, in addition to the researcher. Very few health procedures were private (e.g., cervical cancer screening) and the researcher did not observe or attempt to observe those procedures. Instead, he relied on the nurses' descriptions and opinions [e.g., see 65]. The ethnographic literature confirms that health concerns are a community affair for Madiha, and healing ceremonies are public and involve the community.[67]

Consequently, there was no apparent invasion of privacy and the researcher did not impose a presence or role that was different from that of other onlookers, with the exception of registering some actions with a video or photographic camera. Even so, this behavior was not extraordinary as the nursing staff also took photographs of their work for their own reports.

Data collection methods

The objective of the article is to infer premises or assumptions about health and health care that underlie the behaviors and interactions of health care workers with the patient population [e.g., see 59,60].

For this article, the main instrument was the observation of behaviors, in particular the interactions between staff and patients. The secondary instrument was the conversations and interviews with the staff. The main variable considered was the degree to which health care actions required transported knowledge and resources, including human resources. The main indicators being the potential independence of the knowledge and resources from the location of delivery, and the role assigned to local knowledge, resources and personnel [e.g., 61,62,63].

The findings presented here focus on a single issue that emerged from a larger research study that aimed to analyze how biomedical health care workers perceived their agency to work in an intercultural health care context.[9] The data presented here is a subset of the data obtained from the larger study. The purpose of isolating a subset of the data is to focus analytical attention specifically on the clinical encounters between health care professionals and patients as signifiers of the general approach to health and health care implemented in the medical missions.[64]

The principal research for this article was conducted by accompanying three medical mission trips, during which the researcher lived on the boat with the health workers and shared all living spaces with them. He shadowed them as they worked and rested [e.g., see 66].

The main data collection method relevant to this article was passive observation of the health workers carrying out health procedures with patients. Three techniques were used: short film recordings, photographs, and direct naked-eye observations registered in a journal.

The main justification for using observations was to register behaviors. The intention was to determine regularities and patterns in the health workers' behaviors when interacting with patients, focusing on the clinical encounter for this article.

The researcher carried out the film recordings and photographs, and obtained consent prior to shooting. The recording technique consisted of remaining standing near the interactions without interfering or participating, only witnessing the actions. The types of interactions were selected for their representativity, registering samples of the whole range of procedures carried out by the staff. The film recordings demonstrated interactions, procedures and roles. The photographs were useful to reveal relative roles, spatial layout and positioning.

As a research method, the use of visual records (such as videos, photography) has received some critique in the literature, for instance, as a colonial medium of museumification or for photogenic montage of subjects and actions [e.g., 68]. In this research, however, none of the recorded actions were staged, there was no purposeful composition, and the selection was based on a convenience sample of representativity of the range of clinical interactions. The researcher did not interfere with or direct any of the actions.

Interviews were a complementary data collection method. These mainly consisted of informal unstructured conversations with participants during the trips, bringing up certain topics and questions depending on the convenience of the occasion. Some formal semi-structured interviews were also carried out in the office in Manoel Urbano town, between trips.

As a research method, the interview technique has been discussed and critiqued by some authors. The researcher recognizes that the quality of his relationship with the participants, their personal contextual and biographical conditions, contextual issues of the setting, and other elements may affect the co-production of meaning and responses in the interview encounter. Many of the responses, though, were repeated by participants when questioned at different opportunities and in their conversations among themselves, suggesting reliable representativity of their responses in interviews [e.g., 65,66,69].

The main justification for carrying out interviews was to complement observations with respondents' own opinions about their behaviors and their work, as well as their views and values regarding diverse aspects of their work, their relationship with the patient population, their experience and biography, and to obtain some information about past events and circumstances.

The formal interviews were carried out in private in a room in the office. Informed consent was obtained prior to the interview. The interviews were recorded, with the recorder remaining visible on the table in full sight of the participant. The interview guide and journal were also kept on the table and in full sight. The language of interview was Portuguese. An interview guide included some prompts, and respondents were encouraged to speak freely about these prompts. The interviews ranged in duration from 21 minutes to one hour. The interviewees were the staff living permanently in Manoel Urbano: nurse, dental and nursing assistants, and boat crew. As the researcher had already participated in trips and other interactions before the formal interviews, it is expected that participants were at ease and adequate rapport had been sufficiently established previously [e.g., see 65].

The informal interviews or conversations occurred during the trips and also in Manoel Urbano. The researcher usually approached the staff during relaxation moments. Informal interviews were not recorded and were framed as casual conservations. The responses were recorded later in writing in a journal. Unlike the formal interviews, the conversations mostly focused on a single issue or inquiry at a time, involving a short and quick interaction. Some information was also obtained during other conversations, for instance, when initiated by the participants as part of their daily friendly interactions with one another and the researcher.

There was also some degree of participant observation, as the researcher shared the living spaces and some activities with participants. He traveled on the boat, sleeping, eating, bathing and spending all of the time with the team. The researcher assisted with some tasks, such as carrying loads, and also participated in recreational activities. There was a lot of conviviality among the team members, among whom the researcher felt very welcome and at ease, generating adequate levels of rapport to carry out the research tasks unobtrusively. Most of these daily informal interactions and events, and reflections, were recorded in a field journal [e.g., see 55,56].

The researcher held a few unstructured short conversations with some Madiha individuals, mostly the lay health monitors who were fluent in Portuguese. These were not especially extensive or in-depth, and were more focused on the monitors' tasks, training and expectations.

In order to acquire updated information, the researcher conducted two interviews in September 2020 using social media (whatsapp®). One interview was with the head nurse and the other was with a nursing technician, who are by now long-term staff, residents in Manoel Urbano, and whom he met during fieldwork. He asked a structured set of specific questions, exclusively focused on the issues raised in this article, requesting information about delivery since 2010 to the present. The interviewees responded briefly to each question in writing and with some audios. They spontaneously added some other pieces of information about the work, setting, population, and some health actions and logistic improvements. The nurse also spontaneously sent the researcher a number of photographs and short videos, which show some of these logistic improvements, as well as examples of the health care work. These photographs form part of the aforementioned continuous photographic log that the workers carry out of their health actions. These photographs taken by the workers repeat the same kind of photographs taken by the researcher, demonstrate the same kind of positioning and roles he observed, and support the findings he concluded from his photographs and film recordings.

It may be worth noting that the nursing professionals have such a fundamental role in the type of delivery studied, that the researcher approached them right away for updated information in 2020. The nursing staff were "key informants".[56] They have a distinctive view of the phenomenon due to being hierarchically intermediate workers, demonstrated mediatory abilities in their interactions, and consistently exhibited goodwill to assist the patient population and the researcher over the years.

Analytical approach

Analysis for this article is mostly inductive. The attempt has been to distill underlying values or principles on the basis of the observed behaviors and participants' narratives. The analytical focus was placed on repeated and recurring behaviors and interaction modes, which were also the prevalent type of behavior observed [e.g., see 51,61,65,70].

Due to the repetitive nature of the behaviors and somewhat consensual stance of the health workers regarding their work, it seems justifiable to assume that there were shared underlying principles guiding their actions and opinions. The majority of interactions seemed to follow recognizable patterns, especially during health procedures. Health procedures were also the majority of the interactions with the patient population, as the team spent as much time as possible during the day performing procedures, though team members also mingled with the villagers for some of their leisure and relaxation activities (e.g., ball games).

The descriptions of behaviors presented further below in the article provide a summarized and synthetic general representation [e.g., 70], focusing on the recurring behaviors. Visual data was used primarily to identify the behaviors, and also their relative frequency. In turn, information obtained through interviews and observations inform the descriptions of the ideological elements that characterize the health workers' approach towards the villagers' health status and native medical resources. (Examples of singular detailed descriptions of a particular day or activity, and interview excerpts, can be found in [9]).

Research results: Underlying premises and effects of delivery

Succinct statement of argument

The core argument of this article is as follows:

The researcher proposes that the medical mission delivery described here is supported upon two premises: 1) health care is a transferable good or service; and, 2) health is a condition that requires imported knowledge and resources. These presumed premises were not clearly recognized explicitly by any actor, but seem to underlie the practices and approach. These two premises were induced based on observations and interviews.

It is suggested here that these two premises each result in an observable effect: 1) the notion that health care is a transferable good or service is, at least partially, what leads to a chronic perception of insufficient staff and resources; and, 2) the notion that health requires importing foreign knowledge and resources is, at least partially, what reinforces cultural barriers that obstruct patient adherence.

As for these alleged effects, interviewees did explicitly mention these as constant problems. They constantly pined over insufficient staff and resources, and they recognized the existence and relevance of cultural barriers. Yet, while interviewees seemed to perceive them as self-sustaining conditions, this article proposes considering them effects of the delivery format.

That is, with this article, the researcher has organized the data obtained from varied observations and interviews into a causal analytical model. On the one hand, participants recognize certain recurring issues of health care delivery insufficiency or inefficacy as serious problems, but they tend to think that their causes are external to the actual delivery, emerging from structural factors of the setting (such as, its remoteness and the cultural differences). On the other hand, by examining the delivery practices themselves, the researcher instead proposes an alternative causal link (though not exhaustive) with such practices. Consequently, rather than contribute to solving the recognized problems, the delivery practices potentially exacerbate them.

The theoretical complement proposed here is to draw attention to the structural factors of the delivery format itself as a potential iatrogenic source of health care inefficacy, and not just attribute insufficiencies to the availability or quantity of resources, which is how the health care staff think about their problems.

The objective of this article, then, is to propose this analytical model by suggesting causal links between information and facts that seem unconnected to the participants. For this reason, the article moves the discussion from empirical data into inferred premises that seem to underlie the structure of the delivery format.

The way that such alleged effects of the delivery format eventually contribute to the low improvement of health indicators also implies two mechanisms: 1) the reliance on imported goods and services leads to a neglect of the improvement of local conditions that cause health problems or which may improve health status; and, 2) patients are reluctant to comply with foreign medical recommendations that they do not share or which they understand differently.

The following sections present each of the elements of this argument, providing the empirical support and detailing the connections.

Premise 1: Health care is a transferable good or service

The medical missions researched here supply health care as a literally deliverable good or service. The fieldwork shows that health care is provided as a compact bounded set of procedures that are fully detached from any locally habitual tools or behaviors. It is a self-contained commodity that has no metonymic association with any local individuals, relations or objects.

The following is a brief description of how this product or service is executed, according to the researcher's observations. There are four salient observable features that characterize the professionals' health care actions: a) assembly line arrangement, b) concentration on execution of procedure, c) focus on specific body part, and d) minimal or no communication with the patient.

a) The assembly line organization maximizes space and time constraints. The professionals set up their equipment in the same room, creating three independent stations. Patients are then propelled consecutively from one station to the following. This assembly line arrangement creates a constant flow of patients that facilitates universal coverage. There is practically no individuation or differentiation of procedure between patients. With this delivery format, biomedicine is presented as a set of identical technical procedures to which all village residents are consecutively submitted.

b) The professionals spend almost all of their working hours focused on the exclusive performance of required procedures, statically posted at their respective station. There is strong pressure to perform as many procedures as possible within a short time frame. There is little opportunity for performing unplanned procedures or distractions, and no option to delegate procedures onto another worker.

c) At each station, professionals perform only a restricted set of actions. Coupled with the assembly line formation, this steers professionals to an engrossed repetitive and circumscribed focus on specific body parts, one patient after the other. For example, comprehensive immunization coverage is achieved in a short span of time through a highly mechanized process in which the nursing technician is mostly concentrated on filling needles and pricking arms, one after the other, as the line of villagers flows past her.

d) The mechanization of delivery allied with the linguistic barrier make most health care interactions silent encounters. The silence amplifies the focus on mechanical procedure, and fosters a very fragmentary and partial knowledge of the other party. Many Madiha do not understand Portuguese and none of the professionals have any relevant fluency in Madiha language. The professionals who reside in the nearby town have learned some isolated Madiha words and commands that are relevant to their tasks. For instance, they know words such as “man”, “woman”, “come here”, “open your mouth”, and so on. However, they cannot carry out any meaningful conversation or construct a single complete sentence in Madiha language. Newly arrived professionals learn these words from their colleagues and do not pursue further language learning.

Medical consultations constitute the exception to the pattern of silent health care interactions. They primarily consist of verbal interrogation. Yet, there is almost no direct communication between the physician and the patient, and the conversation flow is vectored. Patients do not speak much during consultations. They mostly only answer questions, and usually only speak with the interpreter. The interpreter is usually the village lay health monitor, who does not have any specific training in medical interpretation or in biomedicine.

Consequently, health care is delivered as an impersonal product that is distributed in an identical manner to each patient through a set of fairly uniform procedures. It is composed of discrete set of mechanical procedures repeatedly performed on distinct body parts, one patient after another in an assembly line fashion. Procedures are performed perfunctorily. Minor adaptations are mostly according to the patient’s frailty or resistance. The procedures are usually silent, as there is virtually no verbal communication between patients and workers.

Effect 1: The chronic perception of insufficient staff and resources

It is proposed here that the premise that health care is a transferable good or service, at least partially, leads to a chronic perception among staff that the medical missions suffer from insufficient staffing and resources. That is, the perception of insufficient resources is a distortion that is produced by the delivery format itself.

In regards to the perception of understaffing, according to the researcher’s observations and interviews, most of the mission teams truly were incomplete for most of the time. However, a precision is required. The mission teams did not suffer from generalized understaffing. Rather, they suffered from understaffing of two specific positions: physician and dentist. The teams frequently travelled without a physician and most of the trips did not have a dentist. The other posts (i.e., nurse, assistants, boat crew, cook) were well staffed. Thus, there was a chronic insufficiency of only physicians and dentists.

Yet, because the medical and professional orientation of the delivery model awards those two posts a primary status (in terms of hierarchy, decisions, etc.), their persistent understaffing was perceived as a fundamental obstacle to delivery. The impact of their vacancy was always strongly felt. These two posts were charged with core functions of the mission service. As explained to the researcher, they are the two highest-ranking positions and are assigned the principal medical duties. Meanwhile, the teams always travelled with a sizable number of other competent health care staff, such as nurses and assistants, and supplies, but these were underrated due to the approach.

With the current staffing organizational design, all of these posts are dead-end jobs. Due to the way that the Indigenous health care system in Brazil is structured, there is no opportunity for career promotion or diversification in this delivery model. Thus, the researcher learned that medical mission work was unattractive to professionals seeking to make a career and only retained workers who sought local residential stability. The physicians and dentists on the trips were all recent graduates, who quickly moved on to other employments, and they expressed in interviews why they saw this only as temporary employment. Consequently, the lack of career paths made recruitment and retention attractive only to nearby residents. This rendered the peculiar staffing pattern of the teams a chronic problem. The subordinate positions of nurse, nursing assistant, dental assistant, and boat crew were always well staffed. Town residents wanted to commit to the job as a long-term prospect and filled these positions. In contrast, in the years surrounding the research, only young fresh graduates applied for the posts of physician and dentist. There was a very high turnover rate, as observed between trips, recounted in interviews, and recognized by the administrators that were interviewed. Generally speaking, physicians and dentists did not want this job as life-long career, as they expressed in interviews. Thus, the delivery model is incongruent with the supply and demand conditions for employing physicians and dentists, leading to a chronic situation of understaffing.

Additionally, this staffing problem placed an extra burden on the nurses, who were required to carry out additional (unpaid and unrewarded) duties during the trips without a physician, such as medical consultations and clinical decisions. It is reasonable that the regular staff would feel the brunt of this problem. Nurses' routine duties are already onerous. As observed during the trips and in conversations with a nurse, their regular duties include carrying out an assortment of interventions, such as immunization, pregnancy screening, growth and development assessment, nutritional surveillance, and supervising the nursing assistants who also perform these tasks. The nurse also is the trip manager, who organizes the scheduling, task distribution, control of stocks and supplies, purchases, and so on. The nurse is also the primary mediator between the team members and the villagers. One nurse is a stable figure from trip to trip. Villagers make all sorts of tangential and personal requests through her, such as assistance with government documentation, help with purchases, and so on. Thus, the nurse is a pivotal figure in the particular configuration of relations with the villagers that exceeds not only her specific nursing duties by requiring her to assume other types of circumstantial health care tasks on occasions, but also more generally by helping the villagers in their dealings with the national society and the government.

In regards to the perception of insufficient resources, this article suggests that this impression is induced by the complete reliance on imported technologies and resources. The workers' frustration would be a result of their dependency. Their distorted perception is a consequence of evaluating traveling mission delivery according to the standards of stationary urban delivery, though this comparison could be questionable. Several workers explicitly expressed to the researcher that they desired the boat to operate as a sort of mobile clinic. They wished that the boat was stocked with all the tools and resources typically found in a stationary neighborhood primary health care clinic. Also, several workers considered ideal the eventual installation of a permanently staffed and equipped stationary health post in or near the villages. Thus, it would seem that these workers perceived their medical missions as a rudimentary and incomplete form of delivery. Consequently, they expressed a constant lamentation of insufficient resources.

That is, the workers were measuring or evaluating the quality of their delivery against the standard of an urban clinic, abstractly and without contemplating the particular context and network facilities typically available for an urban clinic. The workers seemed to want to replicate the urban delivery model, but just relocated into the villages or floating on the boat. Thus, they always perceived delivery as deficient, because it always lacked core elements of urban delivery (such as certain staff and resources). Alternatively, a different way of evaluating their delivery could be proposed based on how their resources and capacities fit into the conditions of the target location and facilities, i.e., the congruence with the local context.

Premise 2: Health is a condition that requires imported knowledge and resources

These medical missions provide a form of health care that relies on the importation of all knowledge and resources. The health work is carried out in a way that seems to suppose that health (or, at least, certain types of healing and prevention) cannot be achieved with local resources and cannot be grounded in the current local conditions.

The medical missions conform to the fundamental disposition of so many other types of missionary enterprises, such as religious. In general, missionary activity typically presumes that there is a lack of soteriological resources in a given location and, consequently, missionaries are charged with transporting and delivering such resources to the deprived population. In this research, the health workers saw themselves as trustees of the Madiha population's health, and openly said so in interviews.

The following is a brief description of how the observed delivery format prioritizes imported (i.e., non-local) health means and ignores local health resources. There are three salient observable features that characterized this format of imported health means: a) ideological supremacy of biomedicine, b) subordinate status of local resources, and c) medical segregation.

a) The entire enterprise of the medical mission delivery that was researched is imbued with the certainty of the ideological supremacy of biomedicine. This is evident in the exclusion of Indigenous healers and their practices, but it pervades the activity in more subtle ways. The truth-value of biomedicine is entrenched in the health workers' subjectivities, such that it influences their interpretation of events and issues. For instance, a nurse once praised their work by telling the researcher how the teams "take health" to the villages. Her statement illustrates the assumption that health is perceived to be a transportable good, and also that health does not fully exist in the delivery location.

b) The missionary delivery that was studied involves a hierarchy of resources and knowledge. Generally speaking, local knowledge, resources and personnel are subordinate to their imported or external counterparts. There is a generalized neglect or disregard of local knowledge and local resources. The overall pattern is that the people with the closest and fullest understanding of the location and target population are subordinate to people with less or no experience of the setting. That is, the people with the least first-hand knowledge or direct local interests occupy the highest hierarchical positions.

This pattern of hierarchical subordination pervades the biomedical organizational structure. Firstly, all of the workers are subordinate to the administration, which is located in the capital city and has very little contact with the target population and only a certain degree of interaction with the health workers. Secondly, the personnel who live permanently in the nearby town and who have accumulated experiential knowledge are subordinate to incoming young professionals who often only have knowledge acquired in the university and whom stay for short periods of time due to high turnover. Thirdly, the target population's own medical knowledge, resources and practitioners are entirely excluded from participation in the delivery of the health care.

c) There is a state of segregation between the Indigenous medical system and biomedicine. Although in interviews the health care workers and administration staff recognized the existence and legitimacy of the Indigenous medical system, and did claim that it has its scope of efficacy, in practice, the Indigenous system plays no practical role in the medical mission's health care delivery. The two medical systems coexist side by side in a state of mutual exclusion. There is no support or collaboration between the Indigenous medical system and biomedicine. The team does not considerably discuss health and disease issues with the shamans and midwives, they do not concord to share responsibility for patients' health, and the village healers are not trained or introduced to biomedical concepts and practices. Conversely, the biomedical workers do not participate in the Indigenous healing rituals and do not know much about them. The health workers have only a bare understanding of the Indigenous medical system and have never shown an interest in increasing their knowledge. Their standard strategy is to ignore Indigenous medicine.

Effect 2: Importation reinforces cultural barriers that obstruct patient adherence

It is proposed here that the premise that health requires importing foreign (i.e., non-local) knowledge and resources reinforces cultural barriers that obstruct patient adherence. In this particular setting, biomedicine does not match the legitimacy of the Indigenous medical system. It is a minority medicine in this context. Madiha make constant use of their own medical system and only resort to biomedicine after failed persistent recourse to the native methods, as the researcher observed in some cases and learned from the health workers.

This article does not intend to romanticize the Indigenous medical system, which was not studied directly. Rather, the starting point to be made in this section is that biomedicine is a marginal medical system from the patients' perspective in this particular setting, and cannot count on the type of taken for granted legitimacy that it has in other locations. This was not always entirely obvious to all of the workers, who were all evidently convinced of the utility of their own medical practice. For instance, the idea that there is more than one type of medicine was a novel idea for one physician. He seemed genuinely surprised when the researcher pointed out to him in a conversation that the term "Medicine" that he was using only applied specifically to biomedicine. The physician had been using the word "Medicine" exclusively to refer to biomedicine, as if it were the only medical system. This conversation was also surprising for the researcher, who had imagined that the physician would be aware that the patient population had its own medical system that could also be described with the word "Medicine". Overlooking this legitimacy difference is part of the delivery problem.

Due to total importation, biomedical practices are unrelated and detached from the patient population's daily routines or healing practices, as far as the researcher could ascertain, such that there is no obvious connection between the imported practices and the population's habitual practices. Equally, the knowledge grounding of the biomedical care offered to the population is also unrelated to their cultural knowledge or to their social environment. This is possibly a significant reason why patients show low adherence to professional recommendations and treatments.

Certain biomedical practices also appear to run counter to Indigenous medical understandings. For instance, ethnographic sources state that Madiha are reluctant to take pills because they believe that medications are transformed by the body's digestive system.[67,77] Similarly, the researcher noted that pregnancy and childbirth is the domain of women from the kin group, which automatically excludes consulting with unrelated male physicians.

It was observed that the health workers make no use of the patients' own health knowledge. There is no attempt to render biomedical knowledge comprehensible or approachable to the patients by using terminologies, concepts or practices that are accessible to them. Health workers make only a bare attempt to explore and comprehend the population's own etiological understandings regarding disease. The workers only know that Madiha attribute many diseases to sorcery (dori) but they do not know the particulars of such etiology, such as causation pathways or the details of Indigenous treatments. The workers also do not know in which cases Madiha attribute disease to other sources, cited in ethnographic sources, such as contagion.[67,77]

It was observed that biomedical procedures and explanations are presented to patients in cognitive terms that are generally foreign to them. If there is any potential indigenization or appropriation of this knowledge by the patients, it is a process that occurs independently from the health workers, and of which the workers (and researcher) are unaware. The workers do not really know what the patients understand, how the patients understand, or what the patients make of the information and practices they are exposed to.

Due to the travel schedule of the team, biomedical delivery is a regular, but infrequent, event for the Madiha. As a consequence, most Madiha have only sparse contact with biomedicine. It is a bounded episode that interrupts their habitual routines for a day or two every month or so. They experience biomedicine through only a small restricted set of procedures. It is presented to the patients as a self-contained independent and circumscribed set of practices.

Additionally, biomedical workers only communicate in Portuguese, reinforcing the foreigner status of the medicine. The health workers do not make any significant use of Madiha language in their communications with patients. It was observed that patients are spoken to in Portuguese, and using Portuguese vocabulary for ailments, symptoms and other factors. The workers know very few words and phrases in Madiha. They admitted to the researcher that the language difference makes communication difficult. Yet, they show no attempt to learn the language to any meaningful degree. The use of untrained interpreters increases the vulnerability of the communications. There is no monitoring, evaluation or training of interpreters. The health workers do not know how the interpreter is transmitting information to patients, nor if the patients' responses are being transmitted back to the workers satisfactorily.

Discussion: Program continuation and suggested reorientation

In July 2017, the health care team was able to fulfill the aspiration of having a permanent health post set up in one of the Madiha villages. This new building has simplified some of their work, primarily avoiding the constant transport of heavy equipment and certain supplies, and providing a single stable location for sleeping and resting while they are in the Indigenous territory.

There are many improvements with this health post. As emerged from the update interview with the nurse and some photographs she shared, the team now has an ample and well-built location for carrying out health actions. They have access to better space, more hygienic conditions and solar-powered electricity. They can maintain the vaccines refrigerated. They have desks, several rooms, some laboratory equipment, and so on.

Their leisure and recreation conditions have also improved. Instead of being cramped on the boat, they have more comfortable spaces for cooking, eating, sleeping, bathrooms, and so on.

Thus, the new building has made the working conditions more comfortable for the staff. This may eventually impact the long-term delivery problem of insufficient staff and resources, as larger and more permanent equipment can be gradually incorporated, and improved working and resting conditions may make the work less strenuous and require less heroism.

It remains to be confirmed to what extent the new building will significantly impact the health indicators or patient satisfaction. The fundamental orientation of the delivery approach is unchanged in this new hybrid arrangement. The work still requires the importation of knowledge and resources, and continues to be culturally distant. The basic conceptual underpinnings of the delivery format that have been presented in this article endure. The health post does not substantially modify the underlying premises of delivery, though it is a step in the direction of developing infrastructure.

Continued focus on procedures

The focus of the work continues to be the fulfillment of an established number of technical interventions. The work is still concentrated on the same limited set of procedures and techniques as before. As mentioned before, biomedical presence in the villages is a restricted set of actions.

The nurse spontaneously provided the researcher with photographs from recent years. They show the same kinds of procedures, arrangements, and interactions that the researcher had registered earlier. Thus, the actual health care behaviors and interactions have fundamentally remained the same. Some of them are now carried out in the health post, and many are still carried out in the villages following the same layout and equipment set up that had been observed before, as the nurse explained.

It is possible that the framing of the health actions as institutionally based and not emergent from the villagers' home setting may have been intensified. Previously, the team members would spend all their time in the large boat while anchored at each village. Now, the team individually visits each village during the day using small boats exclusively to carry out health procedures and then returns to the building in the evening. The team members now sleep and take most meals in the new building. So, there is a stronger physical dissociation between work and leisure. They go to the villages to work, while domestic and informal activities are carried out in the new building.

Additionally, as the nurse explained, some procedures are now no longer carried out in the other villages as some equipment is set up permanently in the post. That is, villagers are now required to go to the post for some procedures. This is the case for some dental procedures and some screening tests.

Dependency on the presence of the team

The dependency on the traveling team to carry out biomedical health actions and to use the equipment and resources persists. During the weeks when the team is not there, the health post does not provide care. The nursing technician confirmed in her update interview that the health post remains closed. The nurse explained that the lay health monitor only goes there to regularly check on the functioning of the equipment, such as the freezers.

The nurse and nursing technician both confirmed that the lay health monitors and lay sanitation monitors still do not receive formal training. Their major form of learning comes from advice spontaneously provided by the team members.

Medical segregation and cultural distance

The pattern of medical segregation persists. The nurse and nursing technician confirmed that the biomedical team is not involved with the Indigenous medical system. The nursing technician said that the team members are not invited to the village curing rituals, which are usually held at night. She says she only once participated in a ritual.

A significant indicator of persisting cultural distance is the scarcity of language proficiency improvement. The team members, including the few with a now long-term presence, have not pursued or progressed with language learning. The nursing technician said that one of the main problems they continue to face is language. She said that Madiha women don't speak much Portuguese, and their husbands translate for them during medical consultations. Even so, she feels that the team's knowledge of Madiha language is sufficient. She says that it is basic, but enough for procedures. The nurse explained that they know some relevant terms relating to the illnesses and procedures, but they cannot hold a conversation.

Incipient move towards stationary primary health care clinic model

The opening of the health post suggests that the conceptual orientation of future delivery is to gradually evolve away from medical mission delivery towards providing health care from a permanent stationary primary health care clinic.

This may satisfactorily address some of the perceived problems of delivery, and it seems to be congruent with the expectations and preferences of the health care staff. Their desire to replicate the urban biomedical delivery model was a permanent trope during fieldwork. It is possible that the problem of having sufficient and adequate equipment, and stabilizing the staff turnover rate may be improved.

The nursing technician said that the problem of constant staff vacancies and insufficient materials has improved in recent years. When the researcher specifically asked her about impact of the new Jair Bolsonaro government on Indigenous health care, she named logistic improvements. She said that they have received more equipment, including outboard motors, and the new health post building.

Regarding staff stability, this has also improved. Although staff turnover continued over the years, including nursing and dental assistants, the nurse informed that the team was complete at the time of the update interview. Importantly in reference to this article, there has been a stable physician since 2015 (i.e., for five years), according to the nurse. The physician arrived through the "More Doctors Program" (Programa Mais Médicos). The program existed from 2013-2018.[78,79] It primarily employed Cubans. In 2018, out of a total of 372 physicians employed by the government to work for the Indigenous Health Care Department (Secretaria Especial de Saúde Indígena) all across Brazil, 81% (n=301) were Cubans.[80,81] The new Jair Bolsonaro government changed their work authorization conditions, leading to an abrupt removal of the majority of them, triggering a widespread crisis in Indigenous health care in various parts of Brazil.[80,81,82] However, although she received her medical degree in Cuba, the physician working with this particular team is a Brazilian national and she remained in the post, as the nurse explained. The nursing technician said that the current dentist has been working with them since 2018 (i.e., for two years).

In response to the observation that the health post is closed when the team is not traveling, the nursing technician thinks that the solution would be to duplicate the workforce. Her idea is that there should be two teams that would alternate in the field. That way, there would always be at least one team in the villages.

Thus, it seems that there is an emergent reorientation of the delivery model that would consist of replicating the model of the stationary clinic, through a permanent presence in one of the villages. However, the nurse said that the villagers were reluctant to go to the new post, and that's why the team still had to go out daily with the small boats to each individual village. That is, the apparent forthcoming delivery model still does not capitalize on local resources and persons.

Suggestion for reorientation based on supporting local infrastructure development

Considering the two premises on which medical mission delivery appears to be based, it is possible to propose in this article a reorientation of the delivery model that would award a more active status to local resources and conditions by grounding delivery on opposing premises. This alternative is proposed for medical mission delivery, but also in case of the eventual consolidation of a permanent clinic. The intention of an alternative orientation is for the villagers to become less dependent on the presence of external resources and workers, and increase their access to care in their home locations. Namely, the traveling teams could supplement their work by awarding a more fundamental role to: a) local health care resources and conditions; and, b) local health knowledge and practices.

Notably, convergences between the health care workers and the local population's culture and values have only been spontaneous, either stemming from the health workers' interests or from the initiatives of other sympathetic third agents. Despite the explicit policy directives,[2] there has been no programmatic implementation of a system that stimulates such convergences. Two examples of convergence can be cited here. For instance, the nurse recounted that an NGO organized an event in 2018 in the new health post during which the Madiha shamans and midwives showed the biomedical team some of the herbal plants they used, and participants learned to recognize the plants in the forest. A second example occurred in 2016 in which a researcher invited Madiha shamans, midwives and lay health monitors to meet with all nursing staff that worked in a nursing facility for Indigenous patients in the city of Rio Branco, capital of Acre state, in order to share with them some of their understandings, preferences and claims, in a limited intervention designed to increase the nurses' cultural competency for working with Indigenous patients.[83,84] Both examples were isolated efforts that were well received by the nursing staff, but are not built into the delivery structure in any formal or enduring way.

In the history of medical mission delivery for the Madiha villages contemplated in this article there was a period during the late 1990s in which an indigenist NGO, called the Comissão Pró-Índio do Acre (CPI/AC), provided biomedical health care to the villages.[22,23,24,25] Their medical missions had some relevant differences with the services described in this article, and are illustrative as an alternative model. Although they did not work in collaboration with the village healers or as supports to the Indigenous health system, they did place priority on addressing public health issues, improving local infrastructure, and provided training for the lay health monitors. They also made an attempt to bridge biomedical knowledge with Indigenous understandings, and to learn about the Indigenous medical system.

The CPI/AC team was aware of the problem of the limited acquaintance and legitimacy of biomedicine in this context. For instance, a report from 1999 recounts that "the Kulina practically didn't approach the health team for care. It was necessary to visit every house in the village to see if anyone was sick".[23 p15]

There are three elements that distinguish the CPI/AC approach that can be gleaned from their reports and from the testimony of Madiha in interviews: 1) coordinated multiple fronts of action, 2) focus on the lay health monitors and, 3) social and cultural analysis of health conditions.

1) In regards to the coordinated fronts of action, there were three fronts: medical missions to the villages, lay health monitor training courses, and the promotion of rudimentary infrastructural changes to improve hygiene and sanitation in the villages. These three fronts were interconnected at the level of planning and execution, and carried out by the same staff.[22-25] This kind of coordination no longer happened when the government took over.

2) The focus on the resident lay health monitors was a key element. The monitors were the core focus of the program [22,23,24,25]. For instance, the CPI/AC report states that "medication was administered by members of the CPI-AC team and also the village health monitor in order to acquaint him with

the activity and to obtain legitimacy from the community".[23 p6] The training courses instructed the monitors in community health promotion and disease prevention practices, as well as diagnosis and treatment of disease. Also, the courses did not only deliver biomedical knowledge, but also sought to elicit knowledge of the Indigenous medical system from the participants. In this way, the non-Indigenous participants learned about the Indigenous medical system.[22-25] The health team reported that "the Kulina did not know the names of body organs or body areas in Portuguese".[22 p22] As has been stated in this article, in the current delivery model the lay health monitors have had practically no training and very reduced roles.

3) The project sought to obtain knowledge of social and cultural conditions related to health and disease. For this, each mission trip included an anthropologist. This professional examined the public health conditions of community life, such as living and hygiene circumstances, as well as other relevant features of the society and culture. This knowledge was used to plan future interventions.[22-25] Since the government took over, anthropologists or other similar social scientists do not systematically participate in the teams.

Due to a lack of data, it is not easy to evaluate the lasting health impact of the CPI/AC approach, compared with the later government services. Regrettably, comparative epidemiological data is unreliable, and it is not easy to obtain the opinion of health professionals working at the time, as most of them departed. Furthermore, as far as the researcher could uncover from their records, the NGO only conducted two trips to these specific Madiha villages.[23,24] Yet, twenty years later, when interviewed by the researcher, informants from the patient population tended to recall the CPI/AC interventions as the better ones. This, at least, implies higher levels of satisfaction. Notably, this was a shared opinion among the lay health monitors, who were the key targets of the CPI/AC project.

The CPI/AC approach illustrates how an alternative delivery model could work. The health team members were concerned with analyzing the local infrastructure (housing, drinking water sources, etc.), food production system and diet, personal and domestic hygiene, leadership system, and learning about the Indigenous medical system.[23,24] The CPI/AC approach conforms to the strategy of trying to build up local resources, conditions, knowledge and practices, and to value the role of the resident lay health monitors. One report states that "we think that this type of work will require a medium or long-term period and must be in tune with the cultural characteristics of the group".[23 p24]

Conclusion

This article has argued that the delivery of biomedical care provided by the Brazilian government to Madiha villagers in the form of traveling medical teams is itself part of the reason for the health workers' persisting sense of frustration. The delivery model does not take into account village conditions or the cultural context. Furthermore, it does not provide much support for the development of local abilities to deal with health issues independently from the traveling health care team.

Delivery is primarily offered through a medical mission model, in which health care is conceived of as a transferable good or service, and in which health requires importing knowledge and resources to remote communities. The consequence of these underlying premises is that implementation of delivery leaves health workers with a persisting sense of insufficiency of staff and resources, and that they face a constant obstacle of cultural barriers.

Conforming to the ambitions of some of the workers, a permanent health post was built in one of the villages in 2017, though the style of the work has remained fundamentally the same since the health post is only operative when the traveling team is present, and most of the care still involves visiting each of the villages to perform an established routine of limited health actions. The health post has not reduced dependency on external resources and staff.

While the national policy for health care for Indigenous populations in Brazil mandates a culturally modified delivery, and one in which biomedicine takes on the role of complementary medicine,[2] in practice this is not how it is implemented. Instead, there is no tailoring and there is little development of local conditions for providing health care, for instance, by training the lay health monitors and by involving the Indigenous healers and midwives in the biomedical activities. In its place, the delivery format reinforces the foreign status of biomedicine and the dependency on external actors and resources to provide care.

Reflection on this type of delivery can be helpful to nurses and other health care agents in order to contemplate the extent to which their care may involve similar types of underlying premises. There is a risk that this type of care reinforces colonial types of imposition and unintentionally exerts structural violence.[21,38] The focus on the completion of established impersonal procedures, with a formulaic approach, and the pressure to accomplish as many procedures as possible within a limited schedule, may end up enhancing the perceived alienation of the patient population, already grounded on cultural differences.

Medical missions per se are not the problem, as they certainly can provide resources and skilled professionals to help deal with certain issues. The concern is that biomedical care is being implemented as a disjointed and superimposed service, instead of being an integral and complementary element of the local (Indigenous) health care system. A reorientation of delivery could recognize local health care capacities, and could view health as grounded in local conditions. Similarly, instead of evaluating delivery against the standard of urban stationary clinics, as some team members seem to do, it might be more appropriate to evaluate the service in regards to its coherence with the specific context and conditions.

Health care delivery can be reorganized in several ways. Essentially, the goal should be to reorient or complement the work of the traveling team towards becoming a support for the development of the local health care infrastructure in a way that capitalizes on locally available resources, including the knowledge and prestige of the lay health monitors, shamans and midwives. The traveling teams should contribute to a long-term local capacity-building process,[39 p1450] following public health priorities that emerge from the analysis of the specific village context, and targeting a limited and specific problem or set of problems.[39 p1450]

The biomedical team would work with, and not independently from, the Indigenous health system. Importantly, the travelling workers should receive relevant training in the local culture, health issues, and language. With this, the health trips would not operate as intermittent foreign incursions, but as supports for the local means of health production. By providing support for the local (i.e., Indigenous) health system and infrastructural conditions, they would promote autonomy and local resolution. The teams could also lead epidemiological research specific for the location and help the community identify and develop health goals and program planning. Thus, the medical missions would work as an integral and complementary element of the local health care system, instead of providing a disjointed and superimposed service.

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To contact the author:
Christian Frenopoulo Ph.D.
Universidad de la República
Centro Universitario de Tacuarembó
Universidad de la República
Campus Ruta 5 km 386.
Tacuarembó, CP 4500
Uruguay

Email: freno@gorfain.com

6

Résumé
Ce texte propose une réflexion critique à partir de différents travaux autant théoriques qu'empiriques sur la signification du « prendre soin de soi » et plus particulièrement de ceux de Michel Foucault sur la généalogie du souci de soi et des techniques de soi. Des réflexions sur les interrelations entre le souci de soi et l'individualisme ainsi que les interrelations entre les règles sociales et les techniques de soi sont exposées. Il sera vu comment prendre soin de soi consiste autant en une attention à l'âme et à l'esprit qu'à une attention au corps et que prendre soin des autres et de son environnement est indissociable du prendre soin de soi. Seront aussi présentées de multiples dimensions du prendre soin de soi qui se détachent du « prendre soin de sa santé », dont des dimensions intersubjectives qui s'insèrent dans les grands mouvements sociaux et forces sociales influençant nos moindres gestes, même les plus intimes.

Mots clés individualisme, gouvernementalité des vivants, prendre soin de soi, techniques de soi

Significations et représentations du prendre soin de soi à la confluence de l'intersubjectivité, des techniques de soi et de la gouvernementalité des vivants

HÉLÈNE POLIQUIN

Introduction

Intimement lié à la santé, le soin est un besoin fondamental relié à la survie de l'être humain. Le prendre soin ou le « care » évoque la sollicitude, l'affection, la préoccupation, l'importance accordée à soi ou à l'autre.[1,2] Le « care » évoque aussi les vulnérabilités et les interdépendances propres aux êtres humains.[1,2] Selon Collière « le soin et le prendre soin est l'une des plus vieilles pratiques de l'histoire de l'humanité et des êtres vivants »[3 p3], puisque dès que la vie apparait, le soin existe « car il faut prendre soin de la vie pour qu'elle puisse demeurer » [3 p23]. Pour Levine[4], la conservation est le but principal du prendre soin : il s'agit d'aider l'autre à conserver son énergie et son intégrité personnelle et sociale. De plus, prendre soin de l'autre est au cœur de l'action de porter assistance à une personne souffrante, malade ou vulnérable. Les connaissances et expertises liées au prendre soin notamment de personnes malades ou fragilisées par des évènements de vie, constituent les assises principales de la discipline infirmière pour Henderson[5]; Leininger[6], Orem,[7] ou encore Sitzman et Eichelberger[8], et ce thème a suscité une grande partie du développement théorique lié à la pratique infirmière que ce soit en ce qui concerne des approches et philosophies de soin, des techniques et des connaissances en santé chez Henderson[5]; Leininger[6]; Levine[4]; Neuman et Fawcett[9]; Orem[7]; Roy[10], pour ne nommer que ces auteures. Selon les travaux de Collière[3] « prendre soin » englobe tous les gestes, paroles, pratiques, attitudes et croyances pour préserver la vie et comprend toutes stratégies individuelles mises de l'avant, et apprises au sein d'un groupe donné pour en arriver à préserver sa vie, sa dignité, sa sécurité, son bienêtre. Comme le souligne Collière[3], ces gestes liés au prendre soin des autres sont parfois difficiles à nommer, puisqu'ils font partie de traditions ancestrales ou semblent aller de soi. Il s'agit bien souvent d'éléments très subtils, tout en nuances, relationnels, liés aux émotions, aux impressions, au contexte.

Quant au « prendre soin de soi », il serait un concept moins étudié en sciences infirmières. Ce texte consiste en une synthèse des significations et représentations du prendre soin de soi qui ne se voulait pas réduit à celui de « prendre soin de sa santé » ni à celui d'autosoins (« self-care ») d'Orem.[3] En effet, les autosoins sont mobilisés et encouragés dans la pratique infirmière afin d'aider la personne à maintenir ses capacités fonctionnelles et son autonomie alors qu'elles font face à la maladie ou à des limitations fonctionnelles. Plutôt, le concept « prendre soin de soi » a été abordé comme étant « sensible » selon la définition qu'en donne Blumer[11], c'est-à-dire comme étant un concept large et omniprésent. Cette approche permet une réelle incursion dans les représentations sociales, les processus de socialisation, les intersubjectivités et les significations que les gens donnent à leur expérience. Prenant aussi appui sur les travaux des sociologues Martuccelli et de Singly[12], il s'agit de comprendre davantage comment, en étudiant la signification du prendre soin de soi, les individus éprouvent le monde, s'engagent dans la vie, se tiennent et font face à l'adversité. Devant les impératifs modernes d'être en santé, de s'accomplir soi-même, d'être autonomes et autosuffisants[13], les infirmières et autres lecteurs trouveront à la lecture de ce texte une occasion de réfléchir aux façons par lesquelles les individus s'éprouvent dans le prendre soin de soi. Plus précisément, ce texte présente une réflexion critique à partir de différents travaux autant théoriques qu'empiriques sur la signification du « prendre soin de soi » et plus particulièrement ceux de Foucault[14, 15] sur la généalogie du souci de soi et des techniques de soi depuis la Grèce Antique.

Méthodologie

Ce travail repose sur une recension des écrits réalisée à partir de recherches dans diverses bases de données, dont CINAHL, ERIC, Érudit, Medline, Pascal, Psychinfo, SoIndex Full text, d'index de bibliothèques universitaires et municipales avec des mots-clés de base tels que « prendre soin de soi », « auto-soin », « care of the self », « self-care », « recherche qualitative », « perception », « signification » et des mots-clés additionnels tels que « vulnérable », « sans-abris », « maladie chronique » en anglais et en français. Les références des documents sélectionnés ont aussi été consultées. Les ouvrages retenus l'ont été pour ce qu'ils apportent de nouveau dans une perspective qualitative d'échantillonnage théorique et non d'exhaustivité en termes de quantité.

De plus, les mots-clés ont été choisis afin de comprendre ce que représente prendre soin de soi pour différentes personnes dites « vulnérables » puisque la thèse de l'auteure porte sur la signification de la santé et du prendre soin de soi pour des personnes qui font usage de drogues par injection. Le but était de pouvoir établir des comparaisons avec ces dernières et des personnes atteintes de maladies chroniques, itinérantes, atteintes de troubles mentaux, de statut socioéconomique défavorisé ou en perte d'autonomie, mais aussi pour d'autres personnes sans facteurs particuliers de vulnérabilité, souvent dites de « la population générale ». Enfin, mon but n'était pas d'apposer une valeur quantitative aux différentes significations, mais plutôt de jeter de la lumière sur différentes dimensions du « prendre soin de soi ».

Résultats

La synthèse de la recension des écrits est structurée autour de quatre thèmes centraux:

1) les techniques de soi et les règles sociales liées au prendre soin de soi;

2) l'indissociabilité du prendre soin de soi, et du prendre soin des autres et de son environnement;

3) prendre soin de soi est une attention à l'âme et à l'esprit;

4) prendre soin de soi est une attention au corps.

Les techniques de soi ou les règles sociales liées au prendre soin de soi

Au fil des siècles, les êtres humains pour vivre en société se sont conformés à des règles de conduite qui s'appuient sur ce que Foucault[15] nomme les « techniques de soi » qui sont des mécanismes d'autocontrôle de la personne sur ses gestes, ses comportements, ses pulsions, ses instincts et ses désirs. Foucault a retracé, depuis la Grèce antique, la généalogie des injonctions faites aux individus et de la moralité en étudiant les pouvoirs qui façonnent des codes de conduite humaine, ce qu'il nomme « la gouvernementalité des vivants ». Ses derniers travaux sur la « gouvernementalité des vivants » prennent ancrage dans le constat que des gens se conforment à des règles et des normes sociales alors qu'ils n'en sont pas contraints par la force.[14] La notion de gouvernement des vivants se détache d'une dynamique de biopouvoir, autre concept développé par Foucault, qui agit pour contraindre les gens notamment par le biais de rapports de forces, de politiques, de règles ou de sanctions.

Dans la mythologie grecque, l'« homme libre » est une valeur centrale de la condition humaine qui ne vient pas sans obligations. Ainsi, « le souci de soi, pour Épictète, est un privilège-devoir, un don-obligation qui nous assure la liberté en nous astreignant à nous prendre nous-mêmes comme objet de toute notre application ».[15 p62] Des philosophes dont Aristote et Épictète, croyaient que les mécanismes d'autocontrôle développés par les êtres humains leur permettaient de se distinguer des comportements plus instinctifs et pulsionnels de leur partie animale et de là la volonté des individus de se conformer à certaines règles sociales. Ces mécanismes d'autocontrôle étaient placés au rang des vertus permettant à l'homme de s'élever vers une plus grande humanité. Les impératifs sociaux étaient notamment : « prends soin de toi! et « connais-toi toi-même! » qui visaient justement selon les enseignements de Sénèque et de Platon le développement par la personne de son plein potentiel par la « culture du soi ».[15]

Cependant, cette « culture de soi » ou préoccupation pour soi a été, selon Foucault, faussement assimilée à l'individualisme du monde hellénistique et romain de l'époque.[14] Foucault réfute la théorie selon laquelle l'individualisme serait né de cette « intensité des rapports à soi, c'est-à-dire des formes dans lesquelles on est appelé à se prendre soi-même pour objet de connaissances et de domaine d'action afin de se transformer, de se corriger, de se purifier, de faire son salut ».[15 p56] Dans son tome deux de l'Histoire de la sexualité, intitulé « Le souci de soi », Foucault apporte des distinctions importantes en qualifiant non pas cet individualisme de repli sur soi exempt de préoccupations sociales plus larges, bien au contraire.[15] Par les techniques de soi, en domptant en soi les plaisirs et en se constituant une moralité par les usages des plaisirs et du corps et de l'âme, la thèse que soutient Foucault est qu'au contraire, les personnes sont ainsi mieux à même de voir ce qui est socialement à dénoncer, notamment des attitudes de complaisance égoïste et de relâchement vis-à-vis des devoirs à accomplir pour l'humanité.[15] Foucault soutien aussi que la valorisation sociale et le développement social sont des éléments qui motivent au prendre soin de soi. Les pratiques et les attitudes liées au prendre soin de soi sont également constitutives du développement des sociétés et du politique, et ne sont pas, insistait Foucault, propres aux sociétés dites individualistes.[16] S'étant intéressé aux pouvoirs multiformes qui règlent l'ordre social, Foucault voit au contraire, dans le « gouvernement de soi » une forme de pouvoir sur soi qui n'est pas dissociée des forces sociales et culturelles opérantes multiformes, dont le langage, les régimes de vérité qui incluent les dogmes et la science. Ainsi, il en vient à l'idée maitresse que l'acceptation par un individu des règles de conduite imposées par le social sont de l'ordre de la gouvernementalité des vivants qui consiste en ce que la personne se conforme de son plein gré à des formes de contraintes ou de domination alors qu'elle n'en est pas contrainte par la force physique.[14]

Prendre soin de soi-même (heautou epimeteilisthai) représente un thème fort ancien et important dans la culture grecque.[15] Les Spartiens avaient notamment instauré pour leur vie un régime d'austérité ou des techniques de soi visant à dompter leur corps. Prendre soin de soi signifiait en premier lieu une attention à porter à son âme ou à son esprit ou afin de le nourrir et de le cultiver, ainsi qu'une attention à son corps souvent par un régime austère. [15] Selon Foucault, « les techniques de soi » consistent en des gestes, des tactiques, des disciplines qu'une personne impose à son corps et à son âme par soi-même et souvent avec l'aide d'autres personnes par leur conduite ou façon d'être afin de se transformer dans le but d'atteindre un état de bienêtre, de bonheur, de sagesse, de perfection, de pureté, voire d'immortalité.[14]

Les grandes religions reposent toutes sur différentes règles ou techniques de soi aussi nommées « art de l'existence » visant à contrôler les occupations et les habitudes de vie, dont l'alimentation, et la sexualité des individus.[15] Le sociologue Durkheim voyait d'ailleurs dans ces régulations sociales religieuses même si elles peuvent être aussi oppressives, la base de la construction et de la cohésion des sociétés et des politiques modernes.[17] Foucault place ainsi le devoir de prendre soin de soi aux fondements du Christianisme ascétique au sein duquel les obligations de se connaitre soi-même constituent un élément central. Se gouverner soi-même revient en grande partie à développer et adopter des techniques de soi et des principes qui nécessitent des pratiques constantes et l'adoption d'habitudes de vie.[14]

De plus, selon des philosophes de la Grèce Antique dont Socrate et Platon ainsi que pour le philosophe Sénèque, la critique et la réflexion font partie intégrante de ce qu'implique « prendre soin de soi ». Il faut conserver des dimensions subjectives, soit une saine remise en question des normes imposées pour ne pas se laisser affaiblir par l'enseignement sophistique ou les écrits savants sans dialogue et sans critique.[18] Déjà à cette époque, il est conseillé de se méfier des enseignements et des livres et de faire l'examen par soi-même des prétendues vérités. [18] Ce dialogue est appelé par Foucault le « gouvernement de soi », où il est nécessaire à la fois de se connaitre soi-même et de connaitre l'organisation sociale et politique, à l'époque de la Cité.[14,18] Ainsi, prendre soin de soi implique de pouvoir faire des choix pour soi-même et non de se faire imposer des solutions toutes faites, même si elles proviennent d'un savant ou encore d'un médecin.

L'indissociabilité du prendre soin de soi et du prendre soin des autres et de son environnement

Pour Foucault, le soin de soi a des dimensions intrinsèquement politiques et éthiques, car celui-ci est indissociable des règles de conduite sociale.[14] Il faut souligner ici toute l'importance de l'attention à l'esprit, aux émotions ainsi qu'à l'âme et non uniquement au corps biologique. La culture de soi est à l'époque hellénistique, associée au développement de relations interpersonnelles ainsi qu'au développement d'institutions académiques et à un certain mode de connaissances et d'élaboration d'un savoir.[15] Plusieurs disciplines hellénistiques faisaient des enseignements reçus et donnés une pratique sociale valorisée. En effet, non pas narcissique, non pas en vase clos, prendre soin de soi, bien au contraire, passe par la confrontation avec les autres.[18] Ainsi, prendre soin de soi implique déjà à cette époque un « travail de production de l'unité, qui définit selon Platon la réalisation (énérgéia) pratique du soin, quel que soit le mode de relation au monde : scientifique, social, politique, intellectuel, pédagogique, etc. ».[18, p24] Ce travail de production passe par la réflexion et l'étude afin que la personne se rende vertueuse et imite le divin afin de faire naitre la meilleure part d'elle-même.

Plusieurs penseurs, philosophes, sociologues, psychologues, psychanalystes et féministes en sont également venus à la conclusion que l'être humain ne peut exister sans sa relation à l'autre.[19-22] Pour Mead, « Soi est un terme réflexif, il souligne le va-et-vient entre soi et l'autre et l'autre et soi et donne la facilité de se prendre soi-même comme un objet d'analyse ». [19 p36] Toujours selon Mead dans LeBreton, adopter par rapport à soi une posture extérieure permet notamment « de mieux se comprendre et se définir ».[19 p36] Davantage qu'une réflexivité sur soi, Maffessoli soutient que l'individu essentiellement cherche à sortir de lui-même et que « le ''souci de soi'', s'exprime avec les autres, en fonction des autres et, très souvent, en référence à l'Autre ».[20 p140] Enfin, aller à la rencontre de l'autre, les aventures, le nomadisme, les errances urbaines, la recherche de l'existence sont autant de moyens pour transcender le soi vers une forme d'altérité représentée par un autre que soi. Pendre soin de soi constitue donc une forme de communion vers l'Autre et n'est pas pour Maffessoli une quête nombriliste, bien au contraire.[20] L'hédonisme, le souligne-t-il, et ceci peut paraître paradoxal, est une forme de recherche de sortie de soi, une quête vers la transcendance de soi par le plaisir. Ainsi, pour Maffessoli, prendre soin de soi inclut le souci de son environnement humain, de sa famille, de son entourage, de sa communauté, de son peuple (ce qui rejoint les dimensions politiques évoquées par Foucault), et d'éléments au-delà des frontières dans une perspective holistique et globale.[20] Pour plusieurs auteurs, prendre soin de soi est inséparable de prendre soin des autres.

Le philosophe Lévinas voit dans le souci des autres et les gestes portés à l'attention des autres, un besoin fondamental de l'individu de transcender le soi.[21] Selon les analyses de Foucault, « le soin de soi apparait donc intrinsèquement lié à un ''service d'âme'' qui comporte la possibilité d'un jeu d'échanges avec l'autre et d'un système d'obligations réciproques ».[15p69] Vivre ensemble influence les modes de pensées et les comportements des individus. En outre, nous avons besoin de savoir que nous comptons, que nous avons une valeur aux yeux des autres et que nous leurs sommes également utiles. Enfin plusieurs études qui se sont penchées sur la signification du prendre soin de soi en interrogeant directement les personnes par le biais d'entrevues qualitatives soulignent l'importance des liens sociaux pour le souci de soi, notamment chez des personnes atteintes de troubles mentaux[22], des personnes atteintes de maladies chroniques[23], des personnes âgées et en pertes d'autonomie[24], des personnes vivant avec un handicap [25], ou des personnes de classes socioéconomiques défavorisées.[26] Ainsi, on peut dire d'après ces études que même chez des personnes qui sont en situation de défavorisation et grande précarité sociale (en situation d'itinérance, aux prises avec une dépendance aux drogues, etc.), le souci de l'autre persiste. Pour ces dernières, prendre soin des autres peut aussi être une stratégie de survie et de solidarité au sein de sous-groupes sociaux marginalisés alors qu'elles luttent contre diverses formes de stress et de discrimination.[27,28,29] Entre autres, pour des personnes itinérantes, prendre soin des autres, se préoccuper des autres et donner aux autres une attention bienveillante sont des actions qui nourrissent le sentiment d'appartenance tout en repoussant les sentiments d'ennui, d'isolement et de rejet tant redoutés de ces personnes en situation d'exclusion sociale.[28,29] Des études rapportent également que des personnes, dans des contextes variés de marginalisation sociale vont souvent partager de la drogue, de l'alcool, de la nourriture, de l'information et se soutenir moralement les unes les autres.[27,28,29]

Le sentiment d'être ensemble parmi d'autres est associé aux sentiments de plénitude et d'être en contact avec la vie. Ainsi, vouloir être comme les autres peut déterminer les choix quant aux pratiques liées au prendre soin de soi chez des personnes âgées.[23] Entre autres, l'existence de liens interpersonnels significatifs constitue une source de motivation pour des personnes âgées afin qu'elles prennent soin d'elles et se maintiennent en santé.[24] Canales et al., qui ont mené une étude auprès de femmes autochtones, soulignent que prendre soin d'elles « ne s'inscrit pas dans une approche individualiste ou égoïste face à la santé, il est complémentaire aux efforts pour prendre soin des autres au sein de leur famille et communauté ».[30 p433] Selon Gilligan qui a développé une théorie de l'éthique du « care », « le souci de soi est indissociable du souci d'autrui, et prendre soin de soi implique de prendre en considération une forme de vie plus globale ».[32 p64] Pour Gilligan[31] comme pour Tronto[32], le « care » consiste en un souci d'entendre la voix des autres, surtout les voix qui sont différentes et de reconnaitre que les formes de dépendance et de vulnérabilité sont le lot de tous. En ce sens, le « care » a des fondements politiques et démocratiques. Selon Adorno : « on ne peut penser l'homme sans le considérer comme un être relationnel, qui plus est, est essentiellement dépendant des personnes qui l'entourent ».[33 p109] De plus, d'un point de vue sociologique et interactionniste prendre soin de l'autre permet d'entretenir des relations interpersonnelles, puisque selon Le Breton « le soi n'existe pas que sous la forme de rôles tenus.[19] Mais, l'acteur ne devient lui-même que dans la confirmation aux autres. L'interaction problématise ainsi le sentiment d'identité. Toute affirmation de soi exige l'agrément du public concerné »[19 p66]. Et c'est avec le regard de l'autre qu'un individu vient à s'estimer digne et important. Enfin, Maillard qui a effectué des travaux importants sur la vulnérabilité sociale soutient que « le respect de soi : le respect, l'estime ou la confiance en soi (nous ne distinguons pas ici ces différentes formules), est évidemment nécessaire pour l'expérience de l'autonomie personnelle ».[34 p53]

Prendre soin de soi est une attention à l'âme et à l'esprit

Poursuivant avec les travaux de Foucault, prendre soin de soi, par ses diverses formes, a donné lieu à l'écriture puis à la civilisation que nous connaissons, aux penseurs, à la science réflexive, à la philosophie grecque classique puis ultérieure à celle-ci.[15] À l'époque stoïcienne et hellénistique, il était encouragé pour prendre soin de soi, de passer des moments d'introspection et de réflexion en vue de l'acquisition d'une éducation et d'une sagesse. De plus, la lecture, l'écriture, la relecture de notes personnelles écrites dans un cahier sont des exercices auxquels s'adonnaient plusieurs, dont Socrate, dans une perspective de souci de soi.[15] D'ailleurs, l'écriture sur soi serait l'une des plus anciennes pratiques établies. Elle l'était déjà lorsque Saint Augustin écrit ses Confessions vers l'an 400 de notre ère.[15]

Une lettre de Pline Le Jeune, datant d'av. J.-C., fait foi de sa volonté de se retirer dans une villa pour s'occuper de lui-même « en s'adonnant à la lecture, à la composition, au soin de santé » et en faisant la conversation « avec lui-même et avec ses propres écrits ».[15 p63] Les philosophes de cette époque dont Sénèque, Épictète et Marc Aurèle croyaient essentiel de faire des retraites afin « d'interrompre de temps en temps ses activités ordinaires » [15 p66] en vue d'un tête-à-tête avec soi, d'un recueillement sur son passé, de revoir sa vie, lire, etc. Tout en précisant :

> ce temps n'est pas vide : il est peuplé d'exercices, de tâches pratiques, d'activités diverses [...] Il y a les soins du corps, les régimes de santé, les exercices physiques sans excès, la satisfaction aussi mesurée que possible des besoins. Il y a les méditations, les lectures, les notes qu'on prend sur les livres ou sur les conversations entendues [...] Il y a aussi les entretiens avec un confident, avec des amis, avec un guide ou directeur; à quoi s'ajoute la correspondance dans laquelle on expose l'état de son âme, on sollicite des conseils, on en donne à qui en a besoin [...] .[15 p63]

Le « souci de soi » consistait, principalement à cette époque, à s'occuper à soi de soi, à s'occuper de son esprit, de son âme et ceci bien souvent au détriment du soin au corps qui était jugé de moindre importance. C'est cette attention à l'esprit qui, selon certains, distinguait les hommes des animaux, d'où la préséance qu'elle avait sur celle du corps.[15] Des Alcibiades de Platon, Foucault tire trois principaux thèmes liés au prendre soin de soi : premièrement, la relation entre le souci de soi (« care for oneself ») et le souci de la vie politique. La politique, le partage des biens et des pouvoirs dictent en sorte comment les personnes vont prendre soin d'elles. Prendre soin de soi, et ceci peut être difficile à saisir de prime abord, est un geste politique. Deuxièmement, la relation entre le prendre soin de soi (« taking care of the self ») et le manque de connaissances, et qui consiste ainsi à se corriger et se rendre compte de ses inaptitudes. Le troisième thème consiste en la relation entre prendre soin de soi et se connaitre soi-même, notamment que pour prendre soin de soi il faut sans cesse apprendre sur soi. Selon les analyses de Foucault dans les Alcibiades, un amalgame a été fait entre prendre soin de soi et se connaitre soi-même, deux injonctions faites aux individus de cette époque avec celle de se connaitre soi-même ayant pris l'avant-scène.[15] De plus, d'après les analyses de Foucault une inversion importante a eu cours dans la hiérarchie des deux devoirs « Prends soin de soi ! » et « Connais-toi toi-même! ».[15] Alors qu'aujourd'hui, la connaissance de soi constitue un principe fondamental de l'individu moderne, auparavant dans les sociétés gréco-romaines, se connaitre soi-même arrivait en deuxième lieu et comme une conséquence du prendre soin de soi, notamment par l'adoption d'une approche critique et réflexive face à la vie.[15] D'après sa lecture des travaux de Foucault, Hilfiger soutient que :

> prendre soin de soi-même (épiméléia séautou, 132c), c'est réfléchir : c'est se connaitre soi-même, se reconnaitre comme le sujet d'une connaissance particulière, et se rendre, dans une certaine mesure, semblable au divin. [...] Un travail sur soi, d'expérience de soi, est nécessaire pour éprouver le sens du discours et le faire mien. Cette alchimie, c'est la pensée même, un mouvement de soi vers un autre soi, « subjectivé ». Penser, c'est donc (se) soigner.[18 p27]

Prendre soin de soi, ce n'est pas nécessairement se préserver de tous les risques et rechercher le confort, au contraire. Il consiste également à s'éprouver dans une série de tâches afin de s'accomplir soi-même.[15] Depuis les textes d'Épicure, Foucault retrace que le soin de soi est au fondement de l'ordre social des cités de la Grèce antique qui se voulaient autosuffisantes et autarciques.[15] Ces cités n'auraient pu tenir face au monde extérieur sans que leurs habitants n'adhèrent à des lignes de conduite communes.[15] Ainsi, l'un des premiers textes épicuriens portant sur des principes moraux soit la Lettre à Menoeceus (Diogenes Laërtius 10.122 - 38) soutenait qu'il n'est jamais trop tôt ni trop tard pour porter une attention à son âme.[15] Prendre soin de soi, d'abord de son âme et de son esprit est un principe répandu visant une vie ordonnée et poursuivant des obligations sociales et morales. Néanmoins, prendre soin de soi et de sa santé ou de son corps sont, déjà à cette époque, des préoccupations interreliées.

Prendre soin de soi est une attention au corps

Des changements importants dans la moralité au cœur du Christianisme ont transformé les injonctions liées au souci de soi. Progressivement, le soin du corps est devenu quelque chose de moral alors qu'auparavant une trop grande attention au corps était vue, à certaines époques et dans certaines cultures, comme étant immorale au sein du Christianisme qui appelait davantage au renoncement de soi et au confort matériel.[15] Auparavant, Alcibiades avait établi une dialectique selon laquelle prendre soin de son corps n'était pas prendre soin de soi, avec un corps vu davantage comme un accessoire, comme un vêtement, une possession tout sauf le « soi ».[15]

Un autre élément central au fait de prendre soin de soi, au cours de la modernité, selon Foucault, est l'attention que tout un chacun doit porter envers soi, une relation qu'il qualifie de « médicale » envers soi-même.[15] Selon lui, « une personne doit devenir son propre médecin » surtout que l'objectif du prendre soin de soi dans la modernité n'est plus autant celui « de se rendre à une autre vie », que celui de « traverser la vie ». Il s'agit de vivre vieux, ceci en inversion de la philosophie grecque qui valorise surtout la jeunesse. Les aspects politiques et éthiques du prendre soin de soi passent ainsi par l'examen de soi. Il s'agit de ne pas se laisser pénétrer sans examen, sans « contrôle médical » de soi à soi.[15]

Le pasteur et penseur Ivan Illich, dans sa critique envers ce qu'il a nommé la némésis médicale, soit la médicalisation de la vie en vue d'une santé parfaite, souligne l'importance du maintien des capacités des individus à se prendre en main, à devenir leurs propres « soignants ».[35] Il s'agit d'établir une dialectique entre les savoirs « profanes » (qui émergent de la culture, de l'expérience, du quotidien) et les savoirs « savants » (les savoirs doctes qui proviennent des sciences ou d'experts dans un domaine spécifique de connaissances). Ceci est d'ailleurs recommandé depuis la Grèce Antique afin de se prémunir des doctrines imposées. Par ailleurs, la valorisation de soi est ainsi essentielle, valorisation qui peut être particulièrement difficile chez les personnes exclues et méprisées socialement. Comme le souligne Maillard :

> l'attitude de dévalorisation de soi conduit au contraire à une négation systématique de la valeur de nos qualités et croyances et mène à des conduites de soumission à l'égard de normes d'actions extérieures (au sens où nous ne nous reconnaissons pas) et de la volonté d'autrui.[34 p53]

Les sociologues Adam et Herzlich soutiennent que les personnes atteintes de maladies chroniques sont « la plupart du temps, astreintes à des soins permanents impliquant une attention minutieuse à leur corps et un contact régulier avec la médecine ».[36 p19] Ceci peut mener à ce que certains qualifient de médicalisation de la vie, c'est-à-dire lorsque « le savoir médical a ainsi pris valeur normative par rapport à des secteurs de plus en plus nombreux de la vie individuelle et collective, qui vont être définis et évalués en termes de santé ».[36 p37] De nos jours, nous pouvons observer la place grandissante accordée par la médecine aux approches visant les autosoins, mais aussi à plusieurs approches alternatives, dont la médecine naturelle, l'homéopathie, l'ostéopathie, la réflexologie.[37] Un accent est mis de nouveau sur l'injonction « Prends soin de toi! » et surtout : « Prends soin de ton corps! ».

Ainsi, « devenir son propre médecin » engage la personne envers son corps qui incite à une façon de vivre caractérisée par un dialogue constant avec son corps pour reconnaitre les signes et symptômes de la maladie en intégrant une forme de surveillance médicale envers soi-même comme il a été rapporté par certaines études auprès de personnes âgées ou atteintes d'une maladie chronique.[23, 30] Des études menées auprès de diverses personnes démontrent que ces dernières ont intégré, comme règle de conduite, la nécessité de s'occuper de leur corps. Il s'agit de « repérer les signes indicateurs de bienêtre, tel que le sentiment de paix et de joie, ainsi que les inconforts tels que la douleur, les sentiments de faiblesse et d'inquiétude »[23 p1267], mais aussi d'entretenir la capacité d'écouter son corps, de traduire les messages du corps, d'observer les changements et d'en décoder les signes.[30] Subséquemment, « comprendre le corps est nécessaire afin d'être en contact avec celui-ci et connaitre ce qui est en train de se produire dans le corps ».[30 p423] Cette attention au corps prend du temps et exige parfois, qui plus est, selon une étude auprès de femmes autochtones américaines, de ne pas céder à ses émotions au premier plan, ce qui implique à la base d'avoir de l'intuition, de l'écoute et de l'attention à sa voix intérieure.[30] Pour s'occuper de son corps, parfois, il importe de laisser la part plus rationnelle de soi prendre le dessus, et maitriser ses peurs, ses peines, ses doutes pour adopter des techniques de soi bénéfiques. Cette attention au corps est aussi soulevée par des personnes âgées en perte d'autonomie qui doivent s'ajuster aux changements constamment, et par essais et erreurs, trouver un équilibre de vie.[24]

Discussion

Ce travail présente une réflexion théorique en grande partie à partir des travaux de Foucault sur la généalogie du souci de soi et des techniques de soi depuis la Grèce Antique et permet de discuter des implications morales associées au prendre soin de soi et de leurs interrelations avec les injonctions faites aux individus modernes, notamment de se maintenir en santé et de s'occuper de soi.

Ce texte permet de jeter un éclairage d'une part sur le fait que des gestes des plus intimes liés au souci de soi autant de l'âme que du corps peuvent être motivés par un désir de conformisme social et un désir d'être reconnue comme une personne moralement méritante. Les travaux de Foucault sur la gouvernementalité des vivants permettent aussi de comprendre comment les personnes adhèrent à des codes de conduite et de codes moraux alors qu'elles n'en sont pas physiquement contraintes. Les travaux ultérieurs de Foucault sur le gouvernement des vivants ou le gouvernement de soi se détachent de ses travaux sur les biopouvoirs, par lesquels les individus se voient contraints à adopter des mesures ou pratiques, notamment de santé. Plus subtilement, les techniques de soi sont davantage complexes et tiennent des forces sociales opérantes et d'un large éventail de codes de conduite et d'attentes envers les individus. Ces derniers travaux permettent aussi de mieux saisir les dimensions intersubjectives en causes dans les choix des individus et dans les grands mouvements sociaux. Nous sommes des êtres sociaux, faut-il le rappeler, et des forces sociales sont présentes dans nos moindres gestes et pensées liés au souci de soi.

Selon les travaux de Foucault sur le souci de soi, il semble que, loin d'être individualistes et égoïstes, les techniques de soi s'inscrivent dans les règles sociales et les impératifs sociaux, culturels et politiques pour le développement des sociétés modernes.[15] Nul doute, prendre soin de soi dépasse les préoccupations de survie biologique et sociale pour englober une survie de l'humanité, du vivant et probablement de la matière qui nous échappe largement. Ainsi, cette synthèse des écrits qui ne visait pas à présenter « une vérité » ou une théorie unifiée pouvant expliquer les significations et les représentations du prendre soin de soi, est une humble contribution pour approfondir sur des constructions sociales entourant le prendre soin de soi. Elle peut permettre aux infirmières de tenir compte de ces dimensions dans leur rapport avec les personnes à qui elles offrent des soins et des services et d'ouvrir la discussion sur ce que représentent pour elles le prendre soin de soi afin de ne pas imposer des solutions simplistes et toutes faites qui ne tiennent pas compte des particularités, de la culture, des limitations, mais également des forces et aspirations des premières personnes concernées.

Aussi, ce travail est une amorce de réflexion pouvant susciter des intérêts pour des recherches futures. L'auteure vient d'ailleurs de réaliser une recherche sur la signification du prendre soin de soi pour des personnes qui font usage de drogues par injection.[38] Il serait aussi intéressant de pousser plus loin la réflexion sur le prendre soin de soi et tenter de mieux cerner comment le souci de soi ou le prendre soin de soi s'inscrit dans la lutte pour la reconnaissance menée par des individus dans les sociétés contemporaines. Les individus adhèrent ainsi à des normes de conduite afin de se tenir dans le monde et aussi être reconnus comme des personnes méritantes et morales, ceci depuis déjà des siècles en adoptant certains comportements attendus d'eux, notamment en se maintenant en santé.[13] Si l'on convient que le soi se constitue à partir de relations sociales et de sentiments d'appartenance, il est facile d'adhérer à l'idée de Ricoeur que prendre soin de soi consiste à s'occuper de ses appartenances, de ses liens de relations et de ses capacités d'entrer en relation avec d'autres.[39] Cette synthèse met tout particulièrement en exergue que prendre soin de soi, de son corps comme de son esprit ne se fait pas dans l'isolement des autres, bien au contraire. Prendre soin de soi s'inscrit dans la recherche de ce qui nourrit et donne le sentiment d'exister, soit la reconnaissance de sa propre valeur comme être humain, mais également la reconnaissance de la valeur des autres.

Conclusion

D'après la synthèse des écrits présentée, se reconnaitre soi-même, la relation avec soi ainsi que la relation avec l'autre sont tous des éléments nécessaires, et font partie de prendre soin de soi. C'est ainsi que prendre soin de soi fait partie intégrante d'une vie sociale accomplie puisqu'il comporte des gestes et préoccupations d'ordre moral, politique et humaniste. S'avancer soi-même, se dépasser, vaincre, survivre est un geste solidaire pour son milieu d'appartenance, son ancrage social, sa famille et ses amis. De ce fait, il semble important de poursuivre des recherches infirmières à perspective large et interdisciplinaire sur ce que représente le prendre soin de soi pour diverses personnes dans ses multiples dimensions, notamment physiques, psychiques, spirituelles, politiques ainsi que liées aux interrelations et appartenances sociales permettant d'accroître la compréhension de l'être humain situé dans son contexte.

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Pour contacter l'auteure
Hélène Poliquin, Ph.D.
Institut national de santé publique du Québec
190 Boulevard Crémazie Est, Montréal, Québec, H2P 1E2
Courriel : helene.poliquin@inspq.qc.ca

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