The Experiences of Trans and Gender Diverse Youth Accessing and Receiving Care in Emergency Departments

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Dedicated with respect and admiration to the community partners:
trusted trans and gender diverse youth knowers.

Why would a male patient require an ovarian scan?
By Elijah Foran

I have a riddle
Why would a male patient require an ovarian scan?
As I sat waiting for registration at urgent care, 4 ER nurses were immersed in this debate and could not figure it out.
Any ideas?
Quick! The requisition indicated the request was urgent and should be scheduled as soon as possible as the patient was experiencing extreme pain and inability to void without obvious cause

I read on average, medical students receive less than 5 hours of training about LGBTQ healthcare throughout the entirety of their medical schooling
5 hours is barely enough time to get through the acronym, not to mention the complexity of a body that their textbooks don't account for, a body they are taught doesn't exist
One that exists outside the rigidity of male and female
None of this "born as", "identify as" bullshit
It is an altered body
I inject myself weekly, allowed them to take more than just the weight I carried on my chest They call it mutilation
But I call it beauty
I call it building a home

Doctors talk about my body as if it is a ripped up road map that they can't quite figure out how the pieces fit together
An anomaly they couldn't possibly treat
Couldn't book an appointment for this body

No room in the schedule for a body like mine
"I am transgender" I said
They stared at me in disbelief and I continued,
"The patient you are talking about, I am quite sure it is me. And I am transgender"

The nurse began apologizing profusely realizing she had just spent the last 10 minutes talking shit about a body that was sitting right in front of her

They didn't book my ultrasound that day.

When you've stumped all the doctors in the ER, it's a pretty hopeless feeling
It's even more hopeless when the nurse admits that if you were cisgender they likely would have figured it out by now
She looked at me and recited the serenity prayer

'God grant me the serenity to accept the things I cannot change, the courage to change the things I can
and the wisdom to know the difference'

As a transgender individual navigating an oppressive health care system, I am brutally aware of the things that I cannot change

And my courage to change the things I can is wilting with everyday But at least I have shed some wisdom in the process

I can only hope next time one of those nurses gets an urgent ultrasound request for a man with ovaries, they will at least fucking book it.

Preface

Approvals to Conduct the Research

The proposal for this dissertation was approved by supervisors, Dr. Amanda Vandyk and Dr. Hannah Kia, and thesis committee members, Dr. Patrick O'Byrne and Dr. Wendy Gifford (Appendix A). Ethical approval from the University of Ottawa Research Ethics Board was obtained both for the focus groups with community partners to design the study (Appendix B) and then for the study itself (Appendix C). Recruitment materials were shared on social media in English and in French for both the focus groups (Appendix D&E) and then for the study (Appendices H&I). Volunteers for the focus groups were sent additional information and provided recorded verbal consent (Appendices F, G, & T). For the study, participants who engaged with the questionnaire provided implied consent (Appendices L&M), volunteers for the study interviews were sent additional information and provided recorded verbal consent (Appendices P&Q), and volunteers for the study journal entries were sent additional information and provided written consent (Appendices R&S).

Authors' Contribution to the Dissertation

The first phase of this dissertation project, focus groups with community partners to design and then analyze a study, was conceived with my supervisors and with input from committee members. The study phase of this doctoral dissertation was conceived with community partners, who provided significant community-based content expertise, in collaboration with supervisors, who provided significant methodological and academic content expertise, with feedback from thesis committee members, who provided methodological expertise and academic content expertise from adjacent areas of clinical research. All members of the research team, both community members and academic members, provided feedback and intellectual insight on the included manuscripts. As the primary researcher, I was responsible for identifying the research focus and conducting all research activities. As such, I accept full responsibility for each manuscript and the dissertation.

Abstract

Despite increased visibility in media and health research, trans and gender diverse (TGD) youth continue to experience worse health outcomes and healthcare experiences than their cisgender peers. Contributing to this issue is the historical and evolving context of cisnormativity and erasure. Although emergency departments often serve as 'safety nets' for the medically underserved, emerging research indicates that certain minority groups, including TGD people, report challenges having their needs met in this setting. Barriers to affirming care include a lack of training/education for healthcare providers, including nurses, and a paucity of research about the subjective healthcare experiences of TGD youth. While further research is needed, it must be pursued intentionally. Trans health research is a rapidly growing area of scholarship that, even when well-intended, risks being excessively prescriptive and burdensome to the communities involved.

The purpose of this doctoral project was to collaborate with TGD youth to explore their experiences accessing and receiving care in Canadian emergency departments. This project was guided by a pragmatic, critical theoretical framework informed by three theoretical traditions which have been applied to research efforts involving TGD communities: the Gender Minority Stress Framework, erasure, and intersectionality. The methodological approach was a critical participatory action research project with a multi-phase multimethod emergent research design. Community partners were recruited through social media to create a virtual research group. Focus groups were used to elicit guidance from community partners on overall research design and data analysis. The first phase of our study was a cross-sectional survey and online questionnaire. All quantitative data were analyzed using simple descriptive statistics, including range, mean, prevalence, and percentages. Qualitative data were analyzed using summative content analysis and paired with quantitative data to provide context and nuance to the results. Participants reported highly variable experiences in the emergency department with half (n=14, 50%) reporting having avoided seeking needed care out of concern for how they would be treated. These results support the claim that emergency department avoidance is a health concern that is also experienced by TGD youth and set the foundation for the second phase of the study.

The second phase was a qualitative study wherein participants were invited to participate in whichever of the following ways felt authentic to them: interview, familial focus group, journaling, and art-based approach. Data were analysed via thematic analysis as described by Braun and Clarke. Participants reported feeling that they were not trusted by healthcare providers to know themselves or their health needs. In response, participants reported employing adaptive strategies to conceal stigmatized aspects of their social location in favour of those that align more closely to social norms. These findings can be understood as examples of epistemic injustice and astute understandings of rhetorical credibility.

This doctoral project offers novel theoretical, methodological, and substantive contributions to the fields of transgender health and emergency nursing. Overall, the findings of this dissertation support the assertion that recognizing and supporting the epistemic agency of TGD youth is not only a matter of justice, but also a means of advancing knowledge and promoting improvements in equitable healthcare. Further, this composite work supports calls for intersectional understandings of TGD health and healthcare.

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First and foremost, to the community partners, I cannot begin to thank you enough for joining me on this journey. I am constantly impressed by your creativity, thoughtfulness, enthusiasm, resilience, and wisdom. To the participants, thank you for openness and vulnerability. I am forever grateful that you trusted me with your experiences. To all TGD youth involved in this project, I hope you feel that this work honours you as knowers.

To my supervisors Dr. Amanda Vandyk and Dr. Hannah Kia, the support you have shown me goes well beyond the scope of the PhD. Though the last five years have included many beautiful moments, there have also been significant challenges: a global pandemic, clinical redeployment, pregnancy loss, tragic death, and major emergency surgeries. Your unflappable support through it all kept me on course both in the PhD and more broadly. I know it hasn't always been easy to contain my unbridled enthusiasm, my grand ideas, and my naturally verbose and dramatic approach to language. Despite this, you have coached me with kindness, humour, and thoughtfulness, allowing me to grow without becoming discouraged. I aspire to mirror your approach with any students I am lucky enough to mentor. I can't begin to thank you properly.

To the members of my committee, Dr. Patrick O'Byrne and Dr. Wendy Gifford, thank you for your insights and encouragement throughout this process. Patrick – your nuanced approach to critical theory has had a profound influence not only on the lens through which I view this project, but truly on the way I think about healthcare, health research, and our social structures. Wendy – thank you for introducing me to community-based research and encouraging me to believe that it could be feasible for a PhD. I would also like to acknowledge and thank another source of academic support, Dr. David Kenneth Wright. David – whether writing or teaching together, you have always encouraged me to think more deeply and more expansively. I am so grateful for your mentorship.

To my incredible friends and my wonderful family by birth, by marriage, and by choice, thank you for celebrating, encouraging, commiserating, and believing throughout this process. It truly takes a village. I am so grateful that you are mine.

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Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction

The purpose of this dissertation was to explore the experiences of trans and gender diverse youth accessing and receiving care in Canadian emergency departments. This manuscript style dissertation has eight chapters, including four manuscripts, which describe a multi-phase multimethod critical participatory action research project. While this thesis is my work, the thesis project is a collaborative effort with community partners. As such, throughout my dissertation, I alternate between first-person singular (I) when describing my own thoughts, interpretations, and efforts and first-person plural (we/us) when describing our group efforts. This first chapter orients the reader to the research problem, the study objectives, and the structure for this dissertation.

1.1 Trans and Gender Diverse Youth

The rights and healthcare of *trans and gender diverse (TGD)* youth are increasingly discussed and debated in social and news media, political spheres, and academic work (Barbee et al., 2021; Matsuno & Budge, 2017; Thorne et al., 2019; Wittlin et al., 2023). After generations of invisibility, or *erasure*, this sudden mainstream visibility has led to the misconception that gender diversity among youth is an emerging phenomenon. This false perception contributes to pathologizing and unsubstantiated theories such as ‘Rapid-Onset Gender Dysphoria’ whose proponents claim that TGD youth are actually *cis youth*, youth whose gender identities align with their assigned sex at birth, with maladaptive coping mechanisms succumbing to peer pressure, also referred to as ‘Transtrenders’ (Ashley, 2020; Bauer et al., 2022). The belief that TGD youth are ‘too young’ to know who they are or what healthcare they need has contributed to a wave of conservative policies in the United States and across Europe that aim to limit the rights of TGD youth, under the guise of protecting them from themselves and from healthcare providers who are perceived to ‘pressure’ them (Barbee et al., 2021; Barbi & Tornese, 2023; Kraschel et al., 2022; Mallory et al., 2023). In Canada, the Government of Alberta recently announced restrictive policies limiting access to gender-affirming medical care and social affirmation for TGD youth (Koshan et al., 2024). In addition to the obvious barriers to care caused by age restrictions and requirements of parental consent, the stress of cisnormative political climates has also been shown to exacerbate existing health inequities experienced by TGD youth (Dhanani & Totton, 2023; Wittlin et al., 2023).

Studies with TGD youth participants consistently report higher rates of anxiety, depression, suicidality, substance use, eating disorders, and other mental health issues (Connolly et al., 2016; Wittlin et al., 2023). Specific to Canada, 88% of TGD youth report chronic mental health issues and 64% report having considered suicide and engaging in self-injurious behaviour in the past year (Taylor et al., 2020). These disparities in mental wellness are said to be related to experiences of minority stress specific to TGD people (Meyer, 2003; Testa et al., 2015; Wittlin et al., 2023). Minority stressors can be both proximal (internal), such as internalized stigma, and distal (external), such as discrimination. Proximal stressors are more difficult to measure and thus less reported upon. Rates of external stressors, however, are high in TGD youth and include sexual assault (28%), dating violence (30%), violent threats (35%), sexual abuse (46%), and bullying (66%) (Taylor et al., 2020). While these patterns of experience are consistent in the research about TGD youth, there exists significant individual variation. For example, although TGD youth are generally at an increased risk for homelessness, HIV infection, detention, and incarceration, these risks are amplified in TGD youth who are also racial minorities (Navarro et al., 2021b; Pullen Sansfaçon et al., 2018; Taylor et al., 2020).

TGD youth also face age-related disparities that differentiate them from their adult counterparts, such as increased reliance on family, reduced access to gender-affirming treatments, peer pressure, and lower employment rates (Navarro et al., 2021a; Taylor et al., 2020). They are more likely to be misgendered and may be perceived as ‘too young’ to know themselves, with over a third (36%) of TGD youth surveyed reporting experiencing age-related stigma (Navarro et al., 2021a; Taylor et al., 2020). Some studies indicate that the mental health of TGD youth can worsen over time due to the onset of gender-incongruent puberty (Wittlin et al., 2023). However, experiences of validation and affirmation have been shown to mediate the effects of depressive symptoms in TGD youth, suggesting that poor mental health outcomes are not inevitable (Allen et al., 2019; Gibson et al., 2021; Wittlin et al., 2023).

Another factor contributing to worse health outcomes is that TGD youth report considerable barriers to accessing and receiving healthcare, even when they have a primary care provider (Navarro et al., 2021a). In an online Canada-wide survey of trans and nonbinary people, Trans PULSE Canada, 77% of youth ages 14-24 years reported having access to a primary care provider, yet almost half (47%) reported unmet healthcare needs in the previous year (Navarro et al., 2021a). Similarly, through the Canadian Trans and Non-binary Youth Health Survey, 43% missed needed physical healthcare and 71% missed needed mental healthcare in the year preceding the study, despite 78% of participants having a primary care provider (Taylor et al., 2020). Evidently, being rostered to a primary care provider does not necessarily equate to fulsome access to healthcare for TGD youth.

Healthcare access can be understood through five dimensions: availability, affordability, accommodation, accessibility, and acceptability (Clark et al., 2018; Penchansky & Thomas, 1981). In the Canadian context of universal healthcare, *affordability* does not typically represent a prominent barrier for youth to access primary care. Further, the evidence discussed above suggests that *availability* of primary care providers is not a primary barrier for TGD youth. Certainly, *accessibility* could represent a barrier in rural contexts and *accommodation*, such as hours of operation, could pose an inconvenience. For TGD youth, however, the largest and most consistent barrier to accessing primary healthcare is a lack of *acceptability* (Guss et al., 2019; Taylor et al., 2020). Acceptability refers to an alignment between the attitudes and values of the patient and the care provider (Clark et al., 2018; Penchansky & Thomas, 1981). When a misalignment occurs, youth of all gender identities often forego medical care, especially those who experience marginalization in healthcare settings (Barnet et al., 2020; Clark et al., 2018; Samargia et al., 2006). Despite the facts that most TGD youth have a primary care provider (availability) and Canada has universal healthcare (affordability), about half report avoiding primary care due to experiences of nonaffirmation (provider acceptability), thereby highlighting the importance of understanding the nuance behind healthcare access (Guss et al., 2019; Navarro et al., 2021a; Taylor et al., 2020). When individuals have limited access to primary care, they experience worse health outcomes and may be more likely to rely on emergency departments for healthcare (Duong & Vogel, 2023; Fleet et al., 2015).

The emergency department often serves as an accessible entry point to the healthcare system and a safety net for medically underserved populations (Duong & Vogel, 2023; Willging et al., 2019). Although it represents a haven for some, the emergency department is a complex, dynamic, and highly stressful clinical environment (Milton et al., 2023; Person et al., 2013). Research on patient perspectives of care in the emergency department suggests that empathetic treatment and caring communication, including body language and tone, can profoundly mitigate the stress that patients feel when navigating a health crisis in this context (Milton et al., 2023).

Conversely, stigmatizing treatment can exacerbate this stress, thereby contributing to the avoidance of emergency departments entirely (Allison et al., 2021; Chisolm-Straker et al., 2017; McSky et al., 2023; Samuels et al., 2018; Thompson-Blum et al., 2021; Willging et al., 2019).

People who experience stigma in relation to their social location(s) and lived experiences are particularly vulnerable to these negative interactions with healthcare providers and, therefore, report rates of emergency department avoidance as high as 44% (Samuels et al., 2018). Similar patterns are evident in studies that include TGD youth, suggesting that emergency department avoidance is a phenomenon that affects youth too (Navarro et al., 2021a; Thompson-Blum et al., 2021). The perspectives of youth, however, are grossly missing from the qualitative scholarship, reflecting a significant gap in our understanding of their experiences and what they perceive to be their healthcare needs. While adult and youth TGD people share certain similarities in their experiences, understanding the intersections of age and gender-related issues in the lives of younger people is vital to ensuring that healthcare delivery in emergency departments is sensitive to the unique needs of TGD youth.

1.2 Transgender Research

"If we study issues of domination, marginalization, and social injustice, but do not orient our work toward alleviating them in real, material ways, our scholarship may benefit our careers at the expense of the very communities we research (p.10, Billard et al., 2022).*"*

Despite mention of TGD people throughout documented history, there has been an increase in publications on transgender issues since 2010, suggesting that this is an emergent area of inquiry (Matsuno & Budge, 2017; Thorne et al., 2019). Two different paradigmatic waves characterize contemporary trans health literature (Billard et al., 2022; Schilt & Lagos, 2017). The 1970s through to the 1990s were dominated by the gender *deviance* paradigm, wherein TGD people were considered *objects* of study whose access to care was often gatekept by medical and psychiatric providers seeking to prove their etiological theories of ‘transness’ (Billard et al., 2022; Schilt & Lagos, 2017; Vincent, 2018). This pathologizing and objectifying approach was reflective of the medical context that, until 2013, labelled trans people as mentally ill, using the diagnosis ‘gender identity disorder’ (Kellet & Fitton, 2017).

Beginning in the late 1990s and early 2000s, the gender *difference* paradigm emerged, wherein TGD people are considered the *subjects* of study, whose voices and lived experiences are considered scientifically relevant and important in their own right (Billard et al., 2022; Schilt & Lagos, 2017). This shift in perspective is reflected in the American Psychiatric Association’s decision to remove ‘gender identity disorder’ from the DSM-5, replacing it with ‘gender dysphoria.’ Whereas ‘gender identity disorder’ conceptualized trans identity itself as a ‘mental disorder,’ ‘gender dysphoria’ shifted attention to the (often temporary and treatable) distress experienced by people whose assigned sex is incongruent with their gender as a clinical condition (2013). While this change is generally regarded as a positive step, there is tension in the literature about the continued presence of gender dysphoria as a diagnostic criterion. Some clinicians and researchers believe that retaining a diagnosis facilitates access to hormonal and/or surgical therapy, whereas others believe that a diagnosis suggests the presence of disease and thereby contributes to ongoing stigma (Lev, 2013; Cosgrove, 2021).

There remains a relatively small, yet vocal group within healthcare who continue to actively pathologize gender diversity. This minority of healthcare providers actively fights against gender-affirming medical care - despite nearly all professional organizations in Canada contesting their positions, both on ethical and scientific grounds. This faction will testify as ‘expert’ witnesses in court despite dubious credentials and create pseudo-medical organizations to attempt to validate their unscientific and discredited views (Caraballo, 2022). One way that this is enacted is by perpetuating unsubstantiated and unfalsifiable etiological theories of transness, such as Blanchardian typologies which assert that trans women's gender identities and presentations are a by-product of their sexual orientation (Serano, 2020). Further, healthcare more broadly continues to perpetuate this pathologizing legacy in the form of gatekeeping access to hormonal therapies, surgical interventions, and/or legal affirmation, such as legal name changes (Kellet & Fitton, 2017). In the current political climate, there are even some practitioners who promote highly restrictive and ethically questionable care models in spite of a lack of empirical support for these approaches to care (Ashley, 2023). Even researchers that attempt to engage ethically with TGD participants can unintentionally negatively contribute to ethical issues and *research fatigue* amongst TGD people.

Although all research with human participants in Canada is expected to adhere to the Tri-Council Policy Statement and evaluation by a research ethics board, community members continue to experience many studies involving TGD people as pathologizing and unethical, notwithstanding their approval by ethics boards (Ashley, 2021; Bauer et al., 2019). Some of the common ethical problems include insensitive language, conflating the experiences of sexual minorities with those of TGD people, failing to consider the intersectional social locations of participants, neglecting to share results, and inadequately involving community members (Bauer et al., 2019; Vincent, 2018). These factors often contribute to research fatigue.

Research fatigue refers to a sense of being exhausted by research participation that is reported by participants in small and/or marginalized communities and defined by a reluctance or refusal to continue to participate in research (Ashley, 2021; Patel et al., 2020). Transfeminine jurist, bioethicist, public speaker, and activist Florence Ashley has proposed four determinants of research fatigue: the time commitment (referred to as the ‘concentration of research’), its burdensomeness, its usefulness (value to the participants), and the psychosocial vulnerability of the participants (2021). Ultimately, any research project that involves the participation of TGD people requires critical reflection, a harm reduction approach, and active involvement of community members to avoid it becoming an onerous, useless, and, worst of all, damaging exercise.

1.3 Relevance for Nursing

Nursing has a long history of engagement with social criticism, social change, and social policy, known collectively as social ethics (Fowler, 2017). Despite this, a 2015 systematic review (Hall et al.) found that the levels of subconscious racial bias among healthcare providers, including nurses, were similar to those among the general population. A more recent review similarly concluded that implicit racial bias remains pervasive in healthcare and exacerbates health disparities in racial minorities (Sim et al., 2021). These studies suggest that nurses, like other health professionals, are not immune to the intersectional matrix of oppressive societal forces in which they are socialized, causing them to internalize these biases and engage in discriminatory practices (Kellett & Fitton, 2017; Wesp et al., 2018).

Many nurses report feeling uncomfortable and/or ill-prepared to meet the health needs of TGD patients (Carabez et al., 2015). While there are likely individual factors contributing to this issue, there are also many systemic barriers that prevent nurses from being able to enact affirming care for TGD patients. Nurses contend with complex socio-cultural-political systems of oppression and report not feeling empowered or knowledgeable enough to intervene (Weitzel et al., 2020). However, according to Weitzel et al., “[k]nowledge is inextricably linked with power and, contrary to popular belief, nursing is not a profession void of power. In fact, nurses have the capacity to both exercise and resist power, making nursing care inherently a political activity" (2020, p.112). This suggests that armed with knowledge, both evidence-based and introspective, nurses could position themselves as agents for change in the effort to render healthcare more equitable for TGD youth. The following two paragraphs outline current deficits in nursing education that act as barriers to both nursing agency and trans-affirming care.

Nurses, along with other health professionals, rarely receive formal education about providing trans-affirming care. *Trans-affirming* care is a philosophy of care specific to TGD people that is defined by patient-led care, a trans-affirming culture, and trans-competent healthcare providers (Lightfoot et al., 2021). A recent review of Canadian and American undergraduate nursing curricula concluded that although there has been an increase in one-time educational interventions, such as TGD health-related simulation, the remaining curriculum was rooted in cisnormativity and trans erasure (Crawford et al., 2024). Further, nursing students overall reported feeling inadequately prepared to provide trans-affirming care (Crawford et al., 2024).

In clinical contexts, very few organizations offer trans or LGBT-inclusive training, rather educating nurses to 'treat everyone the same' (Carabez et al., 2015). While this may seem reasonable, this messaging implies that trans-specific education is not necessary or important (a form of institutional erasure discussed in greater detail in Chapter 3) and fails to acknowledge the enduring history of pathologization experienced by TGD patients by healthcare providers (Bauer at al., 2009; Willging et al., 2019). Further contributing to this issue are the considerable gaps in the knowledge that would be needed to create this educational content, including the subjective experiences of TGD people accessing healthcare, particularly those of youth.

1.4 Summary of the Research Problem

Despite increased visibility in media and health research, TGD youth continue to experience worse health outcomes and healthcare experiences than cisgender youth. This is related to social norms that include, amongst other issues, the historical and evolving context of cisnormativity and trans-antagonism that is salient in the health and healthcare experiences of TGD youth, a paucity of research about the subjective healthcare experiences of TGD youth, and a lack of training/education for healthcare providers including nurses. TGD youth also experience age-related considerations that differ from the experiences of gender minority adults that may render them more vulnerable when accessing and receiving care in the emergency department. While further research is needed, it must be pursued intentionally. Trans health research is a rapidly growing area of scholarship that, even when well-intended, risks being excessively prescriptive and burdensome to the communities involved.

1.5 Purpose of the Dissertation

The purpose of this research was to collaborate with TGD youth to explore their experiences accessing and receiving care in emergency departments using a multi-phase multimethod emergent research design aimed at addressing the following objectives:

Objective 1. Engage with TGD youth to create a research team composed of community members and academic partners.

Objective 2. Iteratively develop a research protocol that meets the needs of the community.

Objective 3. Collaborate with TGD youth to create an empowering research process informed by the scholarship on erasure, intersectionality, and the gender minority stress framework.

Objective 4. Uphold the values of critical participatory action research (experiential knowledge, collaborative decision-making, authentic partnership, mutual beneficence) at every stage of the research process - including analysis.

Objective 5. Gain insights into how TGD youth perceive their treatment in the ED.

Objective 6. Develop recommendations for emergency department staff, based on the research findings, on how to provide affirming care to TGD youth.

The content and structure for this manuscript style dissertation is outlined in Table 1. To begin, I review the existing scholarship about the experiences of TGD people accessing and receiving care in the emergency department (Chapter 2). I then outline how a theoretical framework was developed by combining elements of erasure, intersectionality, and the Gender Minority Stress Framework to inform and provide structure to this work (Chapter 3). Next, I describe the methodological approach and considerations for this multimethod Critical Participatory Action Research project (Chapters 4, Objectives 1-4). I then report the results of the online questionnaire (Chapter 5, Objective 5) and the multimethod qualitative study (Chapter 6, Objective 5). Finally, I integrate the dissertation findings and discuss implications and recommendations for nursing practice, education, leadership, and research (Chapter 7, Objective 6).

Table 1. Manuscript Style Dissertation Structure and Content.

Chapter	Chapter Title	Objectives
1	Introduction	To orient the reader to the research problem, the study objectives, and the structure for this hybrid manuscript-and-chapter-based dissertation.
2	Literature Review	To review the existing literature surrounding ED experiences for TGD people.
3	**Manuscript:** A Theoretical Framework for Understanding the Experiences of Trans and Gender Diverse Youth Accessing Healthcare	To describe a pragmatic, critical theoretical framework informed by the central concepts of the Gender Minority Stress Framework reinterpreted through the lenses of erasure and intersectionality. This manuscript was prepared for submission to the journal of Nursing Philosophy.
4	Methodological Considerations **Manuscript:** Engaging in Critical Participatory Action Research During the PhD	To describe methodological considerations for this dissertation. This manuscript was prepared for submission to the journal of Qualitative Health Research.
5	**Manuscript:** Experiences of Trans and Gender Diverse Youth Accessing Emergency Department: Results of a Community-Designed Questionnaire	To report the results of a cross-sectional survey and online questionnaire that captured participants' sociodemographic factors, as well as both quantitative and qualitative information about emergency department use. This manuscript was prepared for submission to the journal of Transgender Health.
6	**Manuscript:** Experiences of Trans and Gender Diverse Youth Accessing Emergency Departments: Results and Recommendations from a Participatory Action Research Qualitative Study	To report the results of a multimethod qualitative research study. This manuscript was prepared for submission to the International Journal of Nursing Studies.
7	Integrated Discussion	To summarize the knowledge generated across all phases of the dissertation project, highlight important considerations, discuss implications of this work for nursing practice, policy, education, and research, identify strengths and limitations of the project, and offer conclusions.

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Chapter 2: Literature Review

The importance of language and social context in trans health scholarship cannot be overstated. Both play a role in defining individual identity, shaping societal attitudes, and informing policy and practice. As such, in this chapter, I introduce key concepts while acknowledging their history, their current context, and how they guide and inform this dissertation project. To my knowledge, there is no existing study that focuses on the subjective experiences of trans and gender diverse (TGD) youth accessing and receiving care in emergency departments. As such, I review, summarize, and identify gaps in adjacent bodies of literature to substantiate the importance of emergency department experiences among TGD youth. In so doing, I argue that TGD youth experience marginalization and erasure in relation to the intersections of their minority gender identities and their minority status as youth. I outline how, in healthcare settings, these individual and community experiences contribute to worse health outcomes and healthcare avoidance. I then situate the phenomenon of healthcare avoidance within the context of the emergency department. Ultimately, the literature review provides the rationale for this dissertation project by highlighting its potential to contribute to improving health outcomes and healthcare experiences for TGD youth, and what is risked if this line of inquiry is not pursued.

2.1 Affirming Language and Key Concepts

The language used to describe people whose gender identities do not match the sex that they were assigned at birth is ever-evolving, deeply political, and highly personal (Coleman et al., 2022; Miyagi et al., 2021). While the term *trans* has reached a high level of acceptability in both queer and research communities, it would be impossible for any single term to be comprehensive of the many varied gender identities and gender expressions that would meet the normative criteria for this term (Coleman et al., 2022; Thorne et al., 2019). ‘Trans’ research is often more representative of binary trans identities, such as trans women and trans men, effectively erasing nonbinary identities, like genderqueer and genderfluid people, and reinforcing a cisnormative binary gender structure (Cosgrove, 2021; Lefevor et al., 2019; Tan et al., 2020). Therefore, some people who are nonbinary may not identify with the term ‘trans’ or may identify with another term that is consistent with their cultural background (Tan et al., 2020). For example, many Indigenous people on Turtle Island use the term Two-Spirit to refer to both non-cisgender and/or non-heterosexual identities that may be tied to specific cultural and community contexts without identifying as trans (Robinson, 2020). Further, people who have lived as their affirmed gender for a long time and/or who transitioned young may not identify as being trans at all. To account for this, the World Professional Association for Transgender Health currently recommends the use of the term *transgender and gender diverse (TGD)*, in part, because it is inclusive of cultural variations and nonbinary gender identities (Coleman et al., 2022). Thus, for this dissertation project, the term TGD has been carefully selected, in collaboration with community partners, to reflect current best practice. Recognizing the ever-evolving nature of language, if you are reading this dissertation at a time when this language has gone out of favour, please know that it was chosen respectfully and intentionally based on the knowledge of the time.

Although often treated as an emerging phenomenon, there is evidence of gender diversity throughout documented history, including in ancient Near East, Mediterranean, Egyptian, and Mesopotamian societies (Stryker, 2013; Thorne et al., 2019; Wilfong, 2007). Establishing the current number and percentage of TGD people amongst the general population is challenging for a number of reasons, including variable definitions of TGD and challenges reaching TGD people in population-level surveys (Deutsch, 2016). In 2021, Canada became the first country to collect and publish data on gender diversity from a national census (Statistics Canada, 2022). According to the results of this census, in May of 2021, TGD people represented 0.33% of the overall population surveyed (aged 15 and older), ranging from 0.12% of respondents over the age of 75 to 0.79% of youth aged 15 to 24 years old (Statistics Canada, 2022). This likely represents a conservative estimate for a number of reasons, including the disproportionate number of TGD people affected by homelessness without a fixed addressed who would not be positioned to respond to a census and because the national census is completed as a collective household, meaning that those not ‘out’ to the other members of the household may not report their gender identity authentically (Deutsch, 2016). Despite this, the existing statistics support the claim that gender diversity is not unusual. Further, the presence of self-reported TGD people across age groups suggests that although TGD identities are sometimes miscategorized as a ‘trend’, the recent increase in visibility likely reflects evolving social acceptance (Abramovich et al., 2023).

Despite these limited societal gains, gender continues to be structured and socially enforced within the constraints of *cisnormativity*, wherein gender is understood as fixed, binary (male or female), and based on one’s assigned sex at birth (Bauer et al., 2009; Linander et al., 2024; Serano, 2020). Cisnormativity underpins *trans erasure*, the societal invisibility of TGD people, which is upheld by deficits in the scholarly literature, omission of TGD perspectives in academic work, and intentional suppression of knowledge that disrupts normative beliefs about gender (Bauer et al., 2009; Mason et al., 2024; Namaste, 2000). Unlike *transphobia*, the fear and/or hatred of trans people, which expresses overtly, trans erasure and cisnormativity manifest insidiously, permeating the fabric of our society and reinforcing problematic social norms that render gender variation unintelligible (Bauer et al., 2009; Linander et al., 2024).

Marginalization refers to the oppression and exclusion of certain social groups as a result of dominant societal structures and ideologies (Abramovich et al., 2023; Van Herk et al., 2011). Marginalization, in the form of systemic racism, has been identified in critical race scholarship as contributing to the health inequities experienced by racial minorities (Hardeman & Karbeah, 2020; Weitzel et al., 2020). Marginalization, in the forms of trans erasure and cisnormativity, has, similarly, been identified as contributing to a social structure in which TGD people experience disproportionate rates of food insecurity, low socioeconomic status, and unstable housing, and a healthcare system in which TGD patients are overlooked and/or treated pathologically (Abramovich et al., 2023; Bauer et al., 2009; Shelton & Bond, 2017; Vincent, 2018). This is particularly concerning given that TGD people are exposed to discrimination, stigma, harassment, and physical and sexual victimization based on their gender (Bauer et al., 2009; Scheim et al., 2022). These risk factors contribute to health inequities, such as higher rates of HIV, mental illness, and suicidality, and are perpetuated by considerable cisnormative barriers to accessing healthcare, social services, housing, employment, and education (Day & Brömdal, 2024; Scheim et al., 2021; Scheim et al., 2022; Winter et al., 2016). Further, both direct and vicarious exposure to manifestations of cisnormativity and trans erasure in healthcare settings, such as providers refusing to provide care on the basis that they have insufficient knowledge of TGD people, contribute to healthcare avoidance and exacerbating health inequities (Mason et al., 2024; Mezza et al., 2024).

Despite the need to focus on and address these inequities and related health deficits, it is also important to recognize how TGD people of all ages manifest resistance, resilience, and even joy in response to oppressive systems (Holloway, 2023; Veale, 2017). Recently, scholars in the field of trans health have acknowledged a 'joy deficit' in the literature and have called for increased focus on vehicles for resilience such as peer support and community connectedness (Holloway, 2023; shuster & Westbrook, 2024). Although this area of inquiry is underexplored and the existing evidence is mixed, a recent systematic review of quantitative studies evaluating the relationship between gender minority stress and mental health outcomes for TGD people highlighted the potential benefits of social supports for contributing to improved mental health (Mezza et al., 2024). Further, in a study by Kia et al., TGD participants describe how peer support encourages resilience through multiple means including connection, validation, shared experience, and sustained well-being, which contributes to mobilizing solidarity and resistance (2023).

Despite significant resilience, TGD people report feeling unsafe accessing healthcare due to experiences of stigma, discrimination, and mistreatment (Chong et al., 2021; Cicero et al., 2019; Heng et al., 2018; Wall et al., 2023; Winter et al., 2016). Amongst these experiences is the phenomenon of *gatekeeping*. In the context of trans health, gatekeeping refers to when healthcare professionals place unnecessary and overly restrictive barriers to medical *gender affirmation* (Verbeek et al., 2022). Gender affirmation refers to both the internal and external processes of recognizing and asserting one's gender socially, legally, and/or medically (Sevelius, 2013; Scheim et al., 2022). In a medical context, gender affirmation refers to a broad range of psychosocial, medical, and surgical interventions, such as puberty blockers or 'masculinizing' mastectomy, designed to support and affirm an individual's gender identity (Hughto et al. 2020, Scheim & Bauer, 2015). These interventions are ideally delivered using a *trans-affirming care* approach, which requires that care be patient-led, situated within a trans-affirming culture, and provided by trans-competent providers (Lightfoot et al., 2021). Numerous studies have demonstrated that access to social and medical gender affirmation contributes positively to reducing symptoms of depression, anxiety, substance use, and suicidality, and increases life satisfaction and social functioning (Almazan & Keuroglian, 2021; Bränström &Pachankis, 2020; Hughto et al., 2020; Nobili et al., 2018). Despite this growing body of evidence highlighting positive outcomes, highly inflammatory narratives about decisional regret – some of which may be anchored in mis- and disinformation regarding gender-affirming healthcare – create hesitancy and fear amongst well-intentioned providers (Billard, 2024; Billard, 2023). Further, until recently, clinical guidelines for how to determine individual readiness were vague and lacked substantive evidence (Verbeek et al., 2022).

The most recent guidelines from the World Professional Association for Transgender Health outline a shift to an informed consent model, which aligns with current expectations for clinicians supporting patients to make informed decisions about any medication or surgery (Coleman et al., 2022). While this represents a positive shift towards rendering trans healthcare less paternalistic, there is evidence to suggest that provider biases about who has capacity for informed consent will continue to disadvantage vulnerable communities within the broader TGD umbrella. For example, TGD patients with stigmatized mental health diagnoses, such as personality disorders, or autism spectrum disorder are often met with an unachievably high threshold for accessing affirming medical and/or surgical care (MacKinnon et al., 2020; Verbeek et al., 2022). TGD youth too face additional age-related barriers to medical gender affirmation based on the premise that they are ‘too young’ to know themselves or their needs (Ashley, 2022; Ashley, 2019; Kassen, 2022.

2.2 TGD Youth

According to the United Nations, *youth* “is best understood as a period of transition from the dependence of childhood to adulthood’s independence” (p.1, n.d.). Although often thought of as the teenage years, cognitive, emotional, physical, and social maturation can extend well into the 20s (Coleman et al., 2022; Ferguson et al., 2021). Due to the highly individualized nature of this series of milestones, there is no consensus on a definitive age range for youth (United Nations, n.d.). For statistical purposes, the United Nations defines youth as ages 14-24, which is consistent with two significant Canadian studies focused on TGD youth, the Trans PULSE Canada project, which defines youth statistically as ages 14-24 years (Navarro et al., 2021), and the Canadian Trans Youth Health Survey, which defines youth statistically as 14-25 years (Veale et al., 2015; Taylor et al., 2020).

Regardless of the specific age range, the period of youth has some defining characteristics that differ from both childhood and adulthood and that contribute to unique experiences navigating health behaviours and healthcare. Most notably, the period of youth involves rapid physical and psychological maturation, including pubertal-signaled changes (Coleman et al., 2022; Ferguson et al., 2021). This period is significant as it signals the development of secondary sex characteristics, which can be distressing for many TGD youth (Horton, 2022). Coupled with disproportionate experiences of distal minority stress, such as sexual assault (28%), dating violence (30%), violent threats (35%), sexual abuse (46%), and bullying (66%) (Taylor et al., 2020), it is unsurprising that TGD youth experience increased rates of mental illness and suicidality when compared to their cisgender peers (Horton, 2022; Wittlin et al., 2023). As such, the importance and timing of treatments like puberty blockers become particularly prominent as a way of pausing these distressing changes and potentially providing psychological relief (Horton, 2022).

Research about the outcomes of gender affirmation for adolescents consistently demonstrates reductions in depression, anxiety, suicidality, and improvements in quality of life and social and school functioning (Durwood et al., 2017; Huit et al., 2024; Olson-Kennedy et al., 2016; Tordoff et al., 2022; Turban et al., 2020; Wittlin et al., 2023). Further, TGD youth who receive gender-affirming medical care at earlier pubertal stages appear to have better mental health, suggesting that earlier treatment may be beneficial (Chen et al., 2021; Lee & Rosenthal, 2023; Sorbara et al., 2020). Longitudinal studies are limited in trans health due to the relatively emergent nature of the scholarship, meaning that the long-term outcomes of hormonal interventions on bone health, for example, are not yet fully understood (Huit et al., 2024). Existing evidence, however, does not imply any significant physical health risks and suggests that improvements in mental health related to gender-affirming medical care are sustained into adulthood (de Vries et al., 2014; Huit et al., 2024; van der Miesen, 2020). Ultimately, for TGD youth, whose positionality exposes them to multiple intersecting axes of marginalization, gender affirmation can be lifesaving.

Despite evolving evidence to support positive outcomes of gender affirmation for youth, TGD youth experience many obstacles to seeking gender-affirming care. In a systematic review and meta-analysis of TGD youth experiences accessing gender-affirming care, Kearns et al. highlighted five dimensions representing potential barriers and experiences during healthcare navigation: disclosure of gender identity, the pursuit of care (finding a provider, geographical location, and wait times), the cost of care, complex family/caregiver dynamics, and patient-provider relationships (2021). Similarly challenging patient-provider interactions and logistical barriers, such as wait times and insurance coverage, are well documented in research involving TGD adults (Cicero et al., 2019; Kearns et al., 2021; Ross et al., 2016). What differentiates youth is that, for most young people, access to care requires parental/guardian approval, whether for consent or for operational support, such as transportation (Kearns et al., 2021). For those with supportive parents, this may represent a protective factor which enables parents/guardians to advocate for youth in medical contexts where they may face medical gatekeeping. For youth whose parents are not supportive, however, they are effectively positioned such that they can experience two levels of gatekeeping (Ashley, 2022).

There has been a recent surge of dangerous, restrictive policies that further limit access to medical and social gender affirmation for youth in areas of the United States, Europe, and Canada (Barbi & Tornese, 2023; Koshan et al., 2024; Kraschel et al., 2022; Mallory et al., 2023). These policies, which are unsubstantiated empirically, contribute additional stress to TGD youth and risk seriously compromising their mental health, physical health, and/or quality of life (Horton, 2022). Providers of gender-affirming care and parents of TGD youth alike have publicly denounced these legal and political attacks, highlighting the significant risk to TGD youth mental health including, most concerningly, increased risk for suicide (Hughes et al., 2021; Kidd at al., 2021). Without access to gender affirmation, TGD people have been known to resort to seeking out medications, such as hormones, from disreputable sources posing numerous risks to their physical health and, depending on the situation, their personal safety (Glick et al., 2018; Kearns et al., 2021). Ultimately, allowing irreversible puberty to progress and banning access to gender-affirming care is not a neutral act and risks immediate and lifelong harmful effects (Coleman et al., 2022; Giordano & Holm, 2020). Further, the stress of cisnormative political climates has in itself been shown to exacerbate existing physical and mental health inequities (Dhanani & Totton, 2023; Wittlin et al., 2023).

The perspective that youth are not capable to make health decisions is in direct conflict with long-standing recommendations from respected authorities in pediatric medicine. In 1995, the American Academy of Pediatrics published guidelines advising that youth should participate in decision-making commensurate with their development. Nearly thirty years later, there continues to be a cultural resistance to this principle in North American healthcare with healthcare providers and/or parents making the vast majority of youths' care decisions (Allen et al., 2024; Katz et al., 2016). For TGD youth, age-related stigma and a volatile political climate position them vulnerably at the intersection of marginalized age and marginalized gender, thereby compounding the effects of marginalization and differentiating their experiences from those of TGD adults and cisgender youth. Research consistently demonstrates that people who face social and health inequities, such as TGD youth, have significant challenges receiving primary health care that meets their needs (Guss, 2019; Kearns et al., 2021; Willging et al., 2019; Varcoe et al., 2022). In light of this, they are thus more likely to be reliant on emergency departments, which often serve as an accessible entry point to the healthcare system and a 'safety net' for the medically underserved (Willging et al., 2019; Varcoe et al., 2022).

2.3 Emergency Department Avoidance

The *emergency department* is a specialized department in a hospital that is equipped to provide medical and psychiatric care to patients experiencing acute illness, injury, or exacerbation of chronic conditions. Its primary function is to assess, stabilize, and treat patients who require emergent/urgent intervention, typically 24 hours a day, seven days a week, regardless of health insurance and/or socioeconomic status. *Emergency medicine* is an expansive specialty in which healthcare professionals must respond to any and all medical and psychiatric presentations, usually without advanced notice or prior knowledge of the patient (McEwen et al., 2018). As such, the emergency department is often described as a complex, dynamic, and highly stressful clinical environment (Milton et al., 2023; Person et al., 2013). Research on patient perspectives of care in the emergency department suggests that empathetic treatment and caring communication, including body language and tone, can profoundly mitigate the stress that patients feel when navigating a health emergency in the emergency department (Milton et al., 2023; Sonis et al., 2018). Conversely, stigmatizing treatment can exacerbate this stress, thereby contributing to the avoidance of emergency departments entirely (Bauer et al., 2014; Kcomt et al., 2020; Mason et al., 2024).

There is a growing body of literature supporting a link between *medical mistrust,* the tendency to distrust medical systems and healthcare providers, and healthcare avoidance (Benkert et al., 2019; Burke & Figueroa, 2021; Bustillo et al., 2017). Medical mistrust and healthcare avoidance are commonly reported by people who experience social inequities, such as those based on race, gender, and age (Varcoe et al., 2022). For example, Indigenous people often report avoiding emergency departments due to previous personal and/or community experiences of racial discrimination (Loppe et al., 2014; Rotondi et al., 2017; Turpel-Lafond, 2020). For youth, whose parents are often deferred to in care decisions, decades of research have affirmed that when they do not trust that a provider will maintain their confidentiality, they will delay or forego care, placing them at higher risk for unintended pregnancy, sexually transmitted infections, substance abuse, and worse mental health outcomes (Agostino & Toulany, 2023; English & Ford, 2018). For youth who have experienced trauma, such as survivors of commercial sexual exploitation, trust is paramount for treatment ‘buy in’ due to a heightened sense of danger and betrayal (Barnet et al., 2017). For these youth and others involved in the judicial system, the consequences of healthcare avoidance may also pose significant legal risks in the context of court-referred mental health and substance use treatment programs (Barnet et al., 2020). Ultimately, studies consistently demonstrate a relationship between medical mistrust and both decreased adherence to treatment and healthcare avoidance (Benkert et al., 2019; Mason et al., 2024).

Although a causal link between emergency department avoidance and negative patient outcomes has not been conclusively determined, trends of increased medical complexity, morbidity, and mortality unrelated to COVID-19 were observed in various countries during the COVID-19 pandemic when emergency department avoidance was prevalent (Mahmassani, et al., 2023; Zhang, 2021). Further, based on the experiences of other marginalized groups, such as Indigenous people (Turpel-Lafond, 2020) and youth involved in the judicial system (Barnet et al., 2020), it is reasonable to extrapolate that TGD youth may experience worse health outcomes related to delaying or foregoing emergency healthcare. This highlights the value of pursuing research that endeavours to contribute to improving their emergency department experiences.

2.4 Experiences of TGD people in the Emergency Department

Across healthcare settings, TGD people commonly report that healthcare providers lack the knowledge to be able to provide trans-affirming care (Heng et al., 2018; Wall et al., 2023). Further, they often report power imbalances in the provider-patient relationship and communication challenges, including both overvaluation and denial of trans identity (Heng et al., 2018). These difficult interactions are then exacerbated by the structure of healthcare systems that reflect social norms related to gender, such as binary gender markers on health cards and electronic medical records (Bauer et al., 2009; Heng et al., 2018; Wall et al., 2023). These patterns are concerning in a routine clinic appointment, but could pose significant risk in a high stress, high acuity environment such as the emergency department where the stakes might be considerably higher.

TGD people commonly report negative interactions with healthcare providers in the emergency department (Allison et al., 2021; Samuels et al., 2018). Specifically, they report experiences of discrimination, such as being subjected to insulting language, being misgendered, and being denied care (Bauer et al., 2014; Chisolm-Straker et al., 2017; Cicero & Black, 2016; Muller et al., 2024). Further, TGD people often describe being treated by healthcare providers who do not have adequate education to be able to provide affirming care (Allison et al., 2021; Bauer et al., 2014; Heng et al., 2018). In many instances, TGD patients will be expected to educate providers, which represents an undue burden, particularly if the patient is experiencing a health emergency (Bauer et al., 2014; Milton et al., 2023). These negative experiences are exacerbated by the power imbalance in the provider-patient relationship (Chisolm-Straker et al., 2017). TGD people report feeling vulnerable when interacting with healthcare providers, causing them to feel disempowered to challenge inappropriate care practices, such as misgendering, out of concern that they would be denied care (Allison et al., 2021; Chisolm-Straker et al., 2017; Samuels et al., 2018; Willging et al., 2019). In a provincial survey of trans Ontarians, 10% reported being refused care in the emergency department or having had care ended once the provider found out they were trans (Bauer et al., 2014). Further, 24% reported having been ridiculed and 32% reported experiencing hurtful or insulting language (Bauer et al., 2014). Ultimately, these negative interactions are described as contributing to future emergency department avoidance (Bauer et al., 2014; Chisolm-Straker et al., 2017; Muller et al., 2024; Samuels et al., 2018).

For TGD people who have not had negative first-hand experiences, the knowledge of the experiences of others contributes to community narratives that the emergency department is not safe for TGD people (Chisolm-Straker et al., 2017; Cicero & Black, 2016). This suggests that negative experiences with the emergency department have a wider spread negative impact beyond the level of the individual seeking care. As discussed above, it is reasonable to extrapolate that there are inherent risks to avoiding emergency medicine when needed, suggesting that exploring this phenomenon as it pertains to youth could potentially contribute to improved health outcomes for this vulnerable population.

2.5 Experiences of Youth in the Emergency Department

Youth experiences of accessing healthcare vary widely and are influenced by developmental, psychosocial, and systemic factors. Developmentally, youth are transitioning from complete reliance on their parents to seeking more autonomy in their healthcare experiences. Often this manifests as desiring more independence in decision-making and their medical information being kept confidential from their parents (Agostino & Toulany, 2023; English & Ford, 2018). Despite this, supportive parental involvement has been demonstrated to improve healthcare access through encouraging proactive health-seeking behaviour, financial support/insurance coverage, and advocacy (Aguirre Velasco et al., 2020; Serbin et al., 2014). Conversely, in studies of street-involved youth in Canada, participants describe receiving suboptimal care in the emergency department, which they attribute, in part, to their young age and lack of parental presence (Ensign & Bell, 2004; Nicholas et al., 2016). These examples suggest that age-related stigma experienced by youth patients can be mitigated by supportive parental presence. Thus, one can infer that youth who are vulnerable due to lack of family support are more likely to have negative healthcare experiences and are, therefore, more likely to avoid healthcare.

Youth presentations to the emergency department for mental health reasons are increasing at a staggering rate with recent data describing a 75% increase in mental health visits between 2006-2007 and 2017-2018 (Campbell et al., 2020; Canadian Institute for Health Information, 2019). These trends are concerning because, while emergency department staff provide crisis intervention, emergency medicine is not designed to meet the often chronic and complex psychosocial needs of youth with mental health challenges or to ensure continuity of care (Campbell et al., 2020; Dolan & Fein, 2011). As such, youth who present to the emergency department for mental health reasons are more likely to experience an extended length of stay, leave before completing care, be dissatisfied with the care received, and need to represent than youth who present for physical health concerns (Campbell et al., 2020; Case et al., 2011).

Younger youth may also experience gaps in provider knowledge due to a lack of *pediatric readiness* (Remick et al., 2018). Based on a policy statement by the American College of Emergency Physicians, pediatric readiness refers to having the knowledge, equipment, medication, and policies to deliver emergency medical and psychiatric care that meets the anatomical, physiological, and developmental needs of pediatric patients (Remick et al., 2018). This suggests that younger youth that live outside of large urban centers and who may not have access to a pediatric emergency department may be less likely to receive developmentally appropriate care.

Clearly, youth experiences with healthcare, especially in the emergency department, are highly varied and dependent on multiple factors, including their level of family support (Serbin et al., 2014), reason for presentation (Campbell et al., 2020), and provider pediatric readiness

(Remick et al., 2018). Given that we know that TGD people also have complicated healthcare experiences (Heng et al., 2018; Wall et al., 2023), it is reasonable to consider that TGD youth may experience prominent challenges accessing affirming care in the emergency department. The continued relative dearth of literature in this area represents a critical gap that contributes to perpetuating TGD health inequities. The following section synthesizes what little we do know.

2.6 Experiences of TGD youth in the Emergency Department

TGD youth, who sit at the marginalized intersections of age and gender, remain grossly underrepresented in the literature addressing the experiences of TGD people accessing and receiving care in emergency departments. This is despite the results of a nationwide study of TGD youth in Canada which reported that 20% had avoided the emergency department when they needed care (Navarro et al., 2021). When submitting my thesis proposal to my advisory committee in fall of 2019, I justified the need for further inquiry, in part, based on the absence of research studies that considered the qualitative experiences of youth. More recently, two review articles (Goulding et al., 2023; Muller et al., 2024) have revealed that the same gap in knowledge persists in 2024 despite the increased visibility of TGD youth in mainstream media since the inception of this project.

The first study is a systematic review of the healthcare experiences of TGD youth (Goulding et al., 2023). Participants frequently reported care avoidance in response to discriminatory experiences and/or anticipation of discriminatory responses from providers (Goulding et al., 2023). While gender clinics were typically described as affirming, participants reported experiences in primary care and mental health settings as predominantly negative. This was due, in part, to experiences of discrimination, including misgendering and deadnaming, and/or providers who lacked sufficient knowledge to provide affirming care (Goulding et al., 2023). Of the sixteen included citations, none were set in the emergency department, and while the negative experiences described in primary care and mental health settings are troubling, the risks may be higher in an emergency setting where patients often present with higher acuity physical and mental health concerns.

The second study is an integrative review of the experiences of TGD patients accessing care in the emergency department (Muller et al., 2024). Overall, the authors identified a perceived lack of provider competence to provide affirming care in the emergency department, which was believed to be associated with inadequate provider knowledge and cisnormative systems (2024). Examples include cisnormative electronic medical records which create confusion and distress at the registration desk, especially when legal documentation is not congruent with the patient's affirmed name and gender (Muller et al., 2024). Further, across studies, TGD people often reported negative interactions with staff including discriminatory use of language. While not all negative interactions were perceived to be intentional, these adverse experiences contributed to poor health outcomes and emergency avoidance (Muller et al., 2024). Of the eleven included studies, however, none focused on the experiences of TGD youth, who may be at increased risk for negative experiences given their positionality.

The two synthesis studies above lend support to the claim that there is a critical gap in the literature about the experiences of TGD youth accessing and receiving care in the emergency department. Further, their findings suggest that this is a valuable area of inquiry based on the conclusions that: a) TGD youth report healthcare avoidance, experiences of discrimination, lack of provider knowledge, and age/developmental stage-specific barriers to affirming healthcare in other healthcare contexts (Goulding et al., 2023); and b) TGD people report emergency department avoidance in response to anticipated and/or real experiences of discrimination and lack of provider knowledge (Muller et al., 2024). It is thus reasonable to infer that TGD youth experience discrimination and lack of provider knowledge in the emergency department, and that these experiences are likely to be different that their adult TGD peers given the influence of age-related social norms and barriers.

In a national survey of TGD youth, 78% reported wanting to change their legal name, but only 30% had done so (Taylor et al., 2020). Further, most reported an inaccurate gender marker was listed on their ID and described barriers to changing it, including concern about increased exposure to discrimination, not being able to afford to make this change, their gender identity not being available within legislative frameworks of their jurisdiction, and not knowing how to change their gender marker (Taylor et al., 2020). This suggests that for most TGD youth, their health cards are incongruent with their affirmed name and/or gender. This is noteworthy because it indicates that the distressing systemic barriers identified in the research about adults are likely to also be relevant to the experiences of youth and pose unique challenges when compared to the experiences of adults.

The existing literature suggests that having a cis support person in the emergency department is a protective factor for TGD patients and having a parent present is a protective factor for youth patients. For TGD youth who have challenging relationships or no relationship with their parents, this represents a significant barrier. In a subsection of a national study of TGD people, only half of youth reported that their parent(s) and/or guardian(s) used their correct name (53%) and pronouns (51%) (Navarro et al., 2021). Further, in a national study of TGD youth over a quarter (27%) of youth with physical health needs and over a third (36%) of youth with mental health needs reported not having accessed healthcare because they did not want their parents to find out. Adding to this, a quarter of participants shared that they only felt safe at home ‘sometimes’ (19%), rarely (5%), or never (1%) (Taylor et al., 2020). Ultimately, these findings imply that parental presence may not be inherently supportive or possible. Further exploration into the role of parents/guardians in the emergency department for TGD youth may contribute novel and nuanced insights for healthcare providers.

To my knowledge, this doctoral project represents the first focused exploration of the emergency department experiences of TGD youth. The historical omissions of qualitative studies in this area have reflected critical gaps in the scholarship that contribute to perpetuating health inequities for this vulnerable population. There is evolving evidence that TGD people frequently report negative experiences in the emergency department. Further, there is evidence that youth, particularly those without parental presence and who present for mental health concerns (Campbell et al., 2020; Case at al., 2011; Ensign & Bell, 2004; Nicholas et al., 2016), experience challenging and variable experiences in the emergency department. As such, it is reasonable to extrapolate that TGD youth, who exist at the intersections of marginalization related to gender norms and marginalization related to widespread beliefs about age/developmental stage, may experience unique challenges in the emergency department. Research in this area could contribute further insight into the experiences of TGD youth and inform policy to improve health outcomes.

2.7 Conclusion

Ultimately, reviewing the existing literature revealed that further research, education, and advocacy work is needed to understand and improve the emergency department experiences of TGD youth. Although there are several significant gaps in our understanding, the existing evidence base reveals a pattern of negative experiences, including disrespectful language, cisnormative healthcare systems, and lack of provider knowledge. These healthcare experiences can be traumatizing and contribute to a pattern of emergency department avoidance, which in turn risks exacerbating physical and mental health conditions. The emergency department experiences of TGD youth have not yet been explored, but it is reasonable to extrapolate that youth may face barriers to trans-affirming care in this context. It is, therefore, important to address these omissions in the scholarship so as to inform trans-affirming practice and policy and improve the experiences of TGD youth accessing and receiving care in the emergency department. In so doing, this research could contribute to ongoing efforts to reduce emergency department avoidance and support improved health outcomes for a vulnerable population.

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Chapter 3: A Theoretical Framework for Understanding the Experiences of Trans and Gender Diverse Youth Accessing Healthcare

This chapter consists of a theoretical framework manuscript in which I describe the theoretical framework for this doctoral thesis project. This manuscript was prepared for submission to the Nursing Philosophy journal.

Abstract

Despite a recent increase in clinical and academic interest, trans and gender diverse (TGD) youth perspectives remain underrepresented in the small but growing body of literature about TGD healthcare experiences and avoidance. This is problematic because TGD youth face age-related disparities that differentiate them from their adult counterparts, such as being perceived as ‘too young’ to understand their gender identity. In the process of conceiving of a research project to explore the emergency department experiences of TGD youth, I recognized the value of theory to guide inquiry in this area. In this paper, I discuss the strengths and limitations of three theoretical traditions: Gender Minority Stress Framework, erasure, and intersectionality, which often guide studies with TGD communities, and explain how they can be combined into a cohesive theoretical framework for work with TGD youth. The proposed theoretical framework supports nursing scholars to find patterns of meaning across experiences without reducing them to gendered stereotypes.

3.1 Background

Across past and contemporary societies, there is evidence of people whose gender identities do not completely align with the sex that they were assigned at birth, often referred to as *trans and gender diverse* (TGD) people (Coleman et al., 2022; Thorne et al., 2019; Wilfong, 2007). Despite this ongoing documented history, gender continues to be understood and socially enforced as fixed, binary (e.g., man or woman), and based on one's assigned sex at birth. This pervasive, normative assumption that people are *cisgender*, or non-trans, is known as *cisnormativity* (Bauer et al., 2009; Linander et al., 2024; Serano, 2020). Health professionals are not immune to the cisnormativity – and other social norms – in which they are socialized, causing them to internalize bias and engage in discriminatory practices (Kellet & Fitton, 2017; Wesp et al., 2018). In fact, many nurses report feeling uncomfortable and/or ill-prepared to meet the health needs of TGD patients (Carabez et al., 2015; Sherman et al., 2021). While there are likely individual factors contributing to this issue, there are also many systemic barriers that prevent nurses from being able to enact affirming care for TGD patients, such as a lack of substantive trans-affirming education (Crawford et al., 2024; Kellet & Fitton, 2017). Without training and education, nurses may not be aware of their internalized biases or how they manifest in the care that they provide (Sherman et al., 2021). TGD patients, however, are reporting poor treatment and lack of provider knowledge across healthcare settings (Heng et al., 2018; Mikovits, 2022).

Despite a recent increase in clinical and academic interest, TGD youth perspectives remain underrepresented in the small but growing body of literature about TGD healthcare experiences and avoidance (Collins, 2021). This is problematic because TGD youth face age-related disparities that differentiate them from their adult counterparts, such as increased reliance on family, reduced access to gender-affirming treatments, peer pressure, lower employment rates, being perceived as ‘too young’ to understand their gender identity, and a wave of cisnormative policies creating barriers to care amid a climate of political volatility (Dhanani & Totton, 2023; Navarro et al., 2021; Taylor et al., 2020; Wittlin et al., 2023). It is, therefore, important to investigate how TGD youth experience and navigate manifestations of cisnormativity in health contexts.

In this paper, I describe a theoretical framework for: 1) engaging in health research with TGD youth and 2) understanding the experiences of TGD youth accessing and receiving healthcare. I begin by describing the pragmatic, critical lens underpinning this work, while responding to common critiques of critical theory and critical theories. I then explain how and why I scaffolded the Gender Minority Stress Framework, erasure, and intersectionality into a cohesive theoretical framework. Finally, I present tangible ways to apply the central tenets of the theoretical framework in research. Ultimately, this framework can be usefully applied to empower nurses to recognize, understand, and challenge cisnormativity whatever their research and/or practice area.

3.2 Critical Theory and Critical Theories

There is a growing awareness in nursing scholarship that the biomedical model of health perpetuates discourses that center white, middle class, cis-heteronormative, and ableist values and realities (Fowler, 2017; Van Herk et al., 2011). By exclusively focusing on biological indicators of health, the person is effectively stripped of their social context. In so doing, for example, the shortened life expectancy of trans women of colour might be perceived as a personal failure to eat well, exercise regularly, get enough sleep, and avoid smoking, while overlooking the interrelated effects of racism, transphobia, cisnormativity, and misogyny on their health (Wesp et al., 2018). Further, without social context, the increased rates of mental illness experienced by TGD youth are often misconstrued and even weaponized as evidence equating transness with mental illness (Wittlin et al., 2023). Instead, these health disparities should be understood as manifestations of minority stress, meaning that TGD youth experience increased rates of mental illness not because they are TGD but because of how society responds to them as people who are perceived to deviate from social norms (Wittlin et al., 2023).

Scholars who align themselves with the critical paradigm have challenged this model of health by confronting oppressive social structures, such as sexism and racism, underpinning their work with theories such as feminist theory and critical race theory. Some of these perspectives have historically been criticized, however, for focusing on single axes of oppression rather than considering the multiplicity of oppressive forces at play across social contexts (Crenshaw, 1989; Collins, 2019). For example, feminism that does not consider sources of oppression other than those related to sex and gender is often critiqued for amplifying the voices of white women and reinforcing racist hierarchies within the feminist tradition (Crenshaw, 1989; Collins, 2019). Theories that consider singular forces of oppression are also criticized for perpetuating dichotomous understandings of privileged/oppressed categories (male/female, white/other) that render invisible and further marginalize certain social locations (genderqueer/white-passing Indigenous) (de Vries, 2015). These single-axis dichotomies reinforce existing hierarchies within marginalized groups since they function to disrupt one system of oppression (e.g., transmisogyny), while leaving others intact and available as sources of power and privilege. As a result, the experiences of those situated at interlocking axes of oppression – often those most prominently marginalized – are effectively erased (de Vries, 2015).

Proponents of critical scholarship are also criticized for adhering too rigidly to their paradigm's history of qualitative methodologies and application of critical theories and frameworks to the exclusion of others (O'Byrne, 2019). Some scholars advocate for a more pragmatic understanding of critical scholarship, suggesting: "if a main goal of critical theory is to work toward social justice for marginalized groups, then researchers' work should not only be judged as critical based on methods or theory, but also based on the outcomes and outputs of their work" (O'Byrne, 2019, p.34). To that end, any approach that can be harnessed to challenge the status quo and contribute to transformational social change might be considered critical. This perspective allows researchers to consider the critical value of a broader range of theories and theoretical frameworks and avoid being limited by prescriptive categories. Below I describe how I applied this pragmatic approach to develop a critical theoretical framework for engaging in research with TGD youth.

3.3 Theoretical Framework for Engaging in Research with TDG Youth

Theoretical frameworks provide philosophical, epistemological, methodological, and analytical structure and consistency to the research process, and render explicit the guiding principles of one's inquiry (Grant & Osanloo, 2014). They can be introduced and applied at various stages depending on the goals of the project and the area of research (Varpio et al., 2020). Below I summarize three research traditions that often inform scholarship about TGD people - the Gender Minority Stress Framework, erasure, and intersectionality - and how I combined them to create a cohesive theoretical framework for research with TGD youth.

3.3.1 Gender Minority Stress Framework

Minority stress was first applied to research with lesbian and gay populations by Virginia Brooks who used the concept to highlight the impact of social, cultural, and economic stressors on the mental and physician health of sexual minority individuals (1981). This seminal research laid the foundation for the Minority Stress Model, which was later popularized by Ilan Meyer (2003), in which the minority stress experienced by sexual minorities living in a heterosexist society is hypothesized to lead to poor mental health outcomes (Rich et al., 2020). While this model was designed for application with sexual minority individuals, it has also been applied in scholarship about TGD people (Hendricks & Testa, 2012; Seelman, 2016). This practice is critiqued for conflating the experiences of TGD people with those of sexual minorities (Tan et al., 2020). Further, because the Minority Stress Model does not identify the role of systems of oppression, institutional ideologies, and social norms as the root of minority stress, it limits a fulsome understanding of the influence of cisnormativity on the experiences of TGD people (Tan et al., 2020). Considering these critiques, Testa and colleagues (2015) expanded upon the original model to develop the Gender Minority Stress Framework, which was further elaborated upon by Tan and colleagues (2020).

According to the Gender Minority Stress Framework, TGD people experience levels of stress that are both specific to their minority group and above the threshold of the daily stress experienced by *majority* group individuals (Tan et al., 2020; Testa et al., 2015). Based on the results of an online survey of 923 TGD youth in Canada, mental health problems are positively correlated with experiences of enacted stigma and negatively correlated with social supports (Veale et al., 2017). Further, the stress that affects TGD people is chronic due to the social structures entrenched in society that perpetuate stigma and discrimination against gender minorities (Tan et al., 2020). Finally, minority stress results from marginalizing ideologies and cisnormativity, rather than from TGD identities themselves (Tan et al., 2020).

The framework classifies minority stress processes as distal and proximal (Meyer, 2003; Tan et al., 2020; Testa et al., 2015). Distal stressors are events experienced by people who are assigned minority *subject positions*. The term ‘subject position,’ in this context, implies that these stressors occur independently of an individual’s personal identification with a social category and are based on society’s perception of a person’s adherence to dominant norms (Meyer, 2003; Tan et al., 2020; Testa et al., 2015). Distal stressors for TGD people include gender-based victimization (verbal or physical violence), gender-based rejection, gender-based discrimination, and non-affirmation (Testa et al., 2015). *Non-affirmation* is a manifestation of cisnormativity wherein people are incapable or unwilling to respect a TGD person’s name, pronouns, and/or gender, among other signifiers of identity (Testa et al., 2015). Proximal stressors reflect how distal stressors are internally appraised and can be categorized as internalized transphobia and negative expectations (Meyer, 2003; Tan et al., 2020; Testa et al., 2015). *Internalized transphobia* is the internalization of pervasive negative societal attitudes towards people who do not conform to gender norms associated with their assigned sex at birth (Testa et al., 2015). Negative expectations are categorized as two processes: anticipatory stress and nondisclosure. *Anticipatory stress* is caused by a state of vigilance related to expected sources of discrimination (Meyer, 2003). *Nondisclosure*, or concealment, of trans identity is a protective strategy used to avoid anticipated judgment and/or violence; however, at times, this can also be a barrier to support (Meyer, 2003).

The Gender Minority Stress Framework also includes protective factors at the individual and social level that contribute to resilience and coping (Testa et al., 2015). An important individual protective factor, *identity pride*, refers to a person’s ability to accept and embrace their self-worth and identity (Tan et al., 2020). Social protective factors include cultural connectedness, family support, and community connectedness (Navarro et al., 2021; Tan et al., 2020; Taylor et al., 2020). Although most research about minority stress focuses more on risk factors than protective factors, there is a growing body of empirical evidence reporting a positive correlation between mental health and family support for both adults and youth TGD people (Bockting et al., 2013; Simons et al., 2013; Veale et al., 2017).

While the Gender Minority Stress Framework is easily attributed to a post-positivist tradition because of its applications in intervention research (Pucket et al., 2022), it includes concepts consistent with critical theory, such as marginalization on the basis of subject position, as well as internalized transphobia. These concepts acknowledge a socially constructed 'reality' based on pervasive (gender) norms that reinforce systems of inequity, which is consistent with critical theory (Guba & Lincoln, 2005). Unlike other stress models, the Gender Minority Stress Framework identifies minority group members as experiencing stress even when they can cope. When stress is defined as an inability to cope, the burden falls on the individual to adapt and not on society or healthcare providers (Lazarus & Folkman, 1984). The Gender Minority Stress Framework challenges this model of stress by conceptualizing structural context as a focal point for change (Meyer, 2003; Tan et al., 2020). In these ways, the Gender Minority Stress Framework aligns logically to a pragmatic understanding of critical theory.

3.3.2 Erasure

Erasure, which was first described as a concept (Namaste, 2000) and then developed into a critical theoretical framework (Bauer et al., 2009), describes the passive and/or active social processes through which TGD people are overlooked and/or treated as anomalies within systems and institutions. Unlike transphobia, which is expressed overtly, trans erasure manifests insidiously, permeating the fabric of our society (Bauer et al., 2009). Examples include bathrooms labelled exclusively as male or female, as well as ‘gender-reveal parties’, wherein the gender of a fetus is assumed based on the genitals visible in the ultrasound and revealed with the use of gendered colours: blue for a boy and pink for a girl (Gieseler, 2018; Toles-Patkin, 2021). These examples contribute to the conflation between sex and gender. Further, they reinforce a binary understanding of gender and uphold problematic social norms that do not allow for gender variation, effectively erasing TGD people.

Healthcare and health research often perpetuate erasure by reinforcing binary notions of gender. This is evident in eligibility criteria for studies or registration forms in healthcare contexts, which typically reduce gender options to checkboxes for male and female (Bauer et al., 2009). Other examples include ‘women’s health’ centres and cohorting by ‘gender’ on inpatient units. Further, sexual and gender minorities are often addressed as a single 2SLGBTQ+ monolith in research, which contributes to the development of knowledge that lacks sufficient attention to the various interwoven structures of power and oppression underlying the health inequities and harms against – and within – 2SLGBTQ+ communities (Chan & Henesy, 2018). Ultimately, people whose social locations reflect privileged identities and subject positions become the most visible, and those experiencing exposure to multiple systems of oppression are ‘erased’ (Bauer et al., 2009).

3.3.3 Intersectionality

Intersectionality began as a response to the limitations of single axis analyses of oppression. Socially structured categories of marginality, such as those related to gender, sexuality, race and ‘ableness’ (Morriss, 2011), ceased to be considered separately and instead were viewed as being produced by interrelated social forces of power and oppression (Crenshaw, 1989; Van Herk et al., 2011). Intersectionality is now considered an action-oriented theoretical framework used to guide critical inquiry and *praxis,* or practice (Collins, 2019). The pragmatic, action-oriented nature of intersectionality is particularly useful when researchers conceptualize how people who navigate marginalization – on the basis of one or more dimension(s) of social location – experience larger social systems, such as healthcare (Damaskos et al., 2018).

Researchers collectively identify people under the 2SLGBTQ+ ‘umbrella’ as facing health inequities related to their status as minorities (Chan & Henesy, 2018). Although these patterns of experience can be understood through other theoretical lenses, such as the Gender Minority Stress Framework, the individual experiences of these health inequities vary widely. The 2SLGBTQ+ ‘umbrella’ reflects a diverse group of individuals of various ages, ethnicities, cultures, socioeconomic statuses and ableness, as well as sexual orientations, gender identities, gender presentations, and gender expressions (Damaskos et al., 2018). As such, intersectional approaches and analyses are necessary to ensure that research with TGD people reflects the heterogeneity within TGD communities and the intersecting vulnerabilities experienced by individuals as they navigate a plurality of social norms (Bauer et al., 2019).

3.3.4 The Framework

Clearly, the experiences of TGD youth can be explored through research underpinned by the Gender Minority Stress Framework, erasure, or intersectionality perspectives. Despite the many strengths of each approach individually, combining them contributes to a more complete and nuanced understanding of the healthcare experiences of TGD youth. Simply put, this theoretical framework is based on the central concepts of the Gender Minority Stress Framework reinterpreted through the lenses of erasure and intersectionality.

The Gender Minority Stress Framework offers a logical structure for engaging in research with TGD youth. Across studies, TGD youth describe navigating stressful experiences related to social gender norms, such as exclusion and violence (Veale et al., 2017; Taylor et al., 2020; Wittlin et al., 2023). Though not always articulated as such, the experiences described align with the concepts of proximal and distal stressors that are unique to TGD people. The Gender Minority Stress Framework, however, was originally conceptualized for correlational and intervention studies within a post-positivist tradition (Pucket et al., 2022). As such, despite the critical content of the framework, its typical application in research allows for the consideration of only two possible outcomes in response to minority stressors: resilience or distress. Further, this framework is critiqued as being one dimensional and failing to consider the many factors that influence cultural connectedness, as well as the intersecting effects of varying systems of marginalization and dominant social norms on TGD people (Tan et al., 2020). For example, while TGD youth are generally at an increased risk for homelessness, HIV infection, detention, and incarceration, these risks are exacerbated in TGD youth who are also racial minorities (Navarro et al., 2021b; Pullen Sansfaçon et al., 2018; Taylor et al., 2020).).

Despite the importance of centering gender minority stress in work with TGD youth, this narrow focus on gender overlooks the influence of social norms related to age and stage of life; this is highlighted when reinterpreting the Gender Minority Stress Framework through the lens of erasure. Further, the Gender Minority Stress Framework is not structured to render visible the experiences of TGD youth who navigate other systems of oppression, such as those related to race, culture, and sexual orientation. As such, intersectionality is a logical addition to the framework - allowing researchers to consider the effects of a plurality of sources of power and oppression, rather than singularly amplifying the voices of the most privileged within a minority group. This combination of theoretical approaches prioritizes gender as a focus, while also acknowledging the other sources of power and oppression navigated by TGD youth.

3.4 Operationalizing the Theoretical Framework in Research

When applying this theoretical framework to research with TGD youth about their healthcare experiences, three central concepts of the Gender Minority Stress Framework must be considered: anticipatory stress, subject position and nondisclosure, and community connectedness. Below, I explain how each concept is reinterpreted through the lenses of erasure and intersectionality. I then situate these concepts within the literature on healthcare experiences for TGD youth.

3.4.1 Anticipatory Stress

Anticipatory stress refers to the anxiety and fear associated with the expectation of future negative events (Tan et al., 2020). Based on personal experience, the experiences of peers, and community narratives, many TGD people anticipate experiences of discrimination when engaging with society and social institutions (Bockting, et al., 2013; Hendricks & Testa, 2012; McSky et al., 2023; Seelman, 2016). As such, many TGD people avoid settings that provoke anticipatory stress, such as hospitals and clinics, schools, and government services (Allison et al., 2021; Bockting, at al., 2013; Hendricks & Testa, 2012; McSky et al., 2023; Seelman, 2016).

The concept of anticipatory stress can orient researchers to the complex decisional processes that TGD people navigate prior to seeking services at any of the institutions in question. Further, understanding this concept can sensitize researchers to the psychological and emotional burden that the TGD person might already be carrying. To fully apply the framework, however, ’anticipatory stress’ needs to be considered through the lenses of erasure and intersectionality, meaning that researchers must remain open to the idea that participants may experience anticipatory stress based on dimensions of social location other than gender, such as age, race/ethnicity, neurodivergence, and educational level. By holding space for individuals whose minority experiences are not solely influenced by gender norms, researchers avoid reducing the participant to a stereotype and potentially glean insights into the intersections of minority stress experiences. These insights allow researchers to identify patterns of similarity across participants as well as individual variance, rather than generate a potentially stereotypical summary of the 'average' experience (de Vries et al., 2015).

3.4.2 Nondisclosure

Nondisclosure, or concealment of TGD identity, is not a passive decision. Rather, it represents a state of vigilance in which TGD people are constantly assessing whether or not they are safe to reveal themselves, as well as whether they are *passing*, a term that refers to not being perceived as TGD (Tan et al., 2020; Testa et al., 2015). In a Canada-wide survey, only half of TGD youth reported living in their affirmed gender full-time (Taylor et al., 2020), meaning that this concept is particularly relevant for this population.

Knowledge of nondisclosure can help guide inclusion criteria, such as, including youth in research about healthcare experiences who do not disclose their TGD identity across contexts and/or do not present publicly as their affirmed gender. This ensures that a common experience for TGD youth is not 'erased'. Further, knowledge of nondisclosure can offset the problematic narrative that being TGD is only valid if done a certain way (National Centre for Transgender Equality, 2023). It can also orient researchers to some of the protective strategies employed by TGD youth to limit their negative experiences accessing healthcare. When reinterpreting nondisclosure through the lenses of erasure and intersectionality, the researchers remain open to the idea that TGD youth may conceal other aspects of their identity when engaging in healthcare to avoid stigmatizing experiences.

3.4.3 Community Connectedness

Developing a sense of connection with TGD communities, such as support groups or social networks, serves as a protective factor for TGD people (Pflum et al., 2015; Tan et al., 2020). By engaging with community, TGD people foster connection, find positive role models, and are able to normalize their emotional reactions to discrimination (Pflum et al., 2015; Tan et al., 2020). In research, some study design choices and methods foster community connectedness, such as collaborative recruitment approaches and data collection through focus groups. In critical participatory action research, for example, community members and researchers partner to create a mutually beneficial and equitable research process and action-oriented outcomes that benefit the community (Baum et al., 2006; Kemmis et al., 2014). By working together, it is possible to cultivate a sense of community connectedness, which contributes to increased resilience and identity pride (Tan et al., 2020).

To align more fully with the framework, researchers must recognize that group members might feel connected - or disconnected - to the community based on their social location. If the focus is narrowed to gender, exclusively, researchers might unintentionally assume that a research group is a safe space for any TGD youth. This poses psychological risks for participants who feel the need to conceal aspects of their social location to conform to the group. Further, this risks limiting the authenticity of the research and contributing to erasing the experiences of TGD youth navigating multiple axes of oppression.

The three central concepts identified in this framework can help inform current practices and advance nursing scholarship about the health, healthcare, and health experiences of TGD youth. Though I propose this framework for TGD youth accessing and receiving care in the emergency department, experiences of minority stress are identified across healthcare contexts in synthesis studies about TGD youth and TGD adults (Chong et al., 2021; Cicero et al., 2019; Heng et al., 2018; Wall et al., 2023). This suggests that nursing researchers can usefully apply this framework in a variety of healthcare contexts, whether more general, such as primary care, or more gendered settings, such as gynecology. Further, applying this framework fosters opportunities to focus on - and partner with - TGD youth who share minority stress experiences other than gender (eg. neurodiverse TGD youth or refugee TGD youth). Ultimately, this framework offers a structure for research with these communities that prioritizes gender as an area of focus while acknowledging, or rendering visible, other intersections of power and privilege.

3.5 Relevance for Nursing Practice

When applying this framework to their practice, nurses benefit from the insights reflected in the literature on the Gender Minority Stress Framework, erasure, and intersectionality, which support them to better address the issues and needs of TGD youth using a trans-affirming approach. *Trans-affirming care* refers to a philosophy of care specific to TGD people that is founded on the principles that 1) TGD people should lead their individual gender exploration and goals of care, 2) clinicians have a responsibility to be informed about TGD care needs in their clinical contexts, and 3) clinical environments should be physically (signage, bathrooms etc.) and culturally (language, systems, etc.) affirming of TGD people (Lightfoot et al., 2021). Below I pair the three central concepts of this framework, anticipatory stress, subject position and nondisclosure, and community connectedness, with specific examples of how nurses might be empowered to enact trans-affirming care in their practice based on this theoretical positioning.

Nurses who recognize that TGD youth patients experience anticipatory stress will be more likely to engage with increased sensitivity and less likely to misinterpret apprehension as noncompliance. This is important because decades of research suggest that the extent to which a patient is labelled as compliant, or a 'good patient', influences the quality and quantity of time healthcare providers spend with them (Fineman, 1991; Higashi et al., 2013; shuster & Bodenheimer, 2021). This is particularly important given recent evidence suggesting that some healthcare providers use their medical authority to hold TGD patients accountable to their own (i.e. the provider's) expectations for health behaviours, subordinate positioning in healthcare interactions, and gender presentation (shuster & Bodenheimer, 2021). Socializing the notion of anticipatory stress and its effect on health interactions should contribute to rendering healthcare more equitable for all patients navigating minority social positions.

Nurses who understand the rationale behind nondisclosure recognize that not all patients will feel comfortable disclosing various aspects of their identities, including gender. This knowledge better positions nurses to create positive patient-provider relationships by fostering intentional use of gender-neutral language and conscious recognition of their assumptions and biases when engaging with patients. Ideally, this will create conditions of trust for all patients who may feel that they need to hide aspects of themselves to receive fair and affirming treatment (Benkert et al., 2019; Burke & Figueroa, 2021; Bustillo et al., 2017).

Finally, nurses who appreciate the importance of community connectedness acknowledge that peer support serves a protective function against the effects of minority stress (Johnson & Rogers, 2020; Kia et al., 2021; Testa et al., 2014). As such, these nurses recognize that overly restrictive visitor policies based on narrow definitions of family may prevent vulnerable patients from having the support they need, resulting in negative impacts on the healthcare experience and health outcomes (The Change Foundation & the Ontario Hospital Association, 2019). These nurses are, therefore, better equipped to advocate for inclusive policies and exemptions to existing policy so that TGD patients are supported to identify *chosen family*, family outside of biological and/or legal bonds, as part of their care team (Jackson Levin et al., 2020). Although their contributions often get overlooked, chosen family members offer emotional support, serve as advocates for patients in health settings, help navigate the healthcare system, and mobilize resources (Jackson Levin et al., 2020). When informed by community connectedness and erasure, nurses acknowledge the value of chosen family and are thus better able to navigate within and outside of institutional policies to ensure that TGD patients, and members of other marginalized groups, such as sexual minorities, are supported by family in healthcare settings.

3.6 Conclusion

There are many theoretical synergies between the Gender Minority Stress Framework, erasure, and intersectionality. These logical connections provide a more fulsome understanding of central concepts relevant to TGD youth experiences of emergency department care: anticipatory stress, nondisclosure, and community connectedness. Exploring the experiences of TGD people through the combined lenses of Gender Minority Stress Framework, erasure, and intersectionality supports nursing scholars to find patterns of meaning across experiences without reducing them to gendered stereotypes. Further, this theoretical framework provides a structure through which nurses can consider how social norms about gender might impact their clinical practices and the healthcare experiences of TGD patients more broadly, while still acknowledging the individual and multifaceted social positions of the TGD patients with whom they interact. Ultimately, we believe that nurses are well-positioned to enact trauma-informed and trans-affirming approaches in clinical practice, education, and research, and that our theoretical framework offers an empowering theoretical foundation to guide these efforts.

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Chapter 4: Methodological Considerations

In this chapter, I present the methodological considerations for this thesis project. First, I briefly describe the history of approaches to trans health research and how community-driven research emerged as a response to being overlooked in mainstream health studies. Second, I describe critical participatory action research (CPAR) and multimethod research. I then align these approaches with the theoretical framework (Chapter 3), the population (ie. trans and gender diverse (TGD) youth) and phenomena of interest (ie. experiences accessing and receiving care in emergency departments). Next, I describe the overarching design for the project and provide a methods manuscript on relevant methodological, operational, and ethical considerations important for graduate students and early career academics to consider when engaging with CPAR.

4.1 Background

Since the late 1990s, the visibility of TGD people in the media has increased significantly, contributing to an increase in scientific and academic interest (Adams et al., 2017; Billard et al., 2022; Vincent, 2018). Prior to this time, research about TGD people was often conducted by physicians seeking to prove their own etiological theories of transness who asserted their power as gatekeepers to hormonal and medical treatments to ensure that their patients participated in their work (Adams et al., 2017; Billard et al., 2022; Serano, 2020; Vincent, 2018). Similarly, psychiatric research involved disseminating pathological psychosexual theories and engaging in intervention studies attempting to prove the effectiveness of conversion therapies (Bernal & Coolhart, 2012; Vincent, 2018; Tan et al., 2020).

More recently, research with TGD participants is criticized for homogenizing sexual and gender minorities under the LGBTQ+ umbrella, resulting in TGD voices being erased (Adams et al., 2017; Vincent, 2018). Further, research involving TGD populations is criticized for its overrepresentation of TGD people who are white, middle-class, and urban, whose experiences are often used to make inferences about TGD populations as a whole (Tan et al., 2020). This has resulted in a paradox whereby some TGD community members, particularly those situated in more privileged social contexts, report experiencing research participation fatigue, while TGD populations more generally continue to be affected by considerable gaps in health scholarship about their experiences, needs, and outcomes (Ashley, 2021; Bauer et al., 2019; Vincent, 2018).

In response, TGD community members have mobilized to champion participatory and other community-engaged research. These collaborative efforts were first visible on an international scale during the AIDS crisis of the 1980s with activists identifying and disseminating knowledge often obscured in mainstream epidemiological studies of this era, including insights on the lives of trans women (Namaste, 2009). This work contributed to greater recognition of the unique positionality of trans women in epidemiological studies and supported the argument that community members not only *can* but *should* be involved in research about themselves (Billard et al., 2022; Namaste, 2009).

4.2 Critical Participatory Action Research

Participatory action research (PAR) is generally described as an approach that involves partnering with community members to engage in action-oriented research that meets the needs of the community (Baum et al., 2006; Kemmis et al., 2014; Kidd & Kral, 2005). Participatory action research, as the name would suggest, is a combination of participatory research and action research. Participatory research posits that research participants can do research for themselves, with academic researchers serving as facilitators (Kemmis et al., 2014). In participatory health research, participants offer an insider perspective, including access to the ‘language’ and needs of the community (Kemmis et al., 2014). These insights offer an authentic view of their lived experience and the opportunity to co-create health interventions that are less prescriptive and more conducive to the community's realities.

Various forms of action research exist reflecting the many fields in which it is applied, including nursing, Indigenous scholarship, education, and agriculture (Kemmis et al., 2014). Despite these differences, a common goal can be inferred from the action research literature: to facilitate tangible improvements or to generate positive change (Kemmis et al., 2014). Action research is often described as being an inherently participatory form of research or even as synonymous with PAR (Kemmis et al., 2014; Melrose, 2001). However, the level of participation in action research reflects varying degrees of community consultation, rather than true collaboration, which is central to PAR.

PAR is rooted in both critical and constructivist paradigms and, therefore, decries objectivity in research as being an impossible and undesirable goal, though the rationale for this differs between paradigms (Baum et al., 2006; Kemmis et al., 2014). Researchers who situate themselves within a constructivist paradigm adopt a relativist ontology, meaning that reality is considered a dynamic concept that is context-dependent and subjective (Guba & Lincoln, 1989). The researcher is, therefore, considered part of knowledge creation, and the data collected are considered richer due to the trusting and respectful relationships built with the participants (Guba & Lincoln, 1989). In contrast, researchers who situate themselves within a critical theory paradigm adopt a critical realist ontology, wherein a socially constructed 'reality' based on pervasive societal norms can be apprehended (Guba & Lincoln, 2005). Critical researchers adopt a transactional and subjectivist epistemological stance. This often means they are guided by the premise that what can be known is inextricably influenced by the researcher and the researcher's relationship to the participants and/or the subject of the research (Guba & Lincoln, 2005).

Researchers who engage in critical participatory action research (CPAR), meaning PAR that is situated within the critical paradigm, recognize and value individuals as social beings (McTaggart, 1991). Therefore, to generate meaningful change in a community, the interrelated social forces of power and oppression at play in society must be unpacked and their influence on the research problem understood. CPAR presents an opportunity to not only challenge traditional approaches to research (which is typical of all PAR), but also to generate emancipatory knowledge that contributes to countering oppressive social norms and addressing inequities. *Emancipatory knowledge* refers to the ideas generated through the examination, identification, awareness, and reduction/elimination of inequities created by social norms and upheld by social institutions (Chinn et al., 2011). By extension, *emancipatory research* refers to knowledge creation that benefits those affected.

CPAR studies uphold the following central tenets: authentic partnership, collaborative decision-making, valuing experiential knowledge, and research that challenges traditional hierarchies to create a process and outcomes that are mutually beneficial and empowering (Baum et al., 2006; Frost et al., 2019; Kemmis et al., 2014; Wagaman, 2015). Each of these interrelated tenets is particularly desirable when working with groups who experience marginalization and related health inequities (Baum et al., 2006), including TGD people. *Authentic partnership* refers to a collaborative and iterative process of data collection, reflection, and action that is meant to blur the line between the researcher and the 'researched' (Baum et al., 2006). Further, it requires that participants have ownership of the knowledge created, which includes how data are collected, analyzed, and disseminated (Frost et al., 2019). Authentic partnership involves *collaborative decision-making* with affected communities at every level of the research, beginning with the direction of the project through to dissemination and the action items (Baum et al., 2006; McTaggart, 1991). Enacting collaborative decision-making is often described as a spiral of planning, acting and observing, and reflecting that repeats itself (McTaggart, 1991). For academic team members, this process must be combined with an openness and willingness to be wrong, thereby recognizing and prioritizing the *value of experiential knowledge* (Kemmis et al., 2014).

CPAR produces three types of knowledge: knowledge developed by the community members, by the group, and by the academic team (McTaggart, 1991). These types of knowledge are interrelated, but the knowledge of the community members must be privileged. In a CPAR study by Frost et al. (2019) and LGBTQ and gender non-conforming youth, for example, the academic authors credit the lived experiences of the youth participants as being imperative to developing research questions that captured the complexity of economic precarity experienced by this population. The group met regularly over several months to co-create a survey that addressed core issues as determined by the youth partners (Frost et al., 2019). Without these insights, the academic partners report that they would have overlooked key elements of this phenomenon, thus limiting the benefits of any interventions developed based on their assessment (Frost et al., 2019). Specifically, the youth partners insisted that questions about political engagement, activism, and solidarities be added to the survey investigating the effects of experiences of economic precarity on health. Without these additional domains, the association in this population between activism and positive health outcomes would have continued to be overlooked (Frost et al., 2019).

In CPAR, both the outcomes and the process must be *mutually beneficial.* This requires transparency on behalf of the researcher and/or research team about their motivations, and how they are benefiting from the work (Vincent, 2018). This is particularly important when working with TGD people who may be apprehensive about engaging in health research that has historically served to pathologize them (Ashley, 2021; Vincent, 2018). Further, community partners must be fairly compensated for their intellectual and emotional labour and *empowered* throughout the research process (Vincent, 2018). Typical power imbalances between researchers and participants can be redressed in CPAR through bidirectional learning, sharing resources, and collaborative decision-making (Wallerstein & Duran, 2010).

A systematic review of 63 youth PAR studies in the United States reported five types of commonly reported beneficial outcomes for youth: agency and leadership outcomes (such as increased civic engagement and/or self-determination), academic or career outcomes (such as improved time management and/or writing skills), social outcomes (such as greater community attachment and/or belonging), interpersonal outcomes (such as enhanced communication skills and conflict resolution), and cognitive outcomes (such as better problem-solving and decision-making) (Anyon et al., 2018). PAR projects with TGD youth have reported additional benefits, such as paid employment for community members, safer research environments, increased depth to the analysis, opportunities to counter reductive discourses of what it means to be trans, engagement in self-reflection and self-expression, and the creation of new queer counterpublics, or advocacy groups that oppose dominant societal norms (Asakura et al., 2020; Pullen Sansfaçon, 2018).

Ultimately, upholding authentic partnership, collaborative decision-making, and valuing experiential knowledge contributes to a beneficial and empowering sense of ownership over the work for community partners, again reflecting the interrelated nature of these values. These principles can successfully be applied using a variety of methodologies/methods, including ethnography, phenomenology, cross-sectional research, and survey research, among others (Baum et al., 2006; Frost et al., 2019; Wagaman & Sanchez, 2017). This suggests that a CPAR study is not defined by a series of steps or singular 'right way' to engage in the work. Instead, it is a flexible methodology defined and guided by its values. This flexibility allows researchers to operationalize CPAR pragmatically to address a variety of research questions and meet the needs of diverse populations (Pullen Sansfaçon et al., 2018; Strang et al., 2019). For example, in a study by Asakura and colleagues in Ontario, Canada, TGD youth were supported by a trans artist to engage in an art-based method wherein they created reimagined cultural representations of what it means to be trans in their chosen medium (2020). In an ongoing qualitative study in Quebec, Canada, Pullen Sansfaçon et al. are investigating the factors that influence the well-being of TGD youth using two rounds of interviews and concluding with focus groups (2018). Although these two studies use different approaches, they are methodologically consistent in that both projects involve partnering with community members to jointly decide on the direction(s) for the projects, thereby valuing the knowledge of the TGD youth partners. This again reinforces the idea that CPAR methodology is defined by adherence to a core set of values which can be applied to multiple methods, and even multimethod research.

4.3 Multimethod Research

Multimethod research design, or methodological pluralism, is most simply defined as the use of two or more methods to address a specific question more profoundly (Hunter & Brewer, 2015). Unlike its subset *mixed methods research* which focuses on combining quantitative and qualitative methods, multimethod research refers to the mixing of any combination of methods

(Hunter & Brewer, 2015). Recognizing that all methods have strengths and weaknesses, multimethod research offers an opportunity to capitalize on the strengths of multiple types of data collection and/or analysis based on their potential to generate knowledge that can address existing gaps (Hunter & Brewer, 2015). This type of research is gaining popularity in health fields as a means to evaluate complex interventions, explore multifaceted phenomena, and to challenge reductionist causational conclusions (Busetto et al., 2017; Hunter & Brewer, 2015). For example, *sociogenetic research*, research seeking links between genetic markers and social behaviours, such as educational attainment, is often informed by a multimethod perspective that challenges genetic determinism by highlighting the need for different types of data to understand the complex interplay of factors at the nexus of genetics and social context (Hunter & Brewer, 2015; Saey, 2013, Shea, 2009).

A multimethod design can either be planned prescriptively or can be approached using an *emergent design* (Busetto et al., 2017). Emergent designs are flexible and involve multiple *data strands*, or processes of data collection, analysis, and interpretation (Busetto et al., 2017), that can be combined in multiple ways. An *interactive emergent* design involves direct interactions between data strands, such as findings from one phase being used to inform the next (Busetto et al., 2017). These approaches are inherently pragmatic and prioritize theoretical and substantive 'fit' as drivers for determining the most appropriate methods, rather than the reverse (Hunter & Brewer, 2015). Of course, many non-multimethod researchers would also argue (pragmatically) that methods should fit the substantive issue(s) being studied. What distinguishes the pragmatism of multimethod design, however, is the perspective that singular methods, both qualitative and quantitative, can be overly restrictive and at odds with the pluralism needed to examine complex phenomena, particularly in applied disciplines (Hunter & Brewer, 2015). This flexible approach also aligns with the values of CPAR in that it allows the research team to design a study that truly fits the priorities of community partners, thereby upholding the values of authentic partnership and collaborative decision-making.

In health research, where a postpositivist biomedical quantitative tradition has clashed with critical qualitative scholarship, pragmatic approaches to methodology, such as multimethod design and community-based research rooted in critical theories such as intersectionality, have been identified as “essential to advancing the field of health disparities” (Hankivsky & Grace, 2016; Kelly, 2009, p.54). For example, in one Ontario-based study, researchers and community partners set out to identify the needs and research priorities of women living with HIV in a two-phase study that began with focus groups and was followed by a focused cross-sectional survey (Logie et al., 2012; 2013). Starting with the focus group was empowering for community members, provided important context, and ensured that the survey was relevant and meaningful. The survey allowed the researchers to identify relationships more clearly between intersecting forms of stigma and health outcomes. Together, the results of these two phases provided a clearer picture of the needs and priorities of community members than would have been gathered by either stage individually. This example clearly highlights how critically informed community-based multimethod research designs can successfully be applied to explore complex health phenomena (Hankivsky & Grace, 2016; Logie et al., 2012).

4.4 Thesis Design

An emergent multimethod CPAR design proved to be the most appropriate methodological approach for this project because it aligned with the theoretical framework, existing ethical standards for engagement in research with TGD people (Bauer et al., 2019), and the thesis objectives. The theoretical framework (outlined in further detail in Chapter 3) is informed, in part, by notions of erasure and intersectionality, which are epistemologically related to CPAR design and, by extension, to multimethod research (Hunter & Brewer, 2015; Perry, 2009). Erasure highlights the passive and active ways in which TGD people are rendered invisible in society and in societal institutions (Bauer et al., 2009). CPAR design can be taken up to account for and address erasure by amplifying the voices and valuing the experiential knowledge of community members through collaborative decision-making and authentic partnership (Baum et al., 2006; Frost et al., 2019; Kemmis et al., 2014; Wagaman, 2015). CPAR's critical lens and action-oriented values are also consistent with intersectionality, given the focus of intersectional scholarship on recognizing how multiple axes of oppression coalesce to shape the social contexts and lived experiences of marginalized people, and its pragmatic role in generating scholarship that potentiates resistance to systems of domination (Crenshaw, 1989; Collins, 2019; Van Herk et al., 2011). Both CPAR and intersectionality are recommended in the Canadian Professional Association for Transgender Health's Six Overarching Principles for Transgender Research and Seventeen Guiding Questions for Transgender Research (Bauer et al., 2019) for researchers engaging with TGD people, which further substantiates their compatibility with each other and with research involving TGD communities.

There exists an emerging mixed method body of work that reflects the pragmatic opportunities of intersectional research (Grace, 2014; Greene, 2007). This mixing of methods to arrive at a more nuanced answer to a research question reflects the way intersectional scholars understand the social world as a mixing of normative social forces (Grace, 2014; Collins, 2019). In our context, multimethod research allowed us to operationalize inquiry that can both account for the context of intersectional oppression, yet still remain loyal to the need for participatory and action-oriented design. Multimethod research, CPAR, intersectionality, and erasure allow for multiple forms of knowledge, a pragmatic critical approach to inquiry, and the amplification of marginalized community voices through methods they deem authentic. These common principles across both our theoretical and methodological frameworks can be usefully applied to research centering the converging perspectives of individuals navigating social structures that affect their health (Hankivsky & Grace, 2016), such as TGD people. Specifically in this thesis project, the tenets of a multimethod CPAR approach removed unnecessarily restrictive boundaries around a 'right' way to engage in research, contributing to meeting the objectives of the thesis (outlined in greater detail in Chapter 1).

The main objective of the first phase of this work was to collaborate with youth to co-create a research protocol that met the needs of their communities. Using a CPAR approach allowed for engagement without a predetermined agenda, thereby ensuring that the research question and the methods were not chosen prescriptively and allowing us to uphold the value of authentic partnership. Further, the multimethod approach allowed for creativity, which has proven to be attractive to youth participants who might otherwise find the research process dry (Goessling & Wager, 2021). The *action* component of CPAR was also needed so as to be consistent with the goals of action-oriented grassroots initiatives often seen in marginalized communities (Namaste, 2009). This allowed community partners to build on their existing mobilization skills, ensured the outcomes were relevant to community members, and upheld principles of mutual beneficence.

Ultimately, this doctoral work followed an emergent and interactive multimethod three-phase CPAR design (Busetto et al., 2017). Phase 1, the Foundational Phase, involved partnering with TGD youth through three online focus groups to create a collaborative research team and design a qualitative research study. Phase 2, the Study Phase, involved the launch of the research study exploring the experiences of TGD youth accessing and receiving care in emergency departments. Participants were invited to complete an extended demographics questionnaire (see Chapter 5) and to participate in a more in-depth exploration of their answers via online interview, online familial focus group, journaling, and/or an art-based approach of their choice (see Chapter 6). Phase 3, the Analysis Phase, involved thematic analysis of the results of Phase 2 with our collaborative research team using two online focus groups (see Chapter 6).

4.4.1. Sample

We recruited TGD youth as both research team members during Phase 1 and as participants in Phase 2. Recognizing that the terms ‘youth’ and ‘trans and gender diverse’ can be interpreted in multiple ways, we identified operational definitions for both. As there is no consensus on a definitive age range for youth (United Nations, n.d.), we based our age range on two significant Canadian studies in this field, the Trans PULSE Canada project, which defines youth statistically as ages 14-24 years (Navarro et al., 2021a), and the Canadian Trans Youth Health Survey, which defines youth statistically as 14-25 years (Veale et al., 2015; Taylor et al., 2020). Ultimately, we defined ‘youth’ as ages 14-25 to be most inclusive.

Given the rapidly evolving nature of trans language, we anticipated and adapted to changes in terminology throughout the thesis project (Lightfoot et al., 2021). For the initial proposal and recruitment material, we used the term ‘trans and nonbinary youth’ which aligned with our clinical practice(s) and literature at the time (Taylor et al., 2020). During our Phase 1 focus groups with our community partners, we decided to adapt our terminology in our recruitment materials to ‘trans, nonbinary, and Two-spirit youth’ so as to be more intentionally inclusive of Indigenous youth. Finally, during our Phase 3 analysis focus groups, we decided to again adapt our terminology to ‘trans and gender diverse youth’, which a) felt more inclusive given that we had multiple participants who identified outside of the prescribed categories that we had previously mentioned and b) aligned with current literature (Coleman et al., 2022). As such, for the purposes of this thesis, the term ‘trans and gender diverse’ is operationally defined as anyone who does not exclusively identify with their sex assigned at birth. This term is inclusive of people who both have and have not pursued medical, legal, and/or social transition, recognizing that however an individual chooses to affirm their gender is valid. This approach is consistent with reported TGD research participants’ preferences (Coleman et al., 2022; Samuels et al., 2018; Taylor et al., 2020).

Ultimately, any youth between the ages of 14 to 25, self-identifying as trans and/or gender diverse, able to provide informed consent, able to communicate in English or in French, and who accessed an emergency department in the last two years was eligible to participate. There are no specific rules for determining sample size in qualitative research (Polit & Beck, 2010). Research using focus groups, however, requires that the size of each group be large enough to generate discussion, but not so large that not everybody is able to participate. As per Jaysekara (2012), most authors suggest that optimal group size is between 5 and 10 people. As such, for our Phase 1 focus groups, we included six community partners, me, and an alternating supervisor for a total of eight people. As for the Phase 2 study, we aimed to include between 20-30 participants so as to do justice to the subject matter, but also be feasible within the timeframe and budget for a doctoral project. Ultimately, 28 participants completed the extended demographics questionnaire, of which 14 participants chose to engage with the qualitative portion – 11 via interview and 3 via journaling. Further, 3 participants who engaged via interview chose to also illustrate their experiences through an arts-based method.

4.4.2. Sampling strategy

Purposive sampling refers to a type of nonprobability sampling wherein specific study participants are intentionally selected for inclusion in a study (Coyne, 1997). For our study, we used principles from two forms of purposive sampling to guide our recruitment: snowball sampling and maximum variation sampling. *Snowball sampling* is a popular method in trans scholarship because it is an effective tool for accessing 'hard to reach populations' (Vincent, 2018). Researchers reach out to a few 'seed' participants who then recruit other members of the community, this second generation then recruits a third generation, etc. For our Phase 1 recruitment strategy, we partnered with a local nonbinary youth artist who we hired to create the art for the recruitment poster and who shared this poster on their social media. This 'second generation' became our focus groups and helped to recruit our 'third generation' which became our Phase 2 study participants. A significant limitation of this method is that 'seeds' are likely to recruit members of the community who share similar attributes with them, which in turn can result in a homogeneous sample (Erickson, 1979). To address this concern, we incorporated principles of maximum variation sampling.

In *maximum variation sampling,* the researcher identifies the categories of variation that they are seeking to maximize and target those people specifically for recruitment (Sandelowski, 1995). Throughout the recruitment process for the Phase 2 study, we observed that we were not reaching certain populations, specifically Two-spirit youth, younger youth, newcomer youth, and racial minority youth. Given the intersectional lens of this work, we chose to engage in more targeted recruitment by reaching out to organizations that serve these populations so that our included participants reflected as diverse a group as possible. As such, we reached out to organizations that serve Two-spirit youth (2-Spirit Collective, Two-Spirited People of Manitoba

Inc.), younger youth (PFLAG, Gender Creative Kids, Youth Services Bureau, LGBT Youth Line, Supporting Our Youth), newcomer youth (Mosaic BC, Rainbow Refugee, Sher Vancouver, Rainbow Railroad), and racial minority youth (Black Queer Youth Collective, Dany Ko). These organizations were identified through Google searches and contacted through the emails on their websites. Of the 15 organizations we reached out to, we heard back from seven. Of the seven, five shared our recruitment posters on social media and via their mailing lists. The two organizations that chose not to were kind enough to provide feedback that they would be happy to share any results that were relevant to the populations they serve. They could not, however, share the recruitment material since they had not been included in the development of the project. Further, one of the organizations that shared the recruitment material provided feedback that the compensation (25$CAD) was not enough for their population and that they expected a minimum of 100$CAD given the ongoing history of researchers profiting off of marginalized groups. Ultimately, we were able to expand the age range for the Study Phase participants (16-25), but the group remained predominantly nonbinary (n=17, 60.7%) and white/Caucasian (n=25, 89.2%).

4.4.3. Data Collection and Analysis

As is typical of participatory action research, there were multiple ways to approach our research question: *What are the experiences of trans and gender diverse youth accessing and receiving care in emergency departments?* (Burgess, 2006; Klocker, 2012; Felner, 2020). To uphold the central tenet of authentic partnership, decisions about data collection methods and analysis were made collaboratively with our community partners. Therefore, the outcomes of the decision-making process can be simultaneously considered both study results and study methods. As such, I have written the manuscript below to fully conceptualizing this process.

4.4.4. Ethics

Ethics approval was obtained from the University of Ottawa Health Sciences and Sciences Research Ethics Board (REB) for both the Phase 1 focus groups (H-04-21-6712) (Appendix B) and the Phase 2 study (H-10-21-7370) (Appendix C). Each participant was asked to read a form emailed to them outlining the potential risks of the project. These risks included emotional and psychological discomfort related to potentially discussing challenging experiences. Links to online and telephone resources for support were provided. Verbal consent was audio recorded. For the focus groups, there was the added risk of revealing sensitive and/or private experiences in front of their peers. There was also the risk that somebody might inauthentically represent themselves to gain access to a TGD space in order to be abusive; thankfully we did not encounter this. If that were to happen, the plan was to mute that person and remove them from the online focus group. For each focus group, a supervisor and I remained on the call for 30 minutes so that anyone experiencing distress could rejoin the call to debrief. We also provided an online survey for group members to provide feedback anonymously if they preferred. Neither option was accessed.

All participants were assigned a pseudonym known only to me and my supervisors, and all data (audio-recordings, transcripts, and any notes) were labeled with these IDs (Polit & Beck, 2010). Identifying information was separated from the data and saved in password protected files. The data will remain at this location for a period of five years, in accordance with the University of Ottawa's storage policy, at which point they will be deleted (Polit & Beck, 2010). Greater detail about the ethical considerations in the manuscript below.

4.4.5 Rigour

It can be challenging to find guidance about what is rigourous community-based research. There are some scholars and advocates who debate whether this term is meaningful in community-based research given that researchers in institutions, such as academia, may have more narrow views of what is considered valuable and valid research than those of their community partners (Kingsley & Chapman, 2013; McTaggart, 1991; Patterson et al., 2023). Conversely, some scholars argue that considerations of rigour are important to establish the validity of community-based research within institutions, such as academia, in order to increase opportunities for funding, advocacy, and knowledge translation (Kingsley & Chapman, 2013; Melrose, 2001).

In CPAR with TGD youth, employing criteria for validity, such as those described by Whittemore et al. (2001), offers a robust framework for ensuring the *credibility, authenticity, criticality, ethical integrity, and social relevance* of the research that aligns with the values of CPAR. *Credibility*, the extent to which the research findings represent an authentic portrayal of participants' experiences, is particularly important in research with TGD youth whose experiences are often marginalized and/or misrepresented. In this research project, credibility was enhanced by ensuring that TGD youth were integrated in the research process and the validation of the findings. Specifically, the community partners were engaged in analysis focus groups meaning that they were able to speak to the accuracy of the findings and their voices were continually centered in data interpretation.

Authenticity consists of ensuring that diverse voices within a community are adequately represented, thereby reducing the risk of overgeneralization and allowing for multiplicity. The theoretical framework that guided this work, described in detail in Chapter 3, allowed for individual variation and lowered the risk of reducing participant narratives to a single monolith. The recruitment strategy was also designed to recruit as diverse a group as possible – although there were limitations to the diversity of the group, described in greater detail in Chapter 8.

Criticality involves the critical examination of assumptions, biases, and power dynamics. This was addressed in several ways across the duration of this project. First, as a cis researcher, I engaged in a reflexive dialogue throughout the project, including keeping a journal documenting my thoughts and feelings and debriefed regularly with my supervisors so as to be held accountable. Second, during the analysis focus groups, I intentionally presented alternate interpretations of the data being reviewed to the community partners and invited them to also consider alternate explanations. Third, recognizing the inherent power dynamics related to academic status, age, and other intersections of privilege, we established an anonymous way for community partners to provide feedback and provided an option for familial focus groups in the qualitative portion of the study – see manuscript below for greater detail. Throughout the thesis project, we found that critical reflexivity aligned with the ethical commitments of CPAR, which seek to avoid exploitative research and foster genuine collaboration with communities.

Prioritizing *integrity* ensures that research practices are consistent, transparent, and ethically sound. This includes protecting the participants' and community partners' privacy, respecting their autonomy, and addressing potential risks of harm, such as re-traumatization or research fatigue. These priorities align well with the underpinning values of CPAR, such as ensuring the process is affirming and that community partners are not merely subjects of study but are respected as co-creators of knowledge. Integrity also requires that the research findings are presented in ways that do not perpetuate stigma but instead contribute to social justice and the well-being of TGD youth. As such, I was conscious to highlight the many contributions of the TGD partners to theory, methodology, and substantive knowledge – described in greater detail in Chapter 8 – and how the knowledge generated might be translated to improve health outcomes and healthcare experiences for TGD youth.

Ultimately, Whittemore et al.'s criteria support concepts that are key in CPAR, such as relevance and utility to the lives and priorities of community members (2001; McTaggart, 1991). In research with TGD youth, the research must go beyond theoretical contributions and strive to make tangible differences in the lives of participants, such as influencing policy and challenging harmful societal norms. Validity in this context is, therefore, tied to how well the research empowers participants, addresses their needs, and leads to meaningful social change. Incorporating these validity standards strengthens the ethical and methodological rigour of research with TGD youth, promoting a more just and accurate representation of their experiences.

4.5 Methods manuscript: Engaging in CPAR During the PhD

The following manuscript was prepared for submission in Qualitative Health Research.

Abstract

Critical participatory action research is gaining popularity in the health disciplines because of its empowering mandate to engage 'with' participants and not 'on' participants. Although appealing in principle to graduate students and their supervisors, the limited formal guidance about how to conduct these types of studies might cause hesitation. The objectives of this discussion article are to highlight the significant benefit to engaging in this collaborative work, address common concerns about participatory research during graduate studies, and provide strategies to navigate them using my doctoral study as an illustrative example. Ultimately, the benefits of critical participatory action research during graduate school can

outweigh the real and potential challenges. Not only can these projects be feasible, but they may even be advantageous during the PhD process.

Background

Community-based research methodologies, such as participatory action research, or PAR, are gaining popularity in health research because of their empowering mandate to engage 'with' participants and not 'on' participants (Baum et al., 2006; Felner, 2020). Although approaches can vary significantly, PAR is generally described as research that involves partnering with community members to engage in action-oriented processes that meet the needs of the community (Baum et al., 2006; Kemmis et al., 2014; Kidd & Kral, 2005). Critical participatory action research, or CPAR, falls under the PAR umbrella, and is simultaneously a methodology and epistemology that involves an explicitly critical orientation to the work (Fine & Torre, 2019). This approach inherently rejects the traditional premise of researchers as 'experts', and instead prioritizes the knowledge of community members (Baum et al., 2006; Kemmis et al., 2014). Further, CPAR calls into question the neutrality of knowledge on the basis that power influences knowledge construction (Baum et al., 2006; Kemmis et al., 2014). This is a particularly relevant consideration when working with groups who experience social marginalization and related health inequities, given the historical role of research and researchers in reinforcing relations of power that shape these social conditions (Baum et al., 2006).

CPAR involves a collaborative and iterative process of data collection, reflection, and action that is meant to renegotiate power imbalances between the researcher and the 'researched' to create a collaborative team (Baum et al., 2006). Researchers operationalize the central tenets of CPAR in heterogeneous ways (Baum et al., 2006; Frost et al., 2019; Wagaman & Sanchez, 2017), and while this flexibility contributes to research being more accessible, authentic, and collaborative, it can be intimidating to doctoral students and challenging for their supervisors. Students are often discouraged from pursuing CPAR because the research process is viewed as ‘messy’, difficult, and time-consuming (Burgess, 2006; Klocker, 2012). Further, some researchers question the value of this work unless there is consistent adherence to the principle that every step be conducted collaboratively, which may not be feasible within the confines of a graduate program (Klocker, 2012).

Despite the concerns outlined above, graduate students in health-related fields are increasingly using participatory research approaches for their studies (Felner, 2020; Lac & Fine, 2018). CPAR offers opportunity to challenge traditional approaches to health research and generate emancipatory knowledge that holds potential for countering existing norms and health inequities that negatively impact the lives of marginalized groups (Felner, 2020). Although appealing in principle to graduate students and their supervisors, the limited formal guidance about how to conduct CPAR studies and inherent messiness of the approach, might cause hesitation to engage in this work (Burgess, 2006; Felner, 2020). The purpose of this article is to describe how I used a CPAR approach in a doctoral study exploring the experiences of trans and gender diverse (TGD) youth accessing and receiving care in emergency departments. I explain the relevance of CPAR for the topic, outline the design and execution of the study, highlight the contributions of community partners to advancing scholarship, address common concerns about CPAR research during graduate studies, and provide mitigating strategies.

Relevance of CPAR for Research with Trans and Gender Diverse Youth

Dominant gender norms in North America continue to socially reinforce the notion that gender is fixed, binary (male or female), and based on one’s assigned sex at birth. This pervasive, normative assumption that people are *cisgender*, or identify exclusively with their sex assigned at birth, is known as *cisnormativity* (Bauer et al., 2009). TGD people are individuals who do not conform to this narrow definition of gender. The term ‘TGD’ includes both those who self-identify as *trans*, as well as those who do not situate themselves under this ‘umbrella’ term. TGD people are exposed to discrimination, stigma, harassment, and physical and sexual victimization on the basis of cisnormativity and – related – intersecting systems of oppression (Bauer et al., 2009). These risk factors contribute to the higher rates of poverty, HIV, substance use, mental illness, suicidality, barriers to care, and inequitable health outcomes among TGD people (Bauer et al., 2009). TGD youth also face age-related disparities that differentiate them from their adult counterparts, such as increased reliance on family, reduced access to gender-affirming care, peer-pressure, and lower employment rates (Veale et al., 2015). While common health inequities and experiences exist, TGD youth navigate a multiplicity of forces of power and oppression in relation to their variable social locations (de Vries, 2015; Wesp et al., 2019). For example, TGD youth who are also racialized and/or migrants face additional and intersecting disparities, such as disproportionate levels of homelessness and incarceration (Chih et al., 2020; Navarro et al., 2021b; Pullen Sansfaçon et al., 2018).

Health research reflects an enduring history of pathologizing, objectifying, and erasing gender variance, which contributes to existing gaps in scholarship and damaging policies (Bauer et al., 2019; Vincent, 2018). In response, TGD communities have mobilized to champion and advocate for community-engaged research approaches, such as CPAR, that prioritize community relevance, respect for community knowledge, and equity in partnership (Bauer et al., 2019; Namaste, 2009; Travers et al., 2013). Further, engaging in CPAR and its associated collective action is linked to positive health outcomes, including increased resilience, in studies of TGD youth (Frost et al., 2019; Wagaman, 2015). Ultimately, I decided that CPAR was the best approach for this topic because it prioritizes the lived experiences and expertise of TGD youth whose voices are largely missing from health research about this group. Below I describe the study design and how it was executed, highlight the contributions of community partners to advancing scholarship, and provide recommendations for graduate students and early career researchers engaging in CPAR.

Study Design and Execution

Framing the Study

This doctoral project was informed by the Canadian Professional Association for Transgender Health's (CPATH) Ethical Guidelines for Research Involving Transgender People & Communities (Bauer et al., 2019). Their recommendations include meaningfully engaging with communities, considering the role of power dynamics and marginalization throughout the research process, and enacting an intersectional approach. These recommendations are consistent with the CPAR values of authentic partnership, collaborative decision-making, experiential knowledge, and mutual beneficence (Baum et al., 2006; Frost et al., 2019; Kemmis et al., 2014; Wagaman, 2015). The goals for the project were to co-create a research protocol, to enact the research study, to analyze the results collaboratively, and to identify action items that could benefit TGD youth accessing and receiving care in emergency departments.

Partnering with Community Members

Early in the planning process for this study, to prioritize community engagement, I (doctoral candidate) sought connection with community stakeholders, including those with lived experience of the phenomenon of interest. I connected with and hired a local artist to develop recruitment materials who also volunteered to help with outreach and advertising the study. Through social media, the artist and I recruited six community members to engage with the study as community partners. I collaborated with members of this group across all aspects of the study, from design to dissemination.

Building Trust

A frequent critique of CPAR projects is that authentic partnership is not achieved due to the inherent power held by academic institutions and the researchers that are affiliated with them (Felner, 2020). This was a particular concern of mine especially when working with TGD youth who already navigate power imbalances related to their age and social norms pertaining to gender (Felner, 2020). As such, I prioritized community comfort and trust throughout the study process.

Preliminary Interviews.

A concrete action I took to build trust included hosting preliminary interviews for potential participants. These brief (15-20 minute) sessions provided an opportunity to build rapport, establish safety, answer questions about the project, and audio record verbal consent. During the preliminary interviews potential participants asked about the research team's motivation and the intersections of my identity as well as those of my two supervisors, citing previous negative experiences engaging in health research and validating my concerns about being 'outsider researchers'. Recognizing that differences in social location and related privileges could pose an obstacle for community partners, I engaged in self-disclosure (Wigginton & Setchell, 2016) related to gender identity, sexual orientation, age, and benefits received from the research process. With permission, I also shared the social locations of my supervisors to ensure that potential partners were aware that we do not share personal knowledge of the specific experience of TGD youth accessing emergency care (Wigginton & Setchell, 2016). These transparent disclosures were well-received.

Community Guidelines.

Several community partners who had previous research experience recommended creating community guidelines, or a set of rules to ensure a standard of behaviour and a safe environment. I felt that this was a concrete way to encourage respectful dialogue and participation. To develop the community guidelines, I first asked all community partners for suggestions individually, which we synthesized into nine preliminary ideas. These ideas were discussed as a group and the final set of community guidelines were agreed upon collectively (Figure 1).

Anonymous Feedback Option.

Several community partners requested an anonymous online survey as an option to provide feedback to me and my supervisors if people were not comfortable providing direct input. I created this survey and provided the option for anonymous voting. Ultimately, neither option was used because the group felt comfortable enough to articulate and resolve concerns, as well as make decisions through discussion and consensus.

Virtual Focus Groups

Community Guidelines

1. Please be respectful of privacy and confidentiality. Do not share another person's private story without their consent. Be careful not to "out" others.
2. Please use "I-statements" to avoid generalizing. Even though group members may share some similar experiences, your perspective is unique!
3. At the beginning of each focus group, we will go around introducing our name and pronouns.
4. When you are interested in sharing, please put your name in the chat so that we can keep track of who was first. It can be hard to keep track of the "hands up" option.
5. If sharing a potentially triggering story, please begin your story by announcing what you will be discussing in broad terms so that others can mute or step off the call if needed.
6. Please be respectful of other people's stories/comments. If you would like to comment on them, please ask for consent, eg. "May I comment on that?"
7. Sophie and either Hannah or Amanda will stay on the call for 30 minutes after the group is over so that anyone can re-join the call and debrief if needed.
8. Your comfort is a priority! If you need to take breaks off camera and/or prefer to engage in the session through the chat function instead of out loud, that's fine!

Figure 1. Community Guidelines.

Focus groups return the balance of power to the group (Jaysekara, 2012) and offer a space for community members to build connections and exchange knowledge (Pryor & Vickroy, 2019). As such, they were the most appropriate mechanism for participant engagement. Given the context of a global pandemic, I opted to use Microsoft Teams, a Voice over Internet Protocol (VoIP) application. This technology allowed for participants across Canada, including those in rural areas, to participate when face-to-face interaction was limited. Most importantly, however, youth who identify as belonging to one or more minority groups, whether based on gender, sexual orientation, or disability, describe online platforms as a preferred means of seeking community and opportunities for advocacy (Miller, 2017). These virtual settings offer safe spaces for youth to explore their identities and rehearse milestones, such as coming out or trialing new pronouns, before taking them offline (Miller, 2017).

Choosing a Study Design and Methods

To select our study design and methods, I held three study design focus groups, which were facilitated by myself and one of my two supervisors who alternated. To ensure that the research process was accessible to those without formal ties to academia, I presented a high-level summary of the significant gaps in existing scholarship and introduced key concepts using various YouTube links. The group members favoured a broad research question, which they described as more inclusive and more conducive to honouring the complexity of emergency department experiences. The research question ultimately agreed upon through consensus was: *What are the experiences of TGD youth accessing and receiving care in emergency departments in Canada?*

We then discussed the pros, cons, and feasibility of different data collection methods, and I presented some ideas about what might work given the research question. The community partners were more familiar with quantitative research, particularly questionnaires. Some expressed concerns that qualitative and art-based approaches would be considered more subjective, and thus, taken less seriously. Others felt that qualitative methods were advantageous in that they could empower participants to express themselves authentically and more persuasively. This idea was reflected in this community partner's statement:

> *I don't know if, like, throwing data at someone is going to change them. Maybe it's, like, the right mixture of data and personal stories. You know that feeling, like, getting to know someone through their story? Maybe they need to get to know a trans person to see their humanity.*

Ultimately, the priorities identified by the community partners were: 'some' numbers to cater to decision makers who would not be swayed by 'our stories' and for participants to be able to express themselves authentically. Through discussion, we (academic team and community partners) decided that our study would include an online questionnaire with the option to also participate in a qualitative study. Both the questionnaire and the interview guide for the qualitative component were developed through discussion with consensus. Community partners highlighted that the questionnaire needed to be relatively short (10-15 multiple choice or scale questions), simple, and user-friendly, and that participants would appreciate having the rationales for the inclusion of each question and the option to skip questions that they did not want to answer. We also decided that participants for the qualitative portion would be offered several options for data collection including interview, journaling, and/or art-based expression, so that they might engage in ways that felt authentic to them. One of our community partners also suggested friendship or ‘naturally occurring’ focus groups, wherein the group members are previously known to each other (Trevisan, 2021). This style of data collection is gaining popularity in research with children and youth, and with people of all ages with communication disabilities (Trevisan, 2021) and resonated with the group, so it was included.

Conducting Data Analysis

Participatory research approaches with youth often fail to include them in the analysis (Foster-Fishman et al., 2010). Recognizing the value of their experiential knowledge, I was grateful that the community partners wanted to be included in this phase, though I was conscious of rendering the process accessible and limiting unnecessary burden (Frost et al., 2019). We used thematic analysis as described by Miles and Huberman (1994), which is an iterative process performed concurrently with data collection, and data analysis was completed over three focus groups. Given the sheer volume of data to review, I, supported by my supervisors, completed the initial data reduction, cluster, and organization stages, paired the descriptive themes with quotes, and presented them to the community partners during a first analysis focus group. During the second analysis focus group, the community partners provided feedback about how the descriptive themes were organized and engaged in discussion about emerging themes at higher levels of abstraction. During the third analysis focus group, community partners identified recommendations, which were then organized to create a comprehensive, succinct set. These recommendations became the ‘action’ piece of the CPAR project. We also discussed strategies for dissemination and implementation online and in emergency departments.

Contributions of Community Partners to Advancing Scholarship

Enhancing informed consent and trust-building

Contributors to CPAR scholarship have, in the past, remarked on the importance of informed consent and trust-building in research with marginalized communities (Felner, 2020; Wigginton & Setchell, 2016). Our work corroborates the relevance of these two principles in research with TGD youth, specifically. Some of the ways in which these concepts surfaced were through self-disclosure of outsider status (Wigginton & Setchell, 2016) and offering a ‘safe space’ to provide anonymous feedback (Felner, 2020). To highlight a novel contribution of our work, in relation to building a rich informed consent process and creating conditions of trust, several participants described the relational importance of including a rationale for questionnaire items in studies involving TGD youth. Community partners explained that not understanding the motivation for a question caused them to feel suspicious or to stop engaging in past projects. This insight was vital and resulted in the inclusion of clear explanations for each section of our questionnaire. For example, at the outset of our demographic questions we added: “*We are interested in getting to know you better so that we can understand how identity plays a role in healthcare encounters and do justice to the variation in experiences within trans/nonbinary/Two-*

spirit youth communities." Our work expands on the existing CPAR literature by describing practical means of operationalizing principles of informed consent and trust-building. As one community partner stated: *"This is how you build layers of trust and consent at every single step and every single stage."*

Identifying Systems of Marginalization

I was not sure to what extent the community partners would be interested in engaging in the theoretical aspects of this work. I was pleased when they not only contributed their feedback, but also advanced my thinking about how intersections of power and privilege manifest in their experiences. While I had considered identity-related concepts such as gender, race/ethnicity, sexual orientation, age, and citizenship, the group advocated for a blank space for participants to share aspects of their identity that they felt were meaningful in this context. Considerations that they mentioned included normative assumptions about health and the perceived morality of health behaviours related to body size and invisible illnesses (such as chronic pain). This push to consider less well-known normative forces was omnipresent for the remainder of the project, strengthening both the analysis and the project overall. Most importantly, offering a space for youth to engage non-prescriptively in discussions about how they feel they are perceived resonated strongly with participants. Ultimately, our work substantiates the relevance of CPAR in identifying systems of oppression, as well as the importance of collaboration at both conceptual and practical levels of research design and execution (Kemmis et al., 2014; Fine & Torre, 2019). Further, our work adds to the CPAR scholarship by highlighting the potential of leveraging community knowledge to uncover relevant power relations not immediately apparent at the start of the research process (Ponic et al., 2010).

Revealing Issues of Epistemic (in)Justice

Issues of *epistemic injustice*, or the discrimination against a person or group's capacity as 'knowers' based on prejudices such as those pertaining to gender and younger age (Fricker, 2007), are often cited as the impetus for engaging in participatory research approaches (Godrie et al., 2020). By virtue of their age and gender, TGD youth are bombarded by messaging that they are 'too young to know' their own identities (George & Goguen, 2021). Being aware of this issue had a considerable influence on my decision to employ a CPAR approach. I was nevertheless surprised when the community partners suggested sending out plans for our study to professional organizations that engage in trans research and/or healthcare for their approval. They rationalized that having their visible support would lend credibility to the work. Further, during the preliminary interviews, some group members expressed that the outsider status of the academic team may also contribute to the work being perceived as more credible. This exemplified a response to *testimonial injustice*, a type of epistemic injustice wherein a person's word is not believed because of their identity (Baumtrog & Peach, 2019; Fricker, 2007).

Throughout the research process, the community partners continued to demonstrate adaptive responses to epistemic injustice in order to navigate the power structures of the academic world (Godrie et al., 2020) and be 'taken seriously' by privileged 'knowers'. I believe that our work contributes to the existing scholarship about epistemic injustice by revealing the extent to which traditional research norms and hierarchical beliefs about knowledge are internalized by TGD youth without explicit ties to academia. This represents an opportunity for both researchers and community members to reevaluate youth as 'knowers' (Baumtrog & Peach, 2019) and supports the use of CPAR practices to contribute to greater epistemic justice in empirical work involving youth (de Bie et al., 2019; Fine & Torre, 2019).

Recommendations for Graduate Students Engaging in CPAR

As a graduate student engaging in this CPAR study, I experienced several challenges when designing and executing my project. In the section below, I introduce some of these challenges and offer mitigating strategies that render CPAR more accessible to PhD students and early career researchers without a lot of research funding.

Challenge 1: Building Trust is an Ongoing Process

Issues of power surfaced during the second focus group when a new supervisor was introduced and challenged about her motivations as a cis researcher. This experience demonstrated the brief ruptures in trust that can occur when a new ‘outsider’ team member is introduced, as well as the extent to which TGD youth might be wary of the ongoing history of trans pathologization in health research. Upon reflection, I had assumed that the ‘in’ with the group established by other team members was transferable, and I failed to realize the importance of allowing the group to screen any ‘new’ cis member of the research team. Ultimately, we were able to regroup and continue productively because of the preexisting relationships that were built and the accountability that I accepted for the error. Researchers engaging in future projects, particularly those working with groups who have reasons to be mistrustful of health researchers, should not assume that acceptance of one member of the team is transferable. Further, this experience highlights the importance of treating trust as an ongoing process in CPAR projects (Felner, 2020).

Challenge 2: Navigating the PhD Timeframe Strategically

The chronology and timeframe of PhD research are cited as barriers to CPAR (Klocker, 2012). A central principle of CPAR is that the direction of the project must be defined collaboratively through a process of shared decision-making, rather than prescriptively determined by the academic team (McTaggart, 1991; Travers et al., 2013). However, prior to engaging with participants, a research proposal and ethics application need to be submitted and approved. To honour both the doctoral process and the principles of CPAR, I chose to submit a tentative proposal that consisted of a two-phase project describing potential research questions and approaches of interest based on the expertise of our team. However, I described our research as iterative and responsive to community feedback by design. Although the supervisory committee was supportive of this approach, recognizing that most PhD projects evolve over time, the research ethics board required two separate applications because concrete details were required for approval. The second ethics application delayed the study by two months. I had anticipated a lengthier approval process, however, and utilized the 'buffer' period to meet other requirements of the doctoral degree (in this case, completion of the comprehensive exams). Doctoral students engaging in CPAR may want to consider whether there are opportunities to engage with their coursework strategically to create similar buffers of time.

As described by Felner (2020), doctoral students risk imposing methodological constraints on their projects because of PhD timelines. I had similar concerns about the time needed to complete the 'action' items of the study. Ultimately, we realized that while it was important to identify the action pieces as part of the doctoral project, their completion could occur following completion of the PhD program. This approach, while strategic in facilitating timely completion, also launches a post-PhD program of research.

Finally, there are very few (if any) times in a post-PhD researcher's life when they will dedicate themselves to a single project for three years (Klocker, 2012). This can lead to varied levels of motivation, especially during 'dryer' tasks, such as interview data transcription. Two significantly motivating benefits of CPAR were a sense of responsibility to the community partners and to their communities, as well as their contagious, inspiring energy. Maintaining communication with our community partners throughout the process contributed to keeping the project on schedule.

Challenge 3: Ensuring Community Partners are Compensated

Literature about engaging in CPAR projects, and collaborative projects with marginalized people generally, reinforces the importance of ensuring a mutually beneficial research process, which includes compensating community partners for their valuable time and experiential expert knowledge (Bauer et al., 2019; Felner, 2020). One of the frequently cited challenges of CPAR, however, is that the research question and the methodology/methods are unknown at the beginning of the project, thus rendering grant applications more complicated and less likely to be funded (Felner, 2020). I was unsuccessful in securing external funding for this project and so self-funded the financial compensation. I am a registered nurse, so this was feasible though not ideal, and for many graduate students, this would pose a challenging barrier. Doctoral students engaging in CPAR studies might want to consider whether there are non-traditional options for fundraising that might be appropriate for their topic/population.

Challenge 4: Honouring a Collaborative Approach

Graduate students are often discouraged from CPAR based on critiques that these projects are not worthwhile unless every step is conducted collaboratively (Klocker, 2012). Throughout this process, I did my best to strike a balance between honouring this priority, while minimizing unnecessary burden. For example, I recognized that while other CPAR and community-based projects include community partners in the writing of the ethics application and the data collection (Pullen Sansfaçon et al., 2018; Travers et al., 2013), this did not prove to be appropriate for our project. I discussed the ethics process with community partners who expressed concerns about the make-up of ethics review boards and the enduring history of approved studies that have been harmful to TGD communities (Bauer et al., 2019). Ultimately, they viewed the ethics review process as a bureaucratic hoop that had to be ‘jumped through’ rather than a meaningful point of engagement for them. Further, we collaboratively decided against including the community partners in data collection (i.e. conducting interviews). The required time commitment was a barrier given the community partners’ employment and school obligations, and the lack of funding for the project made their involvement in data collection difficult to operationalize.

Our team decisions about the degree of involvement at each stage embodied the CPAR values of collaborative decision-making and authentic partnership (Baum et al., 2006; Frost et al., 2019; Kemmis et al., 2014), and throughout the process I checked in with our community partners regularly. The flexible and iterative approach to the research process proved to be acceptable to all involved, thereby demonstrating that authentic collaboration can still be achieved in CPAR without dogmatic, and potentially burdensome, adherence to community involvement at every stage. I would encourage other researchers to engage with their community partners to decide how to achieve this balance, rather than risk unnecessarily burdening them by adhering to a fixed ‘ideal’.

Conclusion

Though CPAR projects are often ‘messy’ and require a great deal of flexibility, openness, and critical reflection, they can be successfully executed as a doctoral project. I outlined our methods to provide much-needed tangible guidance for how community members can be meaningfully incorporated into a research team. I describe the contributions of the community partners to advancing CPAR scholarship, highlighting a significant benefit to engaging in this collaborative work, address common concerns about CPAR research during graduate studies, and provide strategies to navigate them based on our experience. Ultimately, the benefits far outweighed the real and potential challenges, and the CPAR project was feasible and even advantageous during my PhD process.

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Chapter 5: Experiences of Trans and Gender Diverse Youth Accessing Emergency Departments: Results of a Community-Designed Questionnaire

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This chapter consists of a manuscript in which I report the results of a community-designed questionnaire that represents the first phase of this two-phase multimethod doctoral thesis study. This manuscript was prepared for submission to the journal of Transgender Health.

Abstract

Purpose: The purpose of this exploratory study was to discover how TGD youth rate their care in emergency departments and which factors they perceive to affect their care.

Methods: This exploratory cross-sectional survey and online questionnaire was co-designed by a research team comprised of academic members and trans and nonbinary youth.

Results: Participants reported highly variable experiences in the emergency department ranging from 0 (very poor) to 8.5 out of 10 (excellent) with a mean of 4.3. Further, half (n=14, 50%) avoided seeking needed care out of concern for how they would be treated.

Conclusion: The results of this study suggest that there are a number of factors, such as the trans-competence of the provider, the patient's co-occurring positionality, and the type of chief complaint, that may contribute to the poor experiences of TGD youth and their subsequent emergency department avoidance. These findings provide preliminary insights into the experiences of TGD youth.

5.1 Introduction

Trans and gender diverse (TGD) people, those who do not completely and/or exclusively identify with their assigned sex at birth, regularly navigate manifestations of gender minority stress, such as discrimination and bullying (Meyer, 2003; Testa et al., 2015; Wittlin et al., 2023). TGD youth also face age-related disparities meaning that they are more likely to be misgendered and may be perceived as ‘too young’ to know themselves (Navarro et al., 2021; Taylor et al., 2020). These experiences contribute to disproportionate rates of mental illness and inequitable health outcomes (Wittlin et al., 2023). Despite increased health needs, TGD youth report avoiding healthcare due to negative experiences, such as misgendering[1], deadnaming[2], and/or encountering providers who lack sufficient knowledge to provide affirming care (Goulding et al., 2023). In fact, although most report having access to a primary care provider, almost half of TGD youth report unmet healthcare needs in the previous year (Navarro et al., 2021).

In Canada, despite publicly funded healthcare, emergency departments serve as unofficial ‘safety nets’ for marginalized people who experience barriers to healthcare, such as TGD people (Campbell et al., 2015). There is evidence to suggest, however, that up to 44% of TGD people avoid the emergency department due to their own negative experiences, the experiences of peers, and/or community narratives that describe the emergency department as unsafe for TGD people (Chisolm-Straker et al., 2017; Cicero & Black, 2016; Samuels et al., 2018). In a recent integrative review of the experiences of TGD patients accessing care in the emergency

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[1] Misgendering: Being addressed with incorrect pronouns or incongruent gendered honorifics.
[2] Deadnaming: Being addressed with a name not corresponding to one’s gender, typically one associated with a TGD person’s sex assigned at birth.

department, the authors identified inadequate provider knowledge, cisnormative systems (e.g. electronic medical records), and negative provider interactions (e.g. discriminatory use of language) as contributing to negative experiences (Muller et al., 2024). Of note, none of the included studies focused on the experiences of TGD youth, who may face different risks given their positionality.

Youth experience highly nuanced age-related considerations that may represent protective factors and barriers depending on the individual's situation. For example, youth are more likely to present to the emergency department with a parent. This could be beneficial since having an advocate present contributes to positive emergency department experiences (Chisolm-Straker et al., 2017). Conversely, this increased reliance on family could represent a barrier if the parent is not affirming or supportive of the youth's gender identity (Veale et al., 2015). Further, younger youth may experience barriers to their care due to a lack of *pediatric readiness*, or competence in pediatric care, which can manifest as not having the right size equipment or lack of familiarity with weight-based dosing for medications (Remick et al., 2018). Despite evidence that TGD youth report healthcare avoidance and experiences of discrimination in other healthcare settings and face age-related factors that differentiate from their adult counterparts, there is a critical gap in the literature about the experiences of TGD youth accessing and receiving care in the emergency department. The overall aim of this study, therefore, was to identify how TGD youth rate their emergency department experiences and which factors they perceive as affecting their care.

5.2 Methods

5.2.1 Study Design

This was an exploratory cross-sectional survey study using an online questionnaire developed in partnership with TGD youth as part of a larger critical participatory action research (CPAR) project. CPAR is a flexible methodology that prioritizes authentic partnership, collaborative decision-making, experiential knowledge, and mutual beneficence (Baum et al., 2016; Frost et al., 2019; Kemmis et al., 2014; Wagaman, 2015). These values served as both methodological guidelines and ethical imperatives throughout our process. Community partners were involved in development of the research question, decisions about theoretical underpinnings and methods, analysis, and dissemination.

5.2.2 Setting and Recruitment

The study took place in Ottawa, Canada, but was conducted online to be available to TGD youth across the country. Youth were eligible to participate if they were between the ages of 14-25 years old, able to provide informed consent, able to communicate in English or in French, and did not exclusively identify with their sex assigned at birth, which is consistent with other work in this field (Navarro et al., 2021; Veale et al., 2015; Taylor et al., 2020).

Participants were recruited via social media through the individual social media accounts of the research team and the accounts of relevant community organizations. Given the author-developed nature of the questionnaire and the exploratory nature of this project, no target sample size was set and instead, the survey was kept open for a period of five months.

5.2.3 Data collection

Digital recruitment posters included a QR code and a link to access the questionnaire.

The questionnaire was made available on SurveyMonkey, an online survey platform, between December 2021 and April 2022. The questionnaire captured participants' sociodemographic factors, as well as both quantitative and qualitative information about emergency department use. Two questions were drawn from the Trans PULSE Canada Survey with permission (G. Bauer, personal communication, September 9, 2021). (See Appendices J & K for the complete questionnaire.)

Based on priorities identified by youth partners, we developed strategies to ensure our data collection process was flexible, transparent, and consent based. Though important in all research involving human participants and/or collaborators, ensuring an ethical and equitable process is a particularly important focus for work involving communities who have experienced exploitative health research, such as TGD people (Bauer et al., 2019). Recognizing this, each section of the questionnaire was paired with a rationale for why the information was sought. Further, demographic questions did not require participants to align themselves with pre-defined categories. Instead, comment boxes were provided so that participants could report their social positions authentically. Finally, quantitative questions were paired with comment boxes so that participants were able to qualify their responses.

5.2.4 Data analysis

All quantitative data were analyzed using simple descriptive statistics, including range, mean, prevalence, and percentages. Qualitative data were analyzed using summative content analysis (Hsieh & Shannon, 2005) and paired with quantitative data to provide context and nuance to the results.

5.2.5 Ethics

Ethics approval was obtained from the University of Ottawa Health Sciences and Sciences Research Ethics Board (H-10-21-7370). A statement about implied consent was visible at the start of the questionnaire outlining that the decision to complete and submit the questionnaire would be taken as implied consent to participate in the study.

5.3 Results

5.3.1 Participant characteristics

Of the 28 participants who completed the online questionnaire, ages ranged from 16-25, with a mean of 21 years old (see Table 2). Most participants reported a nonbinary gender identity (n=17, 61%) and the use of they/them pronouns (n=21, 75%). Half reported a transmasculine gender identity (n=14, 50%), the use of he/him pronouns (n=13, 46%), and a queer sexual orientation (n=13, 46%). Most participants identified as white/Caucasian (n=25, 89%), and all were Canadian citizens (n=28, 100%). The level of education among participants corresponded with their reported age. Participants were asked to list any other aspects of their identity that influenced the way that they were treated; the most common responses were neurodivergence (n=6, 21%), 'passing' (n=5, 18%), being perceived as assigned female at birth (AFAB) (n=5, 18%), and having chronic health issues (n=4, 14%).

Table 2. Sociodemographic factors

Factor	***n=28, n (%)***
Age	Range 16-25 Mean 21
Gender	
Nonbinary	17 (61%)
Transmasculine spectrum	14 (50%)
Agender spectrum	3 (11%)
Transfeminine spectrum	3 (11%)
Genderfluid	2 (7%)
Pangender	1 (4%)
Pronouns	
They/them/ielle/iel	21 (75%)
He/him	13 (46%)

She/her/elle	3 (11%)
Xe/xer	1 (4%)
It	1 (4%)
Sexual orientation	
Queer	13 (46%)
Asexual/acespectrum	5 (18%)
Pansexual	5 (18%)
Bisexual	5 (18%)
Gay	4 (14%)
Lesbian	2 (7%)
Biromantic	1 (4%)
Aromantic	1 (4%)
Omnisexual/graysexual	1 (4%)
Race/ethnicity	
White/Caucasian	25 (89%)
Black	2 (7%)
Hispanic	1 (4%)
Canadian citizen	
Yes	28 (100%)
Highest level of education	
Some high school	6 (21%)
Completed high school	6 (21%)
Some post-secondary	10 (36%)
Completed university degree	6 (21%)
Self-reported positionality	
Neurodivergent/Autistic	6 (21%)
Passing	5 (18%)
Perceived as AFAB	5 (18%)
Chronic health issues	4 (14%)
Body type	4 (14%)
Not passing	3 (11%)
Mental health diagnosis	3 (11%)
Invisible disability	2 (7%)
Not legally/medically transitioned	2 (7%)
White	1 (4%)
Healthcare worker	1 (4%)
Coloured hair/piercing	1 (4%)
Visibly queer	1 (4%)
Visible disability	1 (4%)
Support dog handler	1 (4%)

5.3.2 Questionnaire results

The most common reason for visiting the emergency department reported by participants was mental health concerns (n=20, 74%), followed by chronic pain (n=6, 22%) and injuries (n=5, 19%) (see Table 2). Participants were most likely to visit the emergency department annually (39%), followed by 3-4 times per year (29%), and twice per year (25%). Most participants attended a general urban emergency department (n=23, 82%), and about half had accessed a mental health emergency department (n=16, 57%). Participants accessed emergency departments in the provinces of Ontario, British Columbia, Quebec, and Alberta, with most visiting emergency departments in Ottawa, Ontario (n=17, 61%), which was expected because of the location of the study.

5.3.2.1 Overall Rating. Participants rated their average emergency department experiences as a mean of 4.3 out of a highest possible score of 10, with a range of 0-8.5. Three participants chose to submit additional comments to explain how they had come to their overall rating, highlighting that their experiences were "*hit or miss"* (Participant 4) and *"like roulette"*(Participant 27) depending on individual providers or the particular ED: *"I think it's either totally fine/good (7-10) or totally shitty/disappointing (0-3), so maybe I'll say 5 to be right in the middle?"* (Participant 16).

5.3.2.2 ED Avoidance. Half of our sample (n=14, 50%) avoided the emergency department when they needed care because of concern about how they would be treated as a TGD person. Of them, eight chose to submit additional comments to qualify their responses. Participants described experiencing fear, worry, and mistrust associated with the emergency department, usually related to experiences of being misgendered: *"I am usually misgendered in these spaces because the name on my health card/gender in [the hospital] database does not match my true identity. This has happened even when I've indicated my chosen name and pronouns to hospital staff"* (Participant 8).

Of the 14 (50%) participants who went to the emergency department every time they needed to, four submitted additional comments to qualify their responses. One participant reported that they were still closeted the last time that they had sought emergency department care, three experienced anxiety and had concerns about their treatment but attended anyways, and two participants emphasized that other aspects of their identities were more influential on their choice to present (i.e. having a diagnosed anxiety disorder and having been assigned female at birth (AFAB).)

5.3.2.3 Having to Educate Providers. Most participants (n=18, 64%) reported that they had to educate their providers. Of them, 12 chose to qualify their responses. Some of the education described was administrative, such as explaining the discordance between legal name on documentation and chosen name. Most, however, reported having to provide education about minority gender identities, pronouns – particularly gender-neutral ones, and medical transitions, including the implications of hormone therapy, which was described as burdensome.

Of the nine participants who had not educated providers while accessing emergency department care, seven chose to add additional comments. All clarified that, despite the need for education, they had determined that it was not worth the effort. As one participant reported: *"It's too emotionally taxing, especially when I'm already trying to deal with a health problem, so I don't bother"* (Participant 3).

Table 3. Questionnaire responses

Questions	***n=28, n (%)***
Which of the following emergency department settings do you have experience interacting with?	
General urban emergency department	23 (82%)
Mental health emergency department	16 (57%)
Pediatric emergency department	5 (18%)
General rural emergency department	4 (14%)
In which cities/regions have you accessed and received emergency department care?	
Ontario	**19 (68%)**
Ottawa	17 (61%)
Toronto	2 (7%)
Waterloo	1 (4%)
Barrie	1 (4%)
Etobicoke	1 (4%)
Kingston	1 (4%)
London	1 (4%)
Oxford County	1 (4%)

Peterborough	1 (4%)
British Columbia	**6 (21%)**
Vancouver	3 (11%)
Ashcroft	1 (4%)
Kamloops	1 (4%)
Kelowna	1 (4%)
Surrey	1 (4%)
Quebec	**2 (7%)**
Montreal	2 (7%)
Alberta	**1 (4%)**
Edmonton	1 (4%)
In the last two years, approximately how many times have you been to the emergency department?	
Yearly	11 (39%)
Twice a year	7 (25%)
Every 3-4 months	8 (29%)
Monthly	2 (7%)
What are the most common reasons that you go to the emergency department?	
Mental health	20 (74%)
Acute illness	9 (32%)
Chronic pain	7 (25%)
Acute injuries	5 (19%)
Acute pain	4 (14%)
Physical symptoms of unknown etiology	3 (11%)
Neurological symptoms	3 (11%)
Trans-specific healthcare	2 (7%)
Follow-up visit	2 (7%)
Post-operative complications	1 (4%)
On average, how would you rate the service you receive in the emergency department on a scale of 0 to 10?	Range 0-8.5 Mean 4.3
How often do you feel like your concern is addressed after a visit to the emergency department?	
A lot of the time	2 (7%)
Some of the time	8 (30%)
A little of the time	13 (48%)
Never	4 (15%)
Have you ever avoided going to the emergency department when you needed care because you are trans/nonbinary/Two-spirit?	
Yes	14 (50%)
No	14 (50%)
Have you ever had to educate an emergency provider regarding your needs as a trans person?	
Yes, provided a lot of education	7 (26%)
Yes, provided some education	11 (41%)
Yes, provided a little education	0 (0%)
Never	9 (33%)

5.4 Discussion

5.4.1 Demographics

The gender identities most significantly represented in our data were nonbinary (n= (n=17, 61%) and transmasculine spectrum identities n=14 (50%). Only n=3 (11%) identified on the transfeminine spectrum. Our results are consistent with recent research highlighting that the majority of TGD youth are reporting identities outside of the binary construction of gender and that transfeminine spectrum identifying youth are significantly less represented in research (Taylor et al., 2020; The Trevor Project, 2019; Veale et al., 2015). Given the additional stigma of *transmisogyny*, the intersections of transphobia and misogyny as experienced by trans women, transfeminine spectrum youth may feel apprehensive or experience barriers to engaging in research (Serano, 2007; Veale et al., 2015). Research led by or collaborating with transfeminine spectrum youth is needed to identify ways to engage respectfully and safely to ensure that their perspectives are reflected in the emerging research about TGD youth.

5.4.2 Intersectionality

Participants reported on whether there were aspects of their identities that they believed influenced the care they received. Neurodivergence, mental health diagnosis/diagnoses, not ‘passing’, being perceived as female, and having chronic health issues were the most commonly reported aspects of identity that affected emergency department experiences (see ‘self-reported positionality’ in Table 2). These findings are reflective of developmental and gender norms, (trans) misogyny, and ableism, which have previously been identified in research with TGD youth as factors influencing well-being (Pullen Sansfaçon et al., 2018). For example, clinicians are often unprepared to care for TGD youth with co-occurring neurodivergence, which can result in delays to gender-affirming medical care (Strang et al., 2019). Further, the two most common reasons for emergency department presentation amongst our participants were mental health concerns and chronic pain, two chief complaints that are known to be poorly addressed in emergency department settings due to the complex nature of the conditions and the stigma with which they are associated (Hoge et al., 2022). A literature review by Hoge and colleagues (2022) reported that emergency departments are poorly equipped to support children and youth experiencing mental health challenges other than to intervene during acute psychiatric crises. Even then, appropriate resources are often not available. Further, the authors noted increased disparity in the quality of care received amongst youth belonging to 'special populations' including TGD youth, neurodivergent youth, youth with mental illness, and racial and ethnic minority youth. Ultimately, our findings suggest that TGD youth may be more likely to present to emergency departments for conditions that are heavily stigmatized, placing them at increased risk for experiences of compounded marginalization in healthcare settings.

5.4.3 ED avoidance

The rate of emergency department avoidance (50%) reported in our study is high relative to previously published rates: 20% (Navarro et al., 2021), 28% Thompson-Blum et al., 2021), 44% (Samuels et al., 2018). While this could be influenced by our small sample size, it might also reflect an age-related trend consistent with reports of avoidance of healthcare generally, but particularly for mental health reasons (Goulding et al., 2023). A national Canadian online survey by Navarro et al. found that 68% of younger youth (ages 14-18) had not accessed mental healthcare when needed in the last year (2021). The most common reasons for avoidance included hoping the problem would go away, feeling afraid of how they would be treated, and not wanting their parents to know. Our findings support the notion that emergency department avoidance is a phenomenon experienced by TGD youth and provides a foundation for needed qualitative exploration.

5.5 Takeaway for Healthcare Workers

The wide range of ratings for overall experience and the related comments indicate that individual providers are able to make an impact on the experiences of TGD youth. In particular, participants spoke to the burden of having to educate providers about minority gender identities, pronouns, and medical transitions and how these might affect their presenting concern. We noted that none of the participants were expecting emergency department providers to be experts in trans healthcare, but rather to have sought a baseline understanding of gender beyond a cisnormative definition and sufficient education to be able to treat TGD patients affirmingly and competently within the scope of emergency medicine. These results align with previous studies about the experiences of TGD adults accessing and receiving care in emergency departments (Chisolm-Straker et al., 2017, Cicero & Black, 2016) and contribute new insights into the experiences of youth. We hope that healthcare workers find these conclusions empowering and reflect upon how they might be able to enact trans-affirming care within their own practices.

5.6 Strengths and Limitations

This study is strengthened by its CPAR design and consent-based approach, which allowed for participants to engage in ways that felt authentic to them. By inviting our participants to describe their gender using a comment box, we were able to report our demographics more inclusively and more accurately. Further, this approach allows for the inevitable evolution of language as gender continues to be redefined socially and individually (Hughes et al., 2016). While this is particularly relevant in research with TGD youth, it could also be usefully applied more broadly to render a wider scope of health research more inclusive.

Although offering open-ended options for demographics is critiqued as creating more work for the researcher when coding the responses (Hughes et al., 2016), we found that most responses were easily categorized. The few outlier responses were reviewed and categorized following a brief discussion with our community partners. This simple additional step allowed us to prioritize inclusivity and specificity in our data and subsequent analysis. Given the small sample size and descriptive nature of our research question, this was feasible and appropriate.

This study is limited by its small sample size and the inability to recruit participants representing greater ethnic and racial heterogeneity. As such, its generalizability is limited. However, the results provide preliminary insights into an underexplored research area and met the priorities of the community partners.

5.7 Conclusions

In this exploratory cross-sectional survey study, TGD youth reported highly variable experiences in the emergency department with a low overall score of 4.3/10. Most concerningly, half of participants reported avoiding the emergency department despite needing care, which poses significant risk to their mental and physical health. The results of this study suggest that there are a number of factors that may contribute to the experiences of TGD youth in the emergency department, such as the trans-competence of the provider, the patient's positionality, and the type of chief complaint. These findings are consistent with existing literature about TGD adults and with the experiences of our youth partners, but also provide preliminary insights into the experiences of TGD youth. Further research is needed to understand how these factors, which can be understood as manifestations of dominant social norms, intersect to contribute to poor experiences for this vulnerable population.

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Chapter 6: Experiences of Trans and Gender Diverse Youth Accessing Emergency Departments: Results and Recommendations from a Participatory Action Research Qualitative Study

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This chapter consists of a manuscript in which I report the results of a community-designed qualitative study that represents the second phase of this two-phase multimethod doctoral thesis project. This manuscript was prepared for submission to the International Journal of Nursing Studies.

Abstract

Background: Although emergency departments serve as ‘safety nets’ for the medically underserved, emerging research indicates that certain minority groups, including trans and gender diverse people, report challenges having their needs met in this setting.

Objective: The objective of this study was to explore the experiences of trans and gender diverse youth accessing and receiving care in emergency departments.

Methods: This was a qualitative study using a critical participatory action research (CPAR) methodology co-designed and executed in partnership with TGD youth. The theoretical underpinnings for the study included the Gender Minority Stress Framework, erasure, and intersectionality. Data collection was completed via interview, journaling, and art-based approach. Data analysis was completed during focus groups using thematic analysis.

Results: Participants reported feeling that they were not trusted by healthcare providers to know themselves or their health needs. In response, participants reported employing adaptive strategies to conceal stigmatized attributes and promote those that align more closely to social norms.

6.1 Introduction

Trans and gender diverse (TGD) youth, those who do not completely and/or exclusively identify with their assigned sex at birth, experience inequitable health outcomes, such as higher rates of suicidality and mental health issues, when compared to both same age cisgender peers and TGD adults (Navarro et al., 2021a). When considered through the lens of the Gender Minority Stress Framework, these disparities are understood as being related to external (distal) and internal (proximal) stigma-based stressors affecting TGD people, as well as the *erasure*, or intentional invisibility, of TGD people in health education, training, and policies (Bauer et al., 2009; Namaste, 2000; Tan et al., 2020; Testa et al., 2015). Although most (77%) Canadian TGD youth report having access to a primary care provider, almost half (47%) report unmet healthcare needs based on various barriers to access, including discomfort discussing trans issues with doctors (Navarro et al., 2021a). Further, TGD youth who are affected by intersecting systems of oppression, including racism, face additional barriers to healthcare access and poorer health outcomes (Navarro et al., 2021b; Pullen Sansfaçon et al., 2018).

Researchers, activists, and community members have called for greater focus on the health experiences of TGD youth using an *intersectional lens* (Bauer et al., 2019; Navarro et al., 2021a; Pullen Sansfaçon et al., 2018). Intersectionality began as a response to the limitations of single axis analyses of oppression, shifting our view of socially structured categories of identity, such as gender, sexuality, race and 'ableness' (Morriss, 2011) from separate entities to interrelated social forces of power and oppression (Crenshaw, 1989; Van Herk et al., 2011). Intersectionality has since evolved into an action-oriented theoretical framework used to guide critical inquiry and praxis (Collins, 2019).

The emergency department often serves as the first point of healthcare contact for youth beyond their pediatrician and has traditionally served as a ‘safety net’ for the medically underserved (Lillemoe et al., 2023; Willging et al., 2019). This clinical environment, however, is complex, dynamic, and highly stressful, which impedes providers’ abilities to engage in empathetic treatment and caring communication (Milton et al., 2023). For TGD people who navigate manifestations of gender minority stress and erasure in healthcare settings at baseline, this environment contributes to reported rates of emergency department avoidance as high as 44% (Navarro et al., 2021a; Samuels et al., 2018; Thompson-Blum et al., 2021). While there is no established ‘baseline’ rate of emergency department avoidance for the broader population, this number remains noteworthy without a comparator because of the health inequities and increased risk of poor health outcomes reported in studies of TGD patients. Given the additional age-related considerations relevant to TGD youth, it is concerning that their perspectives are grossly missing from the scholarship, reflecting a significant gap in our understanding about their experiences and what they perceive to be their healthcare needs. The overall aim of this study, therefore, was to fill this knowledge gap by exploring the experiences of TGD youth accessing and receiving care in emergency departments using a theoretical framework informed by the Gender Minority Stress Framework, erasure, and intersectionality.

6.2 Methods

6.2.1 Situating the Research Team

Sophie Lightfoot is a settler, cis, queer, white woman of British descent who immigrated to the lands of the Kanien’kehá:ka Nation, Tiohtià:ke (Montréal) with her family of origin as a child. She currently lives in, studies, and works on the unceded lands of the Anishinaabe Algonquin Nation, Ottawa. Sophie’s experiences as a Registered Nurse working in both community and pediatric emergency care have highlighted how disparities in health equity manifest across health settings and have inspired her doctoral work.

Hannah Kia is a settler trans woman of Iranian descent who immigrated to the lands of Musqueam, Squamish, and Tsleil-Waututh (colonially known as Vancouver) with her family of origin in the late 1990s. Having trained and practiced as a social worker in healthcare before beginning her academic career, Hannah accounts for the role of both lived and professional experience in shaping her assumptions and understanding of what some TGD people may encounter as they engage with healthcare, social services, and other systems of care.

Amanda Vandyk is a cis white woman of European descent living on unceded Anishinabe Algonquin territory. She is a Registered Nurse with practice experience in hospital emergency departments and now works as an Associate Professor in the School of Nursing at the University of Ottawa. Her research is rooted in her clinical experiences, reflective of a pragmatic approach, and aimed at answering questions that are meaningful for health-care providers, patients, and families.

6.2.2 Study Design

This was a qualitative study using a critical participatory action research (CPAR) methodology co-designed and executed in partnership with TGD youth. CPAR is a flexible methodology that prioritizes authentic partnership, collaborative decision-making, experiential knowledge, and mutual beneficence (Baum et al., 2006; Frost et al., 2019; Kemmis et al., 2014; Wagaman, 2015). These values served as both methodological guidelines and ethical imperatives throughout the project.

6.2.3 Setting, Recruitment, and Participant Characteristics

The study took place in Ottawa, Canada, but was conducted online to be available to TGD youth across the country. Youth were eligible to participate if they were between the ages of 14-25 years old, able to provide informed consent, communicate in English or in French, and did not exclusively identify with their sex assigned at birth, which is consistent with other work in this field (Navarro et al., 2021a; Veale et al., 2015; Taylor et al., 2020).

Participants were recruited via social media between December 2021 and April 2022 through the individual accounts of the research team and the accounts of community organizations with permission. Digital recruitment posters included a QR code and a link to a survey on the online platform Survey Monkey, which included consent information. Ultimately, fourteen TGD youth participated in this study. They ranged in age from 18 to 25, with a mean age of 22 years old. Most identified as nonbinary (n=10, 71%) and/or as transmasculine (n=8, 57%), used they/them pronouns (n=11, 76%), and reported queer sexual orientation (n=8, 57%), white ethnoracial identity (n=12, 86%), and having completed some university (n=11, 79%).

6.2.4 Data collection

A semi-structured interview guide was created in collaboration with our TGD youth community partners. The guide included five open ended questions, such as: "*How do you think your gender identity/expression influences your emergency department experiences?*" The same guide was used with all participants; however, they had the option to choose to engage via interview, familiar focus group[3], journaling, and/or art-based response. Of the 14 total

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[3] Familial focus groups or 'naturally occurring' focus groups are a variation of focus groups wherein the participants have a preexisting relationship with each other (Trevisan, 2021).

participants, 11 chose to do a virtual interview and three chose to submit their responses electronically in writing. Further, three of the interviewed participants also provided art submissions - one poem, one song, and one piece of visual calligraphy art. These were not analyzed separately, but rather provided further depth to the interviews and journal entries, as well as an opportunity for authentic self-expression. Specifically, participants were asked to explain their choice of art form, its personal significance, and the message it was meant to convey. This occurred at the start of the interview and served as both an icebreaker and a catalyst for conversation. For participants who chose to engage in an interview, these were conducted online via Microsoft Teams, a Voice over Internet Protocol (VoIP) application. Participants had the option of having a trans member of the research team join the interview, which two participants chose to do. Interviews ranged from half an hour to two and a half hours, with an average length of 84 minutes.

6.2.5 Data Analysis

Both the interview and journal data were analysed via thematic analysis as described by Braun and Clarke (2008; Braun et al., 2022; Clarke & Braun, 2017). This process was iterative and performed concurrently with data collection. Following verbatim transcription of the first three audio-recorded interviews and removal of any identifiers (Polit & Beck, 2010), the primary investigator (PI) and two other team members (HK and AV) completed the initial data reduction, clustering, and organization stages to arrive at descriptive themes. These themes were paired with quotes and presented to community partners during the first of three analysis focus groups. During the second and third analysis focus group, the community partners provided feedback about how the descriptive themes were organized and engaged in discussion about emerging themes at higher levels of abstraction.

The analysis was also guided by a critical, pragmatic paradigmatic stance and a theoretical framework that combines gender minority stress, erasure, and intersectionality. By applying the gender minority stress framework and erasure, we considered how social norms about gender might impact the healthcare experiences of our TGD participants and identified patterns of meaning across experiences. The additional lens of intersectionality, however, prevented us from reducing the participants' experiences to gendered stereotypes and allowed us to acknowledge their individual and multifaceted social positions.

6.3 Results

The participants described feeling like their capacity as a 'knower' of themselves and their health needs was discounted based on intersections of TGD-specific stigma and age. They reported being dismissed, talked over, and not being considered an equal partner in the care team. Ultimately, they felt that their credibility as historians and decision-makers was not trusted or valued by healthcare professionals. These experiences of lacking believability, though common across participants, varied based on intersectional factors, such as diagnosis/diagnoses, neurodivergence, and race. To compensate, participants described adaptive strategies they engaged to be perceived as more acceptable. While functional, these strategies often resulted in unintended consequences.

6.3.1. TGD youth not feeling trusted as 'knowers'

6.3.1.1 Intersections of TGD-stigma and age. Normative assumptions about age were prominently reflected in our participants' narratives. They described being perceived as 'too young' to make their own decisions about their identity, gender-affirmation, and health. They reported not being taken seriously, being discouraged from asking questions about their care, and feeling like they were excluded from decision-making, in part, because of their age.

> *It occurred to me that most youth don't know they are allowed to say no to medical professionals, and even if they do, they are probably too intimidated or scared to actually say no. [...] I think this is tied to practitioners' perceptions of youth as incompetent and lacking independence/autonomy. [They] don't think we are informed or capable enough to make treatment decisions for ourselves. - J3*

In situations where the patient's parent was in the room, healthcare providers often addressed the parents instead. According to the participants there were different challenges depending on the youth/parent dynamic. For participants who reported more difficult relationships with their parents, having providers defer to their non-affirming parents was a significant barrier to care. For example, participants described being unable to advocate for themselves out of concern for how their parent would react, meaning that they were uncomfortable and misgendered. *"I've been in that type of situation, [...] where I've had to lie because my parents were there."- P8.* Participants who were 'out' to their parents and reported a positive dynamic were grateful for their parents' support and felt that they were less likely to be misgendered while in their presence. Yet, they were frustrated that their parents were seen as more credible authorities in conversations about their own health. "*Yeah, it's really complicated because my parents are awesome, like, my biggest supporters by far, which is amazing. But at the same time, having them there gives that option for medical professionals to infantilize you more." – P7.*

Participants also described how TGD-related stigma and mistrust contributed significantly to their perceived credibility. For transfeminine and nonbinary youth assigned male at birth, particularly those using neopronouns and/or who had an 'X' designation on their documentation, or had not yet updated their documentation, their identities and/or presentations were frequently questioned and undermined by healthcare workers.

> *A big barrier for sure is for folks that don't have their names and or gender changed on their ID. It's a big barrier especially if you don't look like the assigned gender on your ID. You're going to get met with a lot of questions, a lot of, probably, transphobia, especially if you're a trans woman or someone who's nonbinary born male, because they do often get a lot more transphobia than, like people like me that are [assigned female at birth]. - P9*

Conversely, there appeared to be a mediating affect for transmasculine, ‘passing’, youth who were undergoing, or who had undergone, a medical transition. These youth described themselves - and were described by other participants - as being more easily understood by healthcare providers because of the perception that they were able to adhere more closely to social norms about gender.

> *So yeah, I feel like prior to getting on the medical transition pathway, [my gender identity] was dismissed. It was like "it doesn't matter". Or if I mentioned my pronouns, it was like "oh we'll deal with that later. Whatever." Whereas after, when I'd started on testosterone – even before it had caused any overt changes, if a doctor asked what kind of medications I'm on and I said I do injections weekly of testosterone, suddenly it was like "ok, so you <u>are</u> trans." It was almost like, as long as I had this medical transition piece then it was more validly accepted and I was <u>actually</u> transgender and they would <u>actually</u> have to take that into consideration. Whereas, if I were to leave that out or before I started, it was like "oh well, that's just in your head," which is a very very toxic narrative to be presenting because a medical transition is something that I have pursued in some ways, but it is absolutely not mandatory in any way." – P1*

6.3.1.2. Variability based on intersectional factors. Although there were common patterns of experience across participants, there was also individual variation related to intersectional factors, such as race, sex assigned at birth, mental health diagnosis, neurodivergence, amongst others. These factors were noted by participants to intersect and compound experiences of marginalization. Below, one participant describes being frequently accused of deception based on stigma related to their age, gender, mental health, and neurodivergence.

> *I feel like, being young, being trans, [having borderline personality disorder], and being autistic, I've never really had the ability to, like, have a say in, like, what's going on or be listened to […] A psychiatrist [prescribed] me too much medication and I didn't wake up the next day. My boss found me. And the nurse at triage was like, "you're lying. You did this on purpose." […] And it's like, it doesn't make you want to go back to the hospital when you need to. - P9*

Many participants reported that they were diagnosed with a health condition that they felt affected their trustworthiness with healthcare workers, such as psychiatric conditions (n=10, 71%), neurodivergence/autism (n=6, 29%), chronic physical illnesses (n=5, 36%), and/or conditions related to 'female' reproductive health (e.g. Endometriosis) (n=3, 21%). Those with a psychiatric diagnosis explained how, by virtue of their psychiatric past, healthcare providers would dismiss physical symptoms as anxiety or somatization without sufficient workup. They were made to feel like all physical symptoms were "*in my head" (P2)* or like their worsening mental health was inevitable.

> *I swear to God I could come with, like, my arm bitten off by a shark and they'd be like "Are you sure this isn't a panic attack?" It's almost as though medical professionals*

> *don't think that people who have mental health issues know themselves. Like, they're unreliable narrators of their own condition. – P4*
>
> *I think one of the biggest things is probably the anxiety disorder because when you faint, they're like, oh, you're stressed and just write it off completely. And it's like it's not normal for, like, a healthy 20-year-old to be, like, fainting all the time. And like if they had done proper tests, they would have figured out that a lot of it had to do with my diet and the fact that I wasn't digesting food properly. P2*

Further, psychiatric diagnostic stigma appeared to intersect with transphobia, further compromising participants' apparent believability as patients. For the participants with chronic physical illnesses, they felt dismissed and/or infantilized because of intersectional assumptions related to age and ability; they 'should' be healthy. Those who required mobility aids and/or service animals were often questioned about whether they actually needed them.

> *I mean like, they wanna take you less seriously because you're not there independently, like I'm there with my [service] dog and my partner. And I need them there but having them there makes people think that I'm less competent, I think. I think there's just like, an infantilization of disabled people generally, but then like, it's worse cause you're trans and you're young. -P7*

Participants with chronic pain explained how they adapted to the chronicity of their symptoms, meaning they believe they had less visible pain markers and, thus, were perceived as less trustworthy. Participants described feeling deprioritized and made to wait longer than others because their pain was less apparent. *"Since most for my emergency room visits have to do with flare-ups and pain, I am often seen among the last patients" (J1).* Overall, participants reported that their chronic illness symptoms were rarely fully investigated.

> *And it's actually interesting, because it's to the point where like, if I'm having something that is the symptoms of a chronic pain flare-up, I'll go in and sometimes I'll start by trying to explain that it's chronic, but it's like that will almost always get it dismissed more quickly. P1*

Participants who were assigned female at birth reported how intersecting biases related to sex, gender, and diagnostic stigma contributed to their reproductive health concerns not being taken seriously. A pointed example of this, was when two participants experienced debilitating abdominal pain, which was dismissed as 'period cramps' without sufficient workup or pain management. This was particularly distressing in the context of experiencing gender dysphoria, a sense of unease or distress related to incongruence between one's gender identity and sex assigned at birth (Coleman, 2022) because the participants described discussions about their menstrual cycles as *"triggering" (P4).*

> *I'm sure that there is a lot of research that has been done about the perception of women and health problems that women in particular experience and women's pain by researchers. I'm in sort of an odd place where I'm not a woman, but all of those things happened to me too. So. Trans men and trans masculine people follow this really weird intersection of... We are men. Some of us pass. Some of us may experience a modicum of privilege by virtue of passing as men. But aspects of my physiology are still associated with women and in the past that has led to discrepancies in the way that conditions that disproportionately affect you… What is known is that women or people with uteruses or estrogen-dominant people are under researched. They are not taken seriously. And I feel those things still affecting me when I'm perceived as a woman. – P4*

Finally, racialized participants discussed the effects of racism and how this further compromised their believability as patients and exacerbated experiences of dismissal based on diagnostic-, sex-, and gender-related stigma. Specifically, participants were fearful that health care providers would assume that they were lying or exaggerating their experiences of pain to gain access to narcotics based on racial stereotypes related to substance use.

> *Totally, ok so I feel like, for, like, a lot of people who are assigned female at birth or whatever, but also with black folk, there's this kind of, like, oppressive kind of inclination that people are, like, either lying about their pain or exaggerating their pain. And like, you know, like their distress is not real or they should be able to tolerate better type thing. And so, you know, it was interesting 'cause, you know, I was in a lot of pain at the time at the hospital. And, I would say I have pretty high pain tolerance. I mean, I experienced pain chronically, generally, so like, it's just, like, a common experience for me. You know, like, I remember when the initial ER doctor was like doing the exam, I winced a little bit 'cause he was pressing on this abscess under my belly button. And he was like, "oh, does that hurt." And I was like, "yeah, it did." But you know, at that time, I was also being very mindful of being like, perceived as drug-seeking as a black person.– P6*

6.3.2. Performing 'acceptability' - Adaptive Strategies

6.3.2.1 Experience of performing acceptability. Participants described adaptive strategies they used both intentionally and subconsciously to modify their behaviour, presentation, and/or narrative when interacting with healthcare providers so as to appear more *"acceptable" (P4)*. Additionally, some participants who reported 'passing' in their authentic gender discussed concealing their trans identity in their interactions with healthcare providers to avoid experiencing stigma as a barrier to care.

> *I feel like I have this obligation when I'm dealing with medical professionals to act very calm, well-mannered, and well put together to be taken seriously, but at the same time, you're in like a 10 out of 10 amount of pain, so it's finding this, like, really difficult balance. And yeah, I've always felt like that, like, facade needs to be there when I'm interacting medical professionals because like, if you go in and you're emotional, you're that emotional trans person. - P10*

Participants reported being aware that their physical appearance affected the care that they received. When they were perceived as cis and male, participants reported being treated more respectfully, meaning that their concerns were more likely to be listened to and addressed appropriately.

> *I'm nonbinary. I present in a multitude of different ways and people's perceptions of me change wildly depending on what I wear [...] so I have found that I am taken more seriously by medical professionals when I appear to be more masculine, when I act more masculine, and when I come on like the facade of a cis gay man, basically. Whereas if I am presenting more feminine or I am acting more emotional, I am taken like as a woman and I am not taking a seriously because of that. At the same time, neither is right because I'm nonbinary. So it's like, it's this constant battle where it's like I want to look how I look and look true to myself, but I know that if I look androgenous or feminine to someone, I'm not going to take taken as seriously as if I look masculine. – P10*

Further, participants described multiple narratives that they presented to healthcare professionals to explain away, or conceal, aspects of their identity that they feared would be perceived as less ‘acceptable’ and affect their care. Youth described being frequently outed by their medication lists. To compensate, youth would claim they had endocrinological conditions to explain away gender-affirming hormonal treatments or would claim they had neurological conditions to explain away psychiatric medications.

> *Like, one of the things that I’ve started doing that’s actually been working really well is just like, tell people I have a testosterone deficiency. And then because I’m legally male and they see testosterone there, it’s like “Oh yes, you are a cis boy with low testosterone.” And I find that I’ve been treated a lot more, like neutrally, I guess. P2*

In clinical contexts where there was no prior medical record, participants experiencing an exacerbation of their chronic physical illness reported that they would conceal the chronicity of their condition, instead presenting them as new. Youth reported that this was the only way to ensure that healthcare providers would investigate the new or worsening symptoms. A similar narrative was used by participants with mental health diagnoses to ensure support and investigation for new and/or worsening symptoms.

Participants also described being aware that there was an acceptable level of pain or distress that would result in the level of care that they needed. This was described as a delicate balance between showing enough distress to be taken seriously, but not so much that they were dismissed as exaggerating. Further, based on stigma related to their social locations, participants who were assigned female at birth, racialized, and/or diagnosed with a mental illness sensed that they were more likely to be perceived as embellishing and, thus, described underplaying the severity of their symptoms.

> *There is an aspect of feeling like I have to almost perform when I'm there. In terms of, I have to seem like I'm in an acceptable level of distress where I need help in order to be*

> *believed that there actually is something wrong. But if I seem too distressed then they write me of as hysterical. So there's this hyper vigilance about my own behavior and about my surroundings and the actions of, you know, medical staff, including doctors, nurses, imaging technicians, porters, even other patients at times. Most of the time it's not a restful or human experience. It's just awful. P4*

6.3.2.2 Unintended consequences of performing acceptability. While participants generally described their adaptive strategies as successful, they were also time consuming, stressful, and even physically painful. For example, participants who were assigned female at birth often reported wearing a binder to reduce the visibility of chest tissue. While this represented an important part of their gender affirmation in their day to day lives, the physical discomfort of wearing this restrictive garment was difficult to tolerate when dealing with other symptoms, such as pain or cardiac arrhythmias. ***"****To make sure to minimize any comments on my gender presentation/identity, I make sure to put a binder which itself can be difficult since it doesn't help with the pain." - J1*. Overall, participants who used this strategy determined that the physical sacrifice was worth the potential to navigate their ED experience without having to out themselves.

Another trade off of 'passing' was the feeling that their needs were not wholly met. For participants with chronic pain who described their exacerbations as new acute onsets, they described being aware that they were only receiving a temporary solution and felt anxious about reoccurrences. Those who chose and were able to conceal their trans identities described an internal conflict between the safety of invisibility and wanting to be seen.

> *So, it's like, cis-passing privilege does add ease in some ways, because I know they're not going to misgender me. They're not going to say my birth name, because they don't have*

> *that anymore. That is such a privilege, but it also means that they're not going to take the trans piece into consideration. This means that I'm just constantly reminding them and re-outing myself and trying to be like, this* <u>*is*</u> *something. Please take it into consideration. And I'm not necessarily being met with understanding. P1*

6.4 Discussion

To our knowledge, this is the first qualitative exploration of the experiences of TGD youth accessing and receiving care in the emergency department. We identified two central themes: 1) TGD youth not feeling trusted as 'knowers' and 2) TGD youth performing 'acceptability' to receive appropriate care. While we identified patterns of experience that were consistent across participant accounts, our theoretical framework allowed for nuance related to intersectional social location. Below, I discuss our findings as manifestations of epistemic injustice and rhetoric credibility, situate our findings within the Gender Minority Stress Framework and intersectionality, and address the relevance of these findings for healthcare professionals.

6.4.1. Epistemic Injustice and Erasure

The TGD youth included in this study explained how they were not trusted as 'knowers'. They described how others did not trust them to know themselves or their health needs based on multiple intersecting normative assumptions related to age, gender, diagnosis/diagnoses, neurodivergence, and race. These experiences can be understood as manifestations of *epistemic injustice,* which refers to discrimination against a person or group's capacity as a 'knower' based on prejudices, such as those pertaining to gender and younger age (Fricker, 2007). Specifically, the many instances in which the TGD youth described how they were not believed because of their social location(s) can be understood as *testimonial injustice*, a type of epistemic injustice wherein a person's word is not trusted because of their identity (Baumtrog & Peach, 2019; Fricker, 2007).

Although many patients report feeling dismissed in healthcare settings, these experiences are more commonly reported in patients who are younger, female, and visible minorities (Cuevas et al., 2016; Grundström et al., 2018; Hildebrand et al., 2022). Research with other marginalized groups, such as patients with chronic illness (McManimen, et al., 2019) and people categorized as 'overweight' (Merrill & Grassley, 2008), reveal similar themes. When people feel that their status as a 'knower' is dismissed, a central part of their identity is denied, or erased (Baumtrog & Peach, 2019). What renders this phenomenon in TGD youth so profound is the body of evidence that consistently reveals that experiences of epistemic injustice and erasure contribute to higher rates of depression, anxiety, self-harm, and suicidality in this population. (Eisenberg et al., 2017; Perez-Brumer et al., 2017). When healthcare providers contribute to the nonaffirmation of their patients, whether intentionally or not, they may contribute to worsening the mental health outcomes of TGD youth (Wittlin et al., 2023). Experiences of nonaffirmation can contribute to psychological distress (Toomey, 2021) and physical dysphoria (Galupo et al., 2020), which in turn contribute to the elevated rates of depression, anxiety, suicidality, and nonsuicidal self-injury reported in TGD youth (Wittlin et al., 2023). This is particularly concerning in the ED context when a TGD youth patient may already be experiencing a mental health crisis.

Despite not feeling trusted as 'knowers', our participants' accounts revealed a considerable amount of insight and knowledge about dominant social norms and their manifestations in healthcare. Further research and education are needed that promote TGD youth as epistemic agents with knowledge to contribute to improving healthcare. For example, community-based research methodologies and community-led educational interventions can serve to highlight barriers experienced by marginalized groups and support healthcare providers to provide more affirming care. Similar work is being conducted by critical scholars in the field of education who have also identified epistemic injustice as a meaningful framework to interrogate the diminished level of credibility attributed to TGD students in the classroom (Francis & Monakali, 2021; Kassen, 2022; Paechter et al., 2021).

6.4.2. Performing acceptability and rhetorical credibility

The second theme, performing acceptability, can then be understood as a strategic response to epistemic injustice in which a person seeks to attain *rhetorical credibility*. Rhetorical credibility, first described by Canadian Philosopher Trudy Govier (1993), refers to the degree that a person is regarded as believable or trustworthy by others. Govier describes those who have rhetorical credibility as *"white and male, who dress well, look professional, appear middle class or upper middle class, speak without an accent in a deep or low-toned voice, and seem unemotional, rational and articulate"* (p. 94, 1993). Conversely, the testimony of children, gender minorities, racial minorities, and other people whose social locations distance them from those described as having rhetorical credibility are less likely to be perceived as trustworthy. This is consistent with research demonstrating a statistically significant relationship between experiences of discrimination and withholding information from providers (Nong et al., 2022). Further, these patterns are consistent with research with TGD adults in primary care settings who reported withholding information about their gender identities, as well as other stigmatized experiences, such as autism or substance use (Alpert et al., 2023).

In our research, TGD youth identified and employed a variety of adaptive strategies to conceal various aspects of their identities and/or presentations that deviated from a rhetorically credible ideal. Our findings reveal that TGD youth have an astute understanding of how complex and intersecting social norms manifest in health settings, suggesting their capacity as ‘knowers’ is greatly underestimated. Further, they have created adaptive strategies to lessen experiences of minority stress and avoid manifestations of discrimination, potentially contributing positively to overall health. If TGD youth are able to rely on these adaptive strategies in the emergency department, they may also be more likely to seek care when they need it, reducing the risk of their health deteriorating.

While these approaches were described as successful by the participants, they are not benign. Providers rely on information provided by their patients to diagnose and treat. Without accurate information, treatment decisions may not be appropriate and may even be harmful (Alpert et al., 2023; Levy et al., 2018). For example, without complete information about medications and/or substance use, a potentially risky interaction might not be considered when prescribing a new medication (Alpert et al., 2023). Ultimately, when patients feel mistrusted in a clinical area frequently accessed for high acuity concerns, such as the emergency department, there are potentially severe risks to their health outcomes – particularly for those who already face health inequities, such as TGD youth. Further, these adaptive strategies may be fatiguing in the context of a health crisis and may contribute negatively to experiences of erasure and minority stress. This study contributes new insights into the knowledge and creativity of TGD youth navigating manifestations of social norms in health settings. While the participants in this study described these strategies as successful, further research is needed that explores the risks to their health.

6.4.3 Gender Minority Stress and Intersectionality

This research supports the notion that TGD youth experience and anticipate manifestations of gender minority stress when accessing and receiving care in emergency departments. In particular, two key concepts from the Gender Minority Stress Framework: *anticipatory stress* and *subject position and nondisclosure*, were visible in all participant accounts and, thus, prominent in the identified themes. Anticipatory stress refers to the anxiety and fear associated with the expectation of future negative events (Tan et al., 2020). The participant accounts support that TGD youth anticipate experiences of discrimination when engaging with emergency departments. Specifically, this was evident in the participant concerns about believability and their corresponding adaptive strategies. Whether or not they are ultimately met with stigmatizing providers, these concerns contribute to negative expectations and stressful interactions. This is consistent with the existing, largely quantitative, literature that describes a pattern of emergency department avoidance among TGD people (Navarro et al., 2021; Samuels et al., 2018; Thompson-Blum et al., 2021). Nondisclosure, or concealment of TGD identity, represents a state of vigilance in response to anticipatory stress in which TGD people are constantly assessing whether or not they are safe to reveal themselves, as well as whether they are passing (Tan et al., 2020; Testa et al., 2015). The adaptive strategies described by our participants represent various approaches to nondisclosure suggesting that this concept is relevant for understanding the experiences of TGD youth accessing the emergency department. This is consistent with reports that only half of Canadian TGD youth live as their affirmed gender full-time (Taylor et al., 2020).

Our results further underscore the need to engage with this type of work using an intersectional lens. Although our participants all described how they felt that they were perceived as less credible due to their age and gender, they also reported many other ways that they felt discredited as a result of variable, yet interlocking systems of oppression. By centering intersectionality, the results of this study also provide a more nuanced and fulsome understanding of the experiences of TGD youth navigating intersecting social norms related to age, assigned sex, gender, race, diagnosis, ability, and neurodivergence, among others. We discovered that some participants experienced anticipatory stress about provider reactions to their chronic pain diagnosis, neurodivergence, assigned sex, or race, among others. In response, our participants described nondisclosure strategies that were not specific to their gender presentations, such as concealing stigmatized diagnoses including borderline personality disorder and chronic pain, because they felt that their concerns would be dismissed. These accounts are consistent with research about other marginalized patients who feel mistrusted in the ED, such as TGD adults (Samuels et al., 2018; Thompson-Blum et al., 2021), people with mental illness, such as borderline personality disorder (Vandyk et al., 2019), and ethnoracial minorities (Darby et al., 2022).Our results highlight the importance of considering the individual social locations of TGD youth even when looking for patterns of meaning across their experiences.

6.4.4 Relevance for Healthcare Providers

Globally, emergency departments are challenged to meet the growing number of annual patient presentations, as well as the increasing patient acuity (Milton et al., 2023). Experiences of *moral distress*, the inability to act in a way conducive to our values due to external/institutional constraints, are well documented in the literature about healthcare providers working in emergency departments, particularly nurses (Fernandez-Parsons, 2013; Wolf et al., 2016). Providers working in the emergency department experience high rates of burnout related to the seemingly unending workload (Berger, 2013). Further, this context contributes to an environment wherein relationality is diminished, and health inequities are more easily perpetuated. Given the existing challenges for providers, negative patient accounts, such as those described in our study, can easily be met with fragility, defensiveness, and frustration. We would instead encourage healthcare providers to view the results of this study as two invitations.

The first invitation is to engage bravely and humbly in self-reflection. Although the process can be uncomfortable (Cicero & Wesp, 2017), it is critical in order to identify subconscious biases and how they manifest in one's beliefs about who is a trusted 'knower'. Epistemic injustice can be harmful both to the speaker as well as the person/people perceived to be discrediting the speaker (Baumtrog & Peach, 2019). For HCPs, dismissing TGD youth represents a lost opportunity to benefit from their knowledge, which may have otherwise contributed to an improved therapeutic relationship with this individual and a more affirming and informed clinical practice more broadly.

The second invitation is to approach all patients with the awareness that they may be apprehensive about seeking healthcare due to negative personal experiences and/or negative community narratives. This awareness can be exemplified by recognizing that building a trusting relationship, one where the patient does not feel that they need to use their adaptive strategies, may take time. This is a quality exemplified by a 'trans-competent provider', a defining attribute of trans-affirming care (Lightfoot et al., 2021). It can also, however, be considered an affirming approach to all patients who experience stigma in healthcare contexts.

6.5 Limitations

There are some limitations of this study that are important to consider. First, data collection occurred during the Covid-19 pandemic, which may have affected the quality of care provided by healthcare providers. This context, however, was not mentioned by participants when describing their interactions with them. Moreover, inclusion criteria required participants to have accessed the emergency department within the last two years, which included the prepandemic context. Some participants also described early experiences outside the two-year window. It is thus possible that their memories of these accounts were affected by the longer gap. Ultimately, however, the identified themes remained consistent across experiences. Second, although we attempted to recruit a diverse group of participants, we were not able to recruit Two-Spirit participants. Further, we were only able to recruit two TGD youth who were part of a visible minority population and one participant who reported a transfemme gender identity. Although visible minority participants represented only 14% of the total sample, we felt that it would be discordant with our theoretical framework to diminish the significance of their experiences based on a quantitative measure. Further, their descriptions are consistent with other publications that reveal inequities in how HCPs assess and manage pain in racial minority patients (Benzing et al., 2020; Joynt et al., 2013; Lee et al., 2019; Rasooly et al., 2014). Our results underscore the importance of further research that is more representative of the experiences of racial minority TGD patients.

6.6 Conclusion

This study explores the subjective experiences of TGD youth accessing and receiving care in the emergency department. Although emergency departments often serve as ‘safety nets’ for the medically underserved, the TGD youth in our study described challenges having their needs met in this setting. The participants reported feeling that their credibility was questioned based on multiple intersecting normative assumptions related age, gender, assigned sex, race, neurodivergence, and stigmatized diagnosis. These findings can be understood as manifestations of epistemic injustice. To compensate, TGD youth described adaptive concealment strategies that they employed to appear more credible to healthcare providers. These compensatory measures can be understood as performing rhetorical credibility, which suggests an astute understanding of how social norms manifest in healthcare. Further, participants described experiences of minority stress stemming from multiple, intersecting social norms, suggesting that Gender Minority Stress and intersectionality are important theoretical frameworks to guide research with TGD youth. Ultimately, this study offers novel insights into the experiences of TGD youth accessing and receiving care in the emergency department and suggests that the capacity of TGD youth as valued ‘knowers’ is greatly underestimated.

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Chapter 7: Integrated Discussion

This dissertation is focused on the experiences of trans and gender diverse (TGD) youth accessing and receiving care in the emergency department. To my knowledge, this is the first focused exploration of this area of inquiry. I used an emergent multi-phase, multimethod critical participatory action research (CPAR) approach grounded in a pragmatic interpretation of the critical theory paradigm. In this chapter, 1) I summarize the four dissertation manuscripts individually, including their novel contributions to research and healthcare; 2) I connect the knowledge generated within each phase of this dissertation project to highlight important contributions to theoretical, methodological, and substantive knowledge; 3) I discuss implications of this work for nursing practice, policy, education, and research; and, finally, 4) I identify strengths and limitations of the project and offer conclusions.

7.1 Dissertation Manuscripts.

I prepared four manuscripts based on this doctoral research project. These were presented in chapters 3, 4, 5, and 6.

Manuscript 1: A Theoretical Framework for Understanding the Experiences of Trans and Gender Diverse Youth Accessing Healthcare

The first manuscript was a theoretical research article that described a pragmatic, critical theoretical framework informed by the central concepts of the Gender Minority Stress Framework reinterpreted through the lenses of erasure and intersectionality. This manuscript was prepared for submission to the Journal of Nursing Philosophy. A narrative abstract, as per journal specifications, is included below:

Abstract. Despite a recent increase in clinical and academic interest, trans and gender diverse (TGD) youth perspectives remain underrepresented in the small but growing body of literature about TGD healthcare experiences and avoidance. This is problematic because TGD youth face age-related disparities that differentiate them from their adult counterparts, such as being perceived as 'too young' to understand their gender identity. In the process of conceiving of a research project to explore the emergency department experiences of TGD youth, we recognized the value of theory to guide the exploration operationally and catalyze the conceptual work. In this paper, I discuss the strengths and limitations of three theoretical traditions which have been applied to research efforts involving TGD communities: Gender Minority Stress Framework, erasure, and intersectionality. I then explain how we combined them into a cohesive theoretical framework that supports nursing scholars to find patterns of meaning across experiences without reducing them to gendered stereotypes.

Manuscript 2: Engaging in Critical Participatory Action Research During the PhD

The second manuscript described how we used a CPAR approach during the course of this doctoral project. This manuscript was prepared for submission to Qualitative Health Research. A narrative abstract, as per journal specifications, is included below:

Abstract. Critical participatory action research is gaining popularity in health research because of its empowering mandate to engage 'with' participants and not 'on' participants. Although appealing in principle to graduate students and their supervisors, the limited formal guidance about how to conduct these types of studies might cause hesitation to engage in this work. The objectives of this discussion article are to highlight the significant benefit of engaging in this collaborative work, address common concerns about participatory research during graduate studies, and provide strategies to navigate them using my doctoral study as an illustrative

example. Ultimately, the benefits of critical participatory action research during graduate school can outweigh the real and potential challenges. Not only can these projects be feasible, but they may even be advantageous during the PhD process.

Manuscript 3: Experiences of Trans and Gender Diverse Youth Accessing Emergency Department: Results of a Community-Designed Questionnaire

The third manuscript reported the results of a cross-sectional survey and online questionnaire that captured participants' sociodemographic factors, as well as both quantitative and qualitative information about emergency department use. This manuscript was prepared for submission to Transgender Health. A structured abstract, as per journal specifications is included below:

Purpose: The purpose of this study was to explore the experiences of trans and gender diverse youth accessing emergency departments.

Methods: This cross-sectional survey and online questionnaire was co-designed by a research team comprised of academic members and trans and nonbinary youth as part of a larger community-based participatory action research project.

Results: Participants reported highly variable experiences in the emergency department with half (n=14, 50%) reporting having avoided seeking needed care out of concern for how they would be treated.

Conclusion: These results support the claim that emergency department avoidance is a health concern that is also experienced by trans and gender diverse youth.

Manuscript 4: Experiences of Trans and Gender Diverse Youth Accessing Emergency Departments: Results and Recommendations from a Participatory Action Research Qualitative Study

The fourth manuscript reported the results of a multimethod qualitative research study. This manuscript was prepared for submission to the International Journal of Nursing Studies. A structured abstract, as per journal specifications is included below:

Background: Although emergency departments often serve as 'safety nets' for the medically underserved, emerging research indicates that certain minority groups, including trans and gender diverse people, report challenges having their needs met in this setting.

Objective: The objective of this study was to explore the experiences of trans and gender diverse youth accessing and receiving care in emergency departments using a theoretical framework informed by the Gender Minority Stress Framework, erasure, and intersectionality.

Methods: This was a qualitative study using a critical participatory action research (CPAR) methodology co-designed and executed in partnership with TGD youth. Study design and analysis were completed via focus group. Data collection was completed via interview, journaling, and art-based approach.

Results: Participants reported feeling that they were not trusted by healthcare providers to know themselves or their health needs. In response, participants reported employing adaptive strategies to conceal stigmatized aspects of their social location in favour of those that align more closely to social norms.

7.2 Composite Dissertation Contributions

While each individual manuscript offers new knowledge, the collective findings offer novel intersectional insights into the phenomenon of emergency department avoidance and the related experiences of epistemic injustice described by TGD youth while accessing and receiving care in emergency departments. Further, the composite work of this dissertation contributes an empowering, theory-informed approach for partnering with TGD youth in research that sets the foundation for a community-driven CPAR program of nursing research. Ultimately, both the multi-phase project's findings and the collaborative research process contribute to redefining TGD youth as epistemic agents. In the section below, I discuss how the key findings of this dissertation project contribute to the broader literature and address the six objectives of this thesis:

Objective 1. Engage with TGD youth to create a research team composed of community members and academic partners.

Objective 2. Iteratively develop a research protocol that meets the needs of the community.

Objective 3. Collaborate with TGD youth to create an empowering research process informed by the scholarship on erasure, intersectionality, and the Gender Minority Stress Framework.

Objective 4. Uphold the values of critical participatory action research (experiential knowledge, collaborative decision-making, authentic partnership, mutual beneficence) at every stage of the research process - including analysis.

Objective 5. Gain insights into how TGD youth perceive their treatment in the ED.

Objective 6. Develop recommendations for emergency department staff, based on the research findings, on how to provide affirming care to TGD youth.

These objectives align with the CPAR methodology which centers process as an end (Baum et al., 2006). In this methodology, a mutually beneficial and empowering research process is considered an emancipatory act in that it challenges traditional research structures and enables community partners to pursue their own research with the skills learned over the course of the project (Baum et al., 2006). Consistent with this approach, the knowledge production in this dissertation is not limited to the findings but is also present in the engagement with the theoretical framework and the operationalization of the methods.

7.2.1 Contributions to Theory.

The theoretical framework for this dissertation (Chapter 3) guided the research operationally and catalyzed the theoretical work. The theoretical synergies between the Gender Minority Stress Framework, erasure, and intersectionality offer a structure for research that prioritizes gender as an area of focus while acknowledging, or rendering visible, other intersections of power and privilege, thus avoiding reducing participants to stereotypes. Across the doctoral project, three central concepts from the Gender Minority Stress Framework featured prominently: 1) anticipatory stress, b) subject position and nondisclosure, and 3) community connectedness. Below I discuss how reinterpreting anticipatory stress and nondisclosure through the lenses of intersectionality and erasure contributed richness and nuance to the findings of this research. Further, I describe how these theoretical contributions might be useful for other work involving TGD youth.

7.2.1.1 Anticipatory Stress. Anticipatory stress, the anxiety and fear associated with the expectation of future negative events (Tan et al., 2020), has been well documented in research with TGD adults (Bockting, et al., 2013; Hendricks & Testa, 2012; McSky et al., 2023; Seelman, 2016). Informed by this, I defined the emergency department experience operationally as starting at the point of identifying a need for emergency care and including the decisional process of whether to seek care, rather than beginning upon arrival at the emergency department. Both community partners and study participants reported experiencing anticipatory stress based on concerns about transphobia and its intersections with ableism, racism, and other forms of oppression. Further, they identified anticipatory stress as a contributing factor to negative emergency department experiences and, thus, emergency department avoidance (Chapter 6). These findings are important because they sensitize researchers and healthcare providers to the complex decisional process and psychological and emotional burden that TGD youth might be carrying when seeking emergency care. By reimagining this concept through the lenses of intersectionality (Crenshaw, 1989; Collins, 2019; Van Herk et al., 2011) and erasure (Bauer et al., 2009; Namaste, 2000), we were able to hold space for other forms of anticipatory stress that were relevant to the participants. For example, we discovered that some participants experienced more anticipatory stress about provider reactions to their chronic pain diagnosis or race, rather than their gender. If we had narrowed our focus to gender, exclusively, we would have unintentionally erased this aspect of their experiences.

The dissertation findings support the notion that anticipatory stress, based on transphobia, is a phenomenon experienced by TGD youth and that it contributes to emergency department avoidance. Further, these findings illustrate the potential negative health risks of clinical spaces that are not perceived to be affirming and, in so doing, highlight how a theoretical concept can be clinically relevant. Specifically, these findings can inform the affirming approach that providers take when engaging with TGD youth who may be experiencing anticipatory stress above the baseline stress of needing emergency care. Further, understanding the correlation between anticipatory stress and emergency department avoidance can support interventions aimed at improving health equity for this population and other marginalized groups.

The dissertation findings also suggest that our theoretical framework provided the structure to allow more nuanced understandings of intersectional anticipatory stress, which contribute novel context to the phenomenon of emergency department avoidance and to health inequities experienced by TGD youth. Research about TGD youth guided by minority stress has previously been critiqued for failing to account for the developmental nuances of youth, such as identity development and limited control over stressors (Goldbach & Gibbs, 2017; Toomey, 2021). Further, this limited body of research has also been critiqued for overlooking intersectional identities, such as racial and sexual minority TGD youth, thereby erasing important components of experience (Galupo et al., 2016; Toomey, 2021). This theoretical framework serves to fill these gaps and can usefully be translated to other minority groups within TGD communities because it guides the researcher to highlight minority gender-related patterns of commonality while holding space for variability in social location .

7.2.1.2 Nondisclosure. Nondisclosure represents a state of vigilance in which TGD people are constantly assessing whether or not they are safe to reveal themselves, as well as whether they are *passing*, a term that refers to not being perceived as TGD (Tan et al., 2020; Testa et al., 2015). In a Canada-wide survey, only half of TGD youth reported living in their affirmed gender full-time (Taylor et al., 2020), meaning that this concept is particularly relevant for this population. As described above, reinterpreting this concept through the lenses of erasure and intersectionality provided a structure through which to learn about the concealment strategies, or nondisclosure, that TGD participants enacted to avoid experiencing bias due to stigmatized health conditions. Although nondisclosure of stigmatized health conditions is a known phenomenon, these insights are novel in the context of TGD youth and have both theoretical and clinical significance.

Researchers informed by intersectionality have identified several gaps in the limited but growing body of research that explores the healthcare experiences of TGD youth (Call et al., 2021). Specifically, the existing evidence base suggests that racial minority TGD youth face increased barriers to health and health care and worse health outcomes (Call et al., 2021; Raynor et al., 2020) but does not capture how these biases are experienced and navigated by TGD youth (Goldbach & Gibbs, 2017; Toomey, 2021). As such, there has been a growing call for research about TGD people that is guided by intersectional understandings of minority stress (Call et al., 2021). The insights obtained through this research about intersectional nondisclosure, such as nondisclosure of chronic pain condition and nondisclosure of chronic mental health condition (described in greater detail in section below on Contributions to Substantive Knowledge) provide empirical support for applying an intersectional lens when engaging in research guided by minority stress.

These findings are clinically important because they are associated with risk to the patient. In the emergency department, hiding relevant health information because of concerns about biased care could result in detrimental health outcomes for TGD youth. Without fulsome health information, healthcare providers may inadvertently treat their presenting concern inappropriately, risk dangerous medication interactions, or omit important health education (Hubach et al., 2017).

7.2.1.3 Conclusion. Ultimately, this dissertation project contributes to theory by providing structure for research that responds to criticisms of the Gender Minority Stress Framework and of the existing evidence base that addresses the health and healthcare of TGD youth (Chapter 3). Further, this project offers an illustrative example of tangible ways to apply a theoretical framework that guides every step of a research project and to render theory accessible to non-academic research partners (Chapter 4). As described above, the empirical results of this project support the relevance of both the theoretical framework and the central concepts of the Gender Minority Stress Framework, which also contributed to new understandings of the experience of TGD youth accessing and receiving care in emergency departments.

7.2.2 Methodological Contributions to Critical Participatory Action Research

7.2.2.1 Community Connectedness. Community connectedness is another central concept of the Gender Minority Stress Framework. While reinterpretations of anticipatory stress and nondisclosure contributed novel theoretical insights in the context of this thesis project, centering an intersectional reinterpretation of community connectedness contributed to meaningful methodological knowledge. Within the research group, there were pre-existing connections between community partners who did not live in the same area. Two had met at a camp for LGBTQ+ youth and others had met as parts of advocacy and/or other research groups. These existing connections served a protective factor and allowed the community partners to engage in a free exchange of ideas at our first meeting. This experience is consistent with existing evidence that highlights the importance of community connection within TGD communities, such as support groups or social networks, for reducing the effects of minority stress (Kia et al., 2021; Pflum et al., 2015; Tan et al., 2020). In the context of this dissertation project, prioritizing community connectedness contributed to several key community-driven methodological innovations.

Community partners were keenly aware of the protective factor offered by community connectedness. As such, they advocated for two options during the qualitative study: familial focus groups, wherein participants could bring their own chosen members, and/or having a TGD member of the research team attend the interview for support. These recommendations offered safer, community supported options which contributed to rendering the research project more accessible to participants who may have hesitated otherwise.

Community members typically have established relationships and trust within their community. Their involvement in research teams, including study planning and execution, helps to build rapport with other community members and reduces barriers to engagement (Resnik & Kennedy, 2010). In this way, the trust generated from having community partners on the research team fosters openness from research participants, ultimately enhancing the authenticity of the data collected. Without the lenses of intersectionality and erasure, however, I may have assumed that the space was inherently safe as all community partners were TGD youth. I learned instead that some group members felt excluded in TGD spaces based on being nonbinary, not being ‘out’, having mental health issues, and/or being persons of colour. To attempt to navigate these risks, we co-created rules of engagement that were reviewed at the beginning of every meeting; I stayed on the call for 30 minutes post-focus group so that team members could rejoin and debrief; and we launched a survey wherein group members could share concerns that they had anonymously.

Community partners also embodied community connectedness by building a rich informed consent process and conditions of trust within the questionnaire. This was achieved by including a rationale for questionnaire items (Chapter 5). Community partners explained that not understanding the motivation for a question had previously caused them to feel suspicious or to stop engaging in projects. This insight was vital and resulted in the inclusion of clear explanations for each section of the questionnaire. Further, this represents a novel methodological contribution that is important for researchers working with communities who may have reasons to mistrust health research.

7.2.2.2 Redefining TGD youth as epistemic agents. Prior to beginning this project, I was aware that, by virtue of their age and gender(s), TGD youth are bombarded by messaging that they are ‘too young to know’ their own identities (George & Goguen, 2021). This discrimination against the capacity of TGD youth as ‘knowers’, or *epistemic injustice*, contributed to my decision to pursue a CPAR approach that inherently prioritizes and values community knowledge (Objective 4). Both the research process and the outcomes of this project reinforce the notion that TGD youth are valuable epistemic agents whose perspectives enrich our understandings of gender diversity, health research, and health experiences. *Epistemic agency* refers to the capacity of individuals or groups to generate knowledge and contribute to the formation of knowledge within a particular domain (Fricker, 2007).

In this project, recognizing TGD youth as epistemic agents required actively listening to their voices and respecting them as partners (Objective 1). Further, it involved creating opportunities for them to participate in decision-making processes that affect their lives and communities, which was supported methodologically by my choice of CPAR approach. As such, I involved them from the point of early conversations about a research question through to dissemination. These holders of firsthand knowledge and lived experiences provided valuable insights into the dynamics, needs, and concerns of their communities. Their input ensured that the research question and research objectives were relevant and aligned with community priorities, thereby enhancing the authenticity of the research outcomes.

The community partners were also instrumental in advancing how intersectional variability in the healthcare experiences of the youth could be addressed in this project. The group advocated for open opportunities for participants to share aspects of their social location that they felt were meaningful in this context, rather than focusing exclusively on age and gender. In the extended demographics questionnaire (Chapter 5), this translated into a blank text box asking about identity rather than a prescriptive drop-down menu. Through this text box, participants most commonly reported neurodivergence, mental health diagnosis/diagnoses, not ‘passing’, being perceived as female, and having chronic health issues as aspects of identity that negatively affected their experiences in emergency departments. These findings are reflective of developmental and gender norms, (trans) misogyny, and ableism, which have previously been identified in research with TGD youth as factors influencing their well-being (Pullen Sansfaçon et al., 2018). Further, the participants most commonly presented for mental health concerns and chronic pain, which are two chief complaints that are known to be poorly addressed in emergency department settings due to the complex nature of the conditions and their associated stigma (Hoge et al., 2022). A literature review by Hoge and colleagues (2022) reported that emergency departments are poorly equipped to support children and youth experiencing mental health challenges other than to intervene during acute mental health crises. Even then, appropriate resources are often not available. Further, the authors noted increased disparity in the quality of care received amongst youth belonging to 'special populations' which includes TGD youth, neurodivergent youth, youth with mental health conditions, and racial and ethnic minority youth. Ultimately, our findings contribute to the existing literature about stigmatized illnesses/conditions by illustrating how members of marginalized communities, in our case TGD youth, experience compounding marginalization in healthcare settings. This is clinically important because it contributes new context to the high rates of emergency department avoidance identified in existing trans scholarship (Navarro et al., 2021). These findings are also methodologically important because they would not have been identified without viewing the TGD youth as true collaborators and incorporating their suggestions for data collection.

7.2.2.3 Summary. The multiple methodological contributions of this doctoral project build on the design innovations seen in other CPAR studies. Although the number of CPAR studies focusing on TGD youth is limited, each offers creative interpretations of this flexible methodology. For example, in an art-based CPAR project, TGD youth received mentorship from a trans* artist and engaged in art focused on challenging dominant cultural representations of trans* identity (Asakura et al., 2020). This methodological approach supported the notion that art can be a transformative research process. Another study set in high schools had participants detail their own narratives of making meaning of their sexual and gender identities in a high school setting. These narratives were compiled into a booklet that was then analyzed as a group using a collective memory analysis (Johnson et al., 2014). Finally, in a study examining how the family environment affects the health and well-being of TGD youth, TGD youth, their families, and community organizations provided considerable feedback about the language and structure of the survey (Katz-Wise et al., 2019). Specifically, one section of the survey addressed risk behaviours in a way that rendered two caregivers of young TGD youth uncomfortable. An innovative solution was to intersperse the more ‘negative’ questions with some more ‘positive’ ones rather than to house them altogether. Further, the research team was able to arrange for skip patterns in the online survey so that participants were not exposed to questions that might distress them or be irrelevant (Katz-Wise et al., 2019).

The multiple methodological innovations of this doctoral project build on this body of work by prioritizing community connectedness and youth as epistemic agents. Specifically, our team enhanced trust in the original focus groups where we met to design the study by co-creating rules of engagement and offering an anonymous space to share feedback. During the questionnaire, we provided rationales for the questions and a blank text box for participants to report how they identify non-prescriptively. During the qualitative study, we offered options for the participants to have a safe person attend with them. Each of these trust-building initiatives are transferable to research with other marginalized communities.

7.2.3 Contributions to Substantive Knowledge.

This multi-phase dissertation project contributes to substantive knowledge about the experiences of TGD youth accessing and receiving care in the emergency department. Specifically, the community partners and research participants described how their experiences were influenced by social norms related to age and gender. They also reported navigating norms related to many other aspects of social location and lived experience, such as neurodivergence, race, and stigmatized illnesses.

The concept of emergency department avoidance was omnipresent in the accounts of both community partners and participants. In the questionnaire (Chapter 5), half of the participants (50%) reported having avoided emergency care when needed, which is consistent with previously reported rates of TGD healthcare avoidance in Canada (Navarro et al., 2021). A national online survey found that 47% of older youth (ages 19-25) and 33% of younger youth (ages 14-18) had not accessed physical healthcare when needed in the last year. Further, 68% of younger youth had not accessed mental healthcare when needed in the same timeframe (Navarro et al., 2021). The most common reasons for avoidance included hoping the problem would go away, feeling afraid of how they would be treated, and not wanting their parents to know. These reasons were consistent with the accounts from both community partners and participants who described anticipatory stress about how they would be treated in the emergency department and having to navigate complicated parental involvement.

In response to negative experiences and anticipatory stress, the participants described adaptive nondisclosure strategies (Chapter 6) to modify their presentations to align more closely with their interpretation of a ‘trusted knower’. Examples included modifying their appearance to reflect their assigned sex at birth and concealing stigmatized diagnoses including borderline personality disorder and chronic pain, because they felt that their concerns would be dismissed otherwise. These accounts are consistent with research about other marginalized patients who feel mistrusted in the emergency department, such as TGD adults (Samuels et al., 2018; Thompson-Blum et al., 2021), people with certain mental illnesses (Vandyk et al., 2019), and ethnoracial minorities (Darby et al., 2022). What is different in our findings is that TGD youth report experiencing many of these issues simultaneously and not in isolation. These results highlight the importance of considering the individual social locations of TGD youth even when looking for patterns of meaning across their experiences. Further, they provide insight into social norms and expertise in navigating how they manifest in healthcare.

7.2.3.1 Age-related epistemic injustice. While not all TGD youth may be able to name the concept of epistemic injustice, the results of this project suggest that many are able to articulate the ways in which their knowledge and experiences are marginalized and invalidated in healthcare contexts. Specifically, both community partners and participants described how cisgender adults were believed to be more reliable authorities than them about their own experiences. This is a powerful example of *testimonial injustice*, a type of epistemic injustice wherein a person's word is not believed because of their identity (Baumtrog & Peach, 2019; Fricker, 2007). Experiences of testimonial injustice were visible at every stage of this project beginning with the initial engagement with community partners (described in Chapter 4).

During these sessions, I disclosed my identity as a cisgender adult, recognizing that our differences in social location could pose an obstacle for community partners. None of the prospective community partners took issue with my gender identity. Instead, there were a few that described my identity as an advantage that would lend credibility to the work. Throughout the research process, the community partners worried that researchers and healthcare providers outside of our research team would not take us and/or the work ‘seriously’. This perception was consistent with the results of our qualitative study (Chapter 6) wherein the participants described being talked over because their cisgender adult parents were seen as greater authorities on their health and healthcare needs. Although many hospitals aim to center both the patient and family in care planning, delivery, and evaluation, through an approach known as family-centered care (Coyne et al., 2016), critics of this model argue that the gatekeeping power held by adult parent(s) and adult healthcare professional creates an asymmetric relationship that takes the focus off the youth and undermines their knowledge (Coyne et al., 2016; Gerlach & Varcoe, 2021; Hallström et al., 2002; Kelly et al., 2012). Our findings support the assertion that there is an imbalance of power in the patient-parent-provider dynamic, which has the potential to contribute to negative healthcare experiences and negative health outcomes.

Research consistently demonstrates that when children and youth are involved in decisions about their care, there are positive physical and mental health benefits, including experiencing less pain and less anxiety (Coyne et al., 2016; Gerlach & Varcoe, 2021; Hallström et al., 2002; Kelly et al., 2012). Conversely, when youth are treated as passive recipients of healthcare, they feel powerless and their sense of personal identity is compromised, which can affect their healthcare seeking behaviour and health outcomes (Coyne et al., 2016; Hallström et al., 2002). Ultimately, the results of this project suggest that TGD youth are aware that they are perceived as less credible because of their age. TGD youth described how this perception negatively affects their healthcare experiences emotionally, by reinforcing experiences of minority stress, but also medically, in that they do not always feel that they are heard or that their needs are adequately met. These negative experiences contributed to future emergency department avoidance and, as such, poses risks to their health.

7.2.3.2 Intersectional epistemic injustice. In addition to age and gender, participants reported other ways that they felt their experiences of being discredited were related to their social locations. Some participants described anticipatory stress about provider reactions to their chronic pain diagnosis, neurodivergence, assigned sex, or race, among others. Conversely, transmasculine participants who described themselves as ‘passing’ reported a modicum of privilege compared to their nonbinary and transfeminine peers. Similar perspectives were described by participants who reported white ethnoracial backgrounds and ‘thin’ body types. These individual experiences of intersecting marginalization and privilege were reported by community partners when we were co-designing the study (Chapter 4), in the participants’ entries in the extended demographics questionnaire (Chapter 5), and in the participants’ responses in the qualitative study (Chapter 6). Ultimately, these findings suggest that, while the experiences of TGD youth in healthcare include patterns of commonality related to age and gender, there is significant variation in experiences related to social location.

Scholars in the field of intersectional epistemology acknowledge that individuals may experience multiple forms of power and oppression simultaneously and argue that recognizing and addressing these configurations of experience fosters more inclusive and equitable knowledge systems (Hill Collins & Bilge, 2016; Nash, 2008). Ignoring intersectionality in health research about TGD youth risks undermining the complexity of their experiences and erasing aspects of their identities. By recognizing the diversity within transgender communities and addressing the intersecting factors that contribute to health disparities, researchers can develop more comprehensive interventions and policies to improve the health and well-being of transgender individuals. For example, intersectional research into the health of TGD people has highlighted significant disparities amongst racial and ethnic minority TGD groups, such as a disproportionate burden of violence and mental health challenges (Operario et al., 2014; Reisner et al., 2016). Ultimately, the findings of this dissertation support existing calls for intersectional understandings of health and healthcare in trans scholarship (Bauer et al., 2019).

7.3 Disciplinary Implications

Given the emergent research design, each study phase resulted in specific implications that informed the next phase. These were presented in all four manuscripts (chapters 3-6). Below, I discuss the disciplinary implications of the composite dissertation project for nursing practice, education, leadership and policy, and research. My recommendations below also represent potential 'action items' from this CPAR project (Objective 6).

7.3.1 Nursing practice

Based on the initial conversations with community partners (Chapter 4), the wide range of ratings for overall experience and the related comments in the questionnaire (Chapter 5), and the accounts in the qualitative study (Chapter 6), individual providers are able to make a significant impact on the experiences of TGD youth. Nurses in Canada are expected to provide care that is free of discrimination to their patients and may face sanctions enforced by their regulatory college if they are unable or unwilling to meet this standard (CNA, 2018). Despite this, participants often spoke to negative interactions and the burden of having to educate providers about minority gender identities, pronouns, and medical transitions and how these might affect their presenting concern.

Trans-affirming care refers to an affirming approach to care specific to TGD people that is patient-led, involves trans-competent providers, and is set within a trans-affirming culture (Lightfoot et al., 2021). This approach is consistent with recommendations from the Canadian Nurses Association (CNA, 2018) and standards of care outlined by the World Professional

Association for Transgender Health (Coleman et al., 2022). According to the eighth and latest edition of the WPATH standards of care, when caring for TGD youth, the individual's emotional, cognitive, and psychosocial development must be taken into account. This is a change from the previous edition that set specific minimum ages for certain gender-affirming interventions. This approach aligns with the findings of this doctoral research that highlight how, despite patterns of commonality across experiences, TGD youth represent a heterogeneous group with individualized needs that should be understood using an intersectional approach. There were many participants who described individual providers who had significant positive effects on their experiences. Below I describe some specific recommendations based on feedback during the qualitative study.

7.3.1.1 Language. Both our community partners and research participants emphasized that they felt safer with healthcare providers who asked them about how they would prefer to be addressed and their pronouns. Further, they reported the importance of using gender neutral language when possible. Research consistently shows that accepting and affirming the gender identity of TGD individuals, including the use of correct pronouns, is associated with better mental health outcomes. For example, one study reported that TGD youth who reported that their chosen name was used by all or most people in their lives, including healthcare settings, had lower rates of severe depression and suicidal ideation compared to those whose gender identities were not respected (Russell et al., 2018). Nurses need to be mindful of chosen names and pronouns and the positive effect that thoughtful use of language can have on patient experiences.

7.3.1.2 Awareness of medical trauma. Our findings suggest that it is important for healthcare providers to be conscious of the hesitancy and mistrust that TGD patients may be navigating due to previous traumatic experiences accessing medical care. Specifically, they recommended asking for consent to discuss sensitive topics and explicitly asking for consent for any physical contact and explaining why it might be necessary. These practices are supported by both the WPATH (Coleman et al., 2022) and the CNA (2018). Research has indicated that TGD children and youth endure high levels of adverse experiences and trauma (Barrow & Apostle, 2018; Chen et al., 2018; Reisner, et al., 2015). As such, nurses need to be aware that their TGD patients may have a history of trauma, both within and outside of the healthcare system, and need to be intentional in their interactions to avoid perpetuating experiences of stigma and discrimination (Coleman et al., 2022).

7.3.1.3 Parental involvement. Based on the experiences of the community partners and research participants in our study, not all parents can be assumed to be supportive. For nurses, this does not necessarily mean writing off parents as potential supports; there are many examples of parents who are able to become more accepting with time, support, and education (Coleman et al., 2022). Research consistently demonstrates that parent and family support is a primary predictor of TGD youth well-being and is a protective factor for mental health (Coleman et al., 2022; Eisenberg et al., 2019; Lefevor et al., 2019; Simons et al., 2013). When parents are supportive, they may provide key information to the clinical team that can contribute to more optimal health outcomes (Coleman et al., 2022). It is, therefore, an important competency for nurses to engage with patients and families to understand and manage the dynamics at play, recognizing that families may not be supportive, and that even when they are, they should not be deferred to at the expense of the youth patient. Specifically, nurses need to speak to youth privately to understand their care goals and how they would like caregiver dynamics to be navigated. In some cases, this may mean using an affirmed name when the caregiver is out of the room and using the legal name when the caregiver is in the room.

7.3.2 Nursing Education.

Both our community partners and our study participants identified gaps in education/training for health care providers limiting their ability to engage in trans-affirming care. In some situations, the gaps in knowledge were related to specific medication interactions, but more often, providers were described as not knowing the very basics of trans-affirming care, such as respecting pronouns and that some patients may present differently than their assigned sex at birth. A recent review of Canadian and American undergraduate nursing curricula concluded that although there has been an increase in formal educational interventions, such as TGD health-related simulation (Crawford et al., 2024). Outside these often-one-time interventions, however, the researchers concluded that curriculum remained rooted in cisnormativity and trans erasure (Crawford et al., 2024). Educational interventions have significant positive effects on the attitudes and the trans-competence of nurses and nursing students (Du Mont et al., 2020; Sherman et al., 2021). However, these interventions must be supported with content across undergraduate nursing curricula that disrupts cisnormativity and trans erasure. One systemic way that this could be improved would be through leadership from the Canadian Association of Schools of Nursing and provincial regulatory colleges. These organization develop entry to practice competency guidelines across Canada and influence national and provincial educational frameworks. As such, they are well positioned to provide specific standards for trans-affirming content in nursing education across Canada. The findings of this doctoral research suggest that an intersectional gender-focused theoretical framework, such as the one guiding this work, would be important to guide the educational content and avoid the risk of reducing the experiences and health care needs of TGD youth to stereotypes. Further, our results suggest that it would be valuable for the educational content to be co-created with community members, thereby recognizing their epistemic agency and their content expertise.

Study participants also spoke of the importance of improving access to education for populations who are at increased risk for socioeconomic challenges and who may be healthcare averse, such as TGD youth. They described how increased TGD representation amongst clinical staff would render emergency departments safer and more affirming. One actionable way that universities could contribute to improving access to education would be through TGD-specific scholarships for TGD youth interested in pursuing nursing education.

7.3.3 Nursing Leadership and Policy.

Based on the experiences of the TGD youth in this PhD project, most hospitals either have no or have insufficient mandatory training related to the provision of trans-affirming care. Institutional policies significantly influence the equity of care received by patients in hospitals by determining mandatory training standards, philosophies of patient care, and health information technology. Beginning with mandatory training, hospitals that prioritize cultural competence training for staff and provide language interpretation may better meet the needs of patients from minority or non-English-speaking backgrounds (Hasnain-Wynia et al., 2007). Conversely, the absence of such policies can contribute to communication barriers and disparities in care (Sentell & Braun, 2012). Nursing leadership set the standards for mandatory training and are, therefore, well positioned to improve the healthcare experiences of TGD patients by including training about trans-affirming care.

The experiences of the TGD youth in this doctoral project suggest that healthcare providers tend to default to the parent in the room regardless of the age of the youth or whether they are in a pediatric or general emergency department. Based on these findings, nursing leaders in hospitals must set the standard for frontline nursing by prioritizing the youth as the epistemic agent in the clinical environment and repositioning parents as supports. Further, nursing leadership should build mechanisms to receive patient feedback and respond accordingly to concerns brought forward by TGD patients. Institutional policies that prioritize patient-centered care and shared decision-making can enhance patient satisfaction and engagement in care (Beach et al., 2005). Hospitals that involve patients in care planning, respect patient preferences, and provide comprehensive support services may also promote equity by addressing individual patient needs and preferences (Beach et al., 2005).

I did not ask about information technology as part of the interview guide; however, it regularly came up organically in interviews. Despite significant recent technological advancements in major cities across Canada, none of the TGD youth involved in this doctoral project had experienced an electronic medical record that accommodated nonbinary identities. Further, they described concerns about the open accessibility of their health information recognizing that this prohibited them from using adaptive strategies, such as concealing stigmatized diagnoses. The participants explained how open accessibility of their health information prohibited them from using adaptive strategies, such as concealing stigmatized diagnoses. This is an interesting perspective given that research consistently shows that hospitals that invest in infrastructure, such as electronic health records and patient portals, have improved care coordination, communication, and access to health information for patients (Gibbons, 2013). Although the results of this project and the existing literature about electronic medical records appear to clash, upon closer inspection, I argue that they are well aligned, although in a nuanced way. Ultimately, there is great potential for electronic health records to promote accessibility of health information and care coordination, so long as the technology does not perpetuate problematic social norms. One specific actionable item is to structure the electronic medical record with capacity to capture gender, pronouns, and chosen name, paired with training sessions for nurses and clerical staff on how to collect this information respectfully.

7.3.4 Nursing Research

Nursing scholars have played a critical role in advancing research on the health and healthcare of trans and gender diverse youth in Canada. One notable example is the Canadian Trans and Non-Binary Youth Health Survey which has thus far been circulated twice, once in 2014 (Veale et al., 2015) and most recently in 2019 (Taylor et al., 2020). The results of this survey have been instrumental in identifying health disparities and barriers for TGD youth in Canada. The five-year gap between surveys has also allowed for certain trends to be identified, such as a significant increase in TGD youth living in their felt gender fulltime (Taylor et al., 2020). Certainly, there is great value in this survey continuing.

This doctoral project is informed by many of the findings of the survey described above, which report barriers to access and health inequities. We were able to build on this quantitative work by exploring some of these notions qualitatively which provided rich nuance and context. Our results support that qualitative, community-based explorations of these concepts are not only possible but advantageous because they advance theoretical, methodological, and substantive knowledge. Further, some important future directions in this substantive area include focused research exploring the intersectional experiences of the TGD youth who experience stigmatized diagnoses, such as endometriosis, borderline personality disorder, neurodivergence, and chronic pain.

This doctoral project offers an illustrative example of how TGD youth can successfully be positioned as partners in research in ways that align with the six overarching principles for transgender research as outlined by the Canadian Professional Association for Transgender Health (CPATH) (Bauer et al., 2019). Specifically, I was conscious of the *Impacts on Communities* and aimed to reduce the risk of research fatigue. Ultimately, we collaboratively decided not to involve community partners in administrative tasks they found less interesting and valuable, such as the ethics application and transcription. To prioritize meaningful *Engagement with Communities*, both community partners and research participants in the qualitative study were compensated for their time. Further, community partners who consent will be listed as authors on all manuscripts. I was also conscious of *Consent and Confidentiality* recognizing that while I may perceive quotes as anonymized, the community partners might recognize peer accounts. This contributed to my decision to perform the first round of data analysis and anonymization myself. Further, this doctoral project was guided by a theoretical framework rooted in intersectionality which allowed space for *Consideration of Diversity, Power, Marginalization and Representation*. To prioritize *Accountability to Participants and Trans Communities* community partners were paid as part of the research team and learned about the research process, thereby promoting sustainability in research. One community partner subsequently began to host workshops for researchers interested in partnering with TGD youth. Finally, I engaged in *Reflexivity* through journaling throughout this project. Some of these examples of self-reflection are visible in the methodology manuscript in Chapter 5. Upholding these principles is necessary for building trust and reducing research fatigue (Ashley, 2021; Bauer et al., 2019). They were created in response to TGD community members reporting that they felt stigmatized and exploited by studies that had received Research Ethics Board approval. It became evident that a higher standard of ethical consideration for research with TGD people was required (Bauer et al., 2019). Setting the CPATH guidelines as the ethical standard for nursing research involving TGD youth would strengthen nursing scholarship by improving trust with TGD communities, thereby improving recruitment and engagement with nursing research.

7.4 Strengths and Limitations of the Dissertation

Specific strengths and limitations were reported in each manuscript in chapters 3-6. Below I describe strengths and limitations of the composite doctoral project.

7.4.1. Strengths.

As outlined above, the findings of this dissertation project contribute knowledge that advances theoretical, methodological, and substantive scholarship. Further, these contributions help to inform and guide nursing practice, education, policy, and research. As a CPAR project, however, one of the most important strengths of this work is that the community partners felt ownership over the findings and translated them into personal projects that felt meaningful to them. One community partner created posters for emergency departments based on our results. Another begun a series of workshops for TGD youth who are interested in research and health care providers who are interested in collaborating with TGD youth.

Another strength of this research project is that the majority of participants were nonbinary, which ensured that their perspectives were well represented in the questionnaire data and that their unique experiences were captured in the qualitative themes. A significant proportion of TGD youth identify as nonbinary (Diamond, 2020; Taylor et al., 2020). Despite this, the existing literature is more representative of binary TGD youth (Call et al., 2021; Cosgrove, 2021). This is noteworthy since nonbinary TGD youth are less likely to disclose their gender identity and report higher levels of mental health concerns (Toomey et al., 2021; Veale et al., 2015). One caveat, however, is that AFAP people were more represented than AMAB people amongst the nonbinary participants, meaning that there may have been specific insights related to the issues of the AMAB group that did not surface, including transfeminine experiences of transmisogyny (Serano, 2020). Further challenges related to sample diversity are discussed below.

7.4.2. Limitations.

There are limitations to consider for this doctoral project with respect to sample diversity. This limitation was seen for all phases of the project. Specifically, of the community partners, four (67%) were white, of the questionnaire respondents 25 (89%) were white, and of the participants in the qualitative study, 12 (86%) were white. After the first month of recruitment for the extended demographics questionnaire and qualitative study, we identified that our sample was primarily white Canadian citizens who were in their late teens/early twenties. We began to recruit using purposive sampling via community organizations serving 1) gender diverse children and their families, 2) racial and/or ethnic minorities, and/or 3) immigrants and refugees. These organizations were identified through Google searches and contacted through the emails on their websites. Of the 15 organizations we reached out to, we heard back from seven. Of the seven, five shared our recruitment posters on social media and via their mailing lists. The two organizations who chose not to offered to share results that were relevant to the populations they serve. They could not, however, share the recruitment material since they had not been included in the development of the project. Further, one of the organizations who did share the recruitment material provided feedback that the compensation (25$CAD) was not enough for their population and that they expected a minimum of 100$CAD given the ongoing history of researchers profiting off of marginalized groups. Ultimately, we were able to expand the age range, but the group remained predominantly nonbinary and white/Caucasian. As such, our findings may be more representative of older youth who are nonbinary and white/Caucasian. Further research is needed that focuses on minority populations within this group.

7.5 Conclusions

This dissertation offers novel theoretical, methodological, and substantive contributions to the fields of transgender health and emergency nursing. Overall, the findings of this doctoral project support the assertion that recognizing and supporting the epistemic agency of TGD youth is not only a matter of justice, but also a means of advancing knowledge and promoting improvements in equitable healthcare. Further, this composite work supports calls for intersectional understandings of TGD health and healthcare. Ultimately, the findings and collaborative networks generated lay the groundwork for an impactful program of research that advances knowledge about the health and healthcare of TGD youth while repositioning them as epistemic agents.

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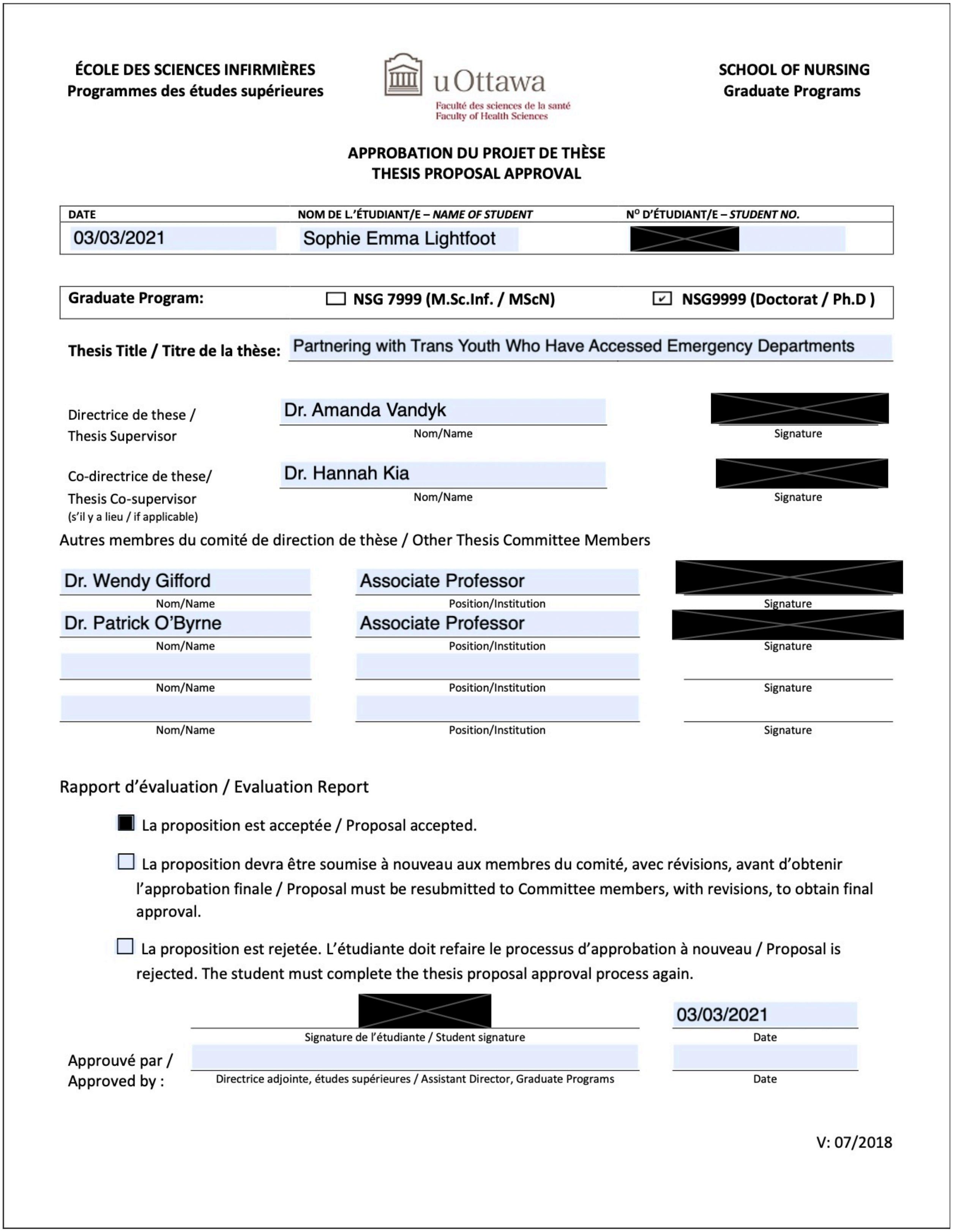
Appendix A: Approval of Dissertation Proposal by Thesis Advisory Committee



ÉCOLE DES SCIENCES INFIRMIÈRES
Programmes des études supérieures

uOttawa
Faculté des sciences de la santé
Faculty of Health Sciences

SCHOOL OF NURSING
Graduate Programs

APPROBATION DU PROJET DE THÈSE
THESIS PROPOSAL APPROVAL

DATE	NOM DE L'ÉTUDIANT/E – *NAME OF STUDENT*	N^O D'ÉTUDIANT/E – *STUDENT NO.*
03/03/2021	Sophie Emma Lightfoot	[redacted]

Graduate Program: ☐ **NSG 7999 (M.Sc.Inf. / MScN)** ☑ **NSG9999 (Doctorat / Ph.D)**

Thesis Title / Titre de la thèse: Partnering with Trans Youth Who Have Accessed Emergency Departments

Directrice de these / Thesis Supervisor: Dr. Amanda Vandyk (Nom/Name) — [redacted] (Signature)

Co-directrice de these/ Thesis Co-supervisor (s'il y a lieu / if applicable): Dr. Hannah Kia (Nom/Name) — [redacted] (Signature)

Autres membres du comité de direction de thèse / Other Thesis Committee Members

Nom/Name	Position/Institution	Signature
Dr. Wendy Gifford	Associate Professor	[redacted]
Dr. Patrick O'Byrne	Associate Professor	[redacted]

Rapport d'évaluation / Evaluation Report

☒ La proposition est acceptée / Proposal accepted.

☐ La proposition devra être soumise à nouveau aux membres du comité, avec révisions, avant d'obtenir l'approbation finale / Proposal must be resubmitted to Committee members, with revisions, to obtain final approval.

☐ La proposition est rejetée. L'étudiante doit refaire le processus d'approbation à nouveau / Proposal is rejected. The student must complete the thesis proposal approval process again.

[redacted]
Signature de l'étudiante / Student signature — 03/03/2021 Date

Approuvé par / Approved by :
Directrice adjointe, études supérieures / Assistant Director, Graduate Programs — Date

V: 07/2018

Appendix B: Certificate of Ethics Approval from the University of Ottawa for Focus Groups

10/05/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE I CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-04-21-6712
Titre du projet / Project Title	Partnering with Trans Youth Who Have Accessed and Received Care in Emergency Departments
Type de projet / Project Type	Thèse de doctorat / Doctoral thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	10/05/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	09/05/2022

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Sophie Emma LIGHTFOOT	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
Amanda VANDYK	École des sciences infirmières / School of Nursing	Superviseur / Supervisor
Hannah KIA	École des sciences infirmières / School of Nursing	Co-superviseur / Co-supervisor

Conditions spéciales ou commentaires / Special conditions or comments

The current review and approval is solely for Phase 2 of the project.

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10/05/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Le Comité d'éthique de la recherche (CÉR) de l'Université d'Ottawa, opérant conformément à l'*Énoncé de politique des Trois conseils* (2014) et toutes autres lois et tous règlements applicables, a examiné et approuvé la demande d'éthique du projet de recherche ci-nommé.

L'approbation est valide pour la durée indiquée plus haut et est sujette aux conditions énumérées dans la section intitulée "Conditions Spéciales ou Commentaires". Le formulaire « Renouvellement ou Fermeture de Projet » doit être complété quatre semaines avant la date d'échéance indiquée ci-haut afin de demander un renouvellement de cette approbation éthique ou afin de fermer le dossier.

Toutes modifications apportées au projet doivent être approuvées par le CÉR avant leur mise en place, sauf si le participant doit être retiré en raison d'un danger immédiat ou s'il s'agit d'un changement ayant trait à des éléments administratifs ou logistiques du projet. Les chercheurs doivent aviser le CÉR dans les plus brefs délais de tout changement pouvant augmenter le niveau de risque aux participants ou pouvant affecter considérablement le déroulement du projet, rapporter tout évènement imprévu ou indésirable et soumettre toute nouvelle information pouvant nuire à la conduite du projet ou à la sécurité des participants.

The University of Ottawa Research Ethics Board, which operates in accordance with the *Tri-Council Policy Statement* (2014) and other applicable laws and regulations, has examined and approved the ethics application for the above-named research project.

Ethics approval is valid for the period indicated above and is subject to the conditions listed in the section entitled "Special Conditions or Comments". The "Renewal/Project Closure" form must be completedfour weeks before the above-referenced expiry date to request a renewal of this ethics approval or closure of the file.

Any changes made to the project must be approved by the REB before being implemented, except when necessary to remove participants from immediate endangerment or when the modification(s) only pertain to administrative or logistical components of the project. Investigators must also promptly alert the REB of any changes that increase the risk to participant(s), any changes that considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project or the safety of the participant(s).

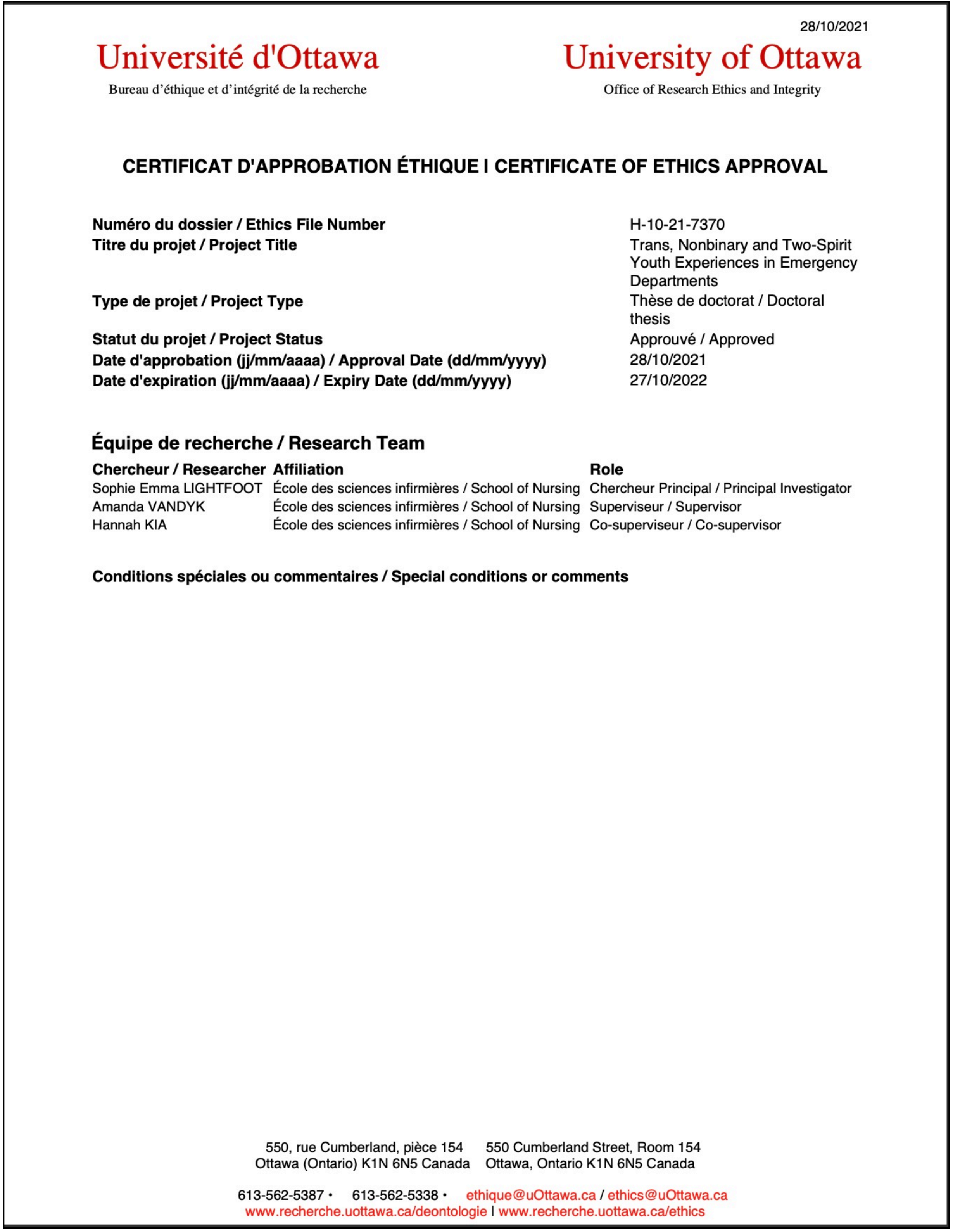
Kim THOMPSON
Responsable d'éthique en recherche / Protocol Officer
Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board**

550, rue Cumberland, pièce 154
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street, Room 154
Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie | www.recherche.uottawa.ca/ethics

Appendix C: Certificate of Ethics Approval from the University of Ottawa for Multimethod Research Study



28/10/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE I CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-10-21-7370
Titre du projet / Project Title	Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments
Type de projet / Project Type	Thèse de doctorat / Doctoral thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	28/10/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	27/10/2022

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Sophie Emma LIGHTFOOT	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
Amanda VANDYK	École des sciences infirmières / School of Nursing	Superviseur / Supervisor
Hannah KIA	École des sciences infirmières / School of Nursing	Co-superviseur / Co-supervisor

Conditions spéciales ou commentaires / Special conditions or comments

550, rue Cumberland, pièce 154
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street, Room 154
Ottawa, Ontario K1N 6N5 Canada

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28/10/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Le Comité d'éthique de la recherche (CÉR) de l'Université d'Ottawa, opérant conformément à l'*Énoncé de politique des Trois conseils* (2014) et toutes autres lois et tous règlements applicables, a examiné et approuvé la demande d'éthique du projet de recherche ci-nommé.

L'approbation est valide pour la durée indiquée plus haut et est sujette aux conditions énumérées dans la section intitulée "Conditions Spéciales ou Commentaires". Le formulaire « Renouvellement ou Fermeture de Projet » doit être complété quatre semaines avant la date d'échéance indiquée ci-haut afin de demander un renouvellement de cette approbation éthique ou afin de fermer le dossier.

Toutes modifications apportées au projet doivent être approuvées par le CÉR avant leur mise en place, sauf si le participant doit être retiré en raison d'un danger immédiat ou s'il s'agit d'un changement ayant trait à des éléments administratifs ou logistiques du projet. Les chercheurs doivent aviser le CÉR dans les plus brefs délais de tout changement pouvant augmenter le niveau de risque aux participants ou pouvant affecter considérablement le déroulement du projet, rapporter tout évènement imprévu ou indésirable et soumettre toute nouvelle information pouvant nuire à la conduite du projet ou à la sécurité des participants.

The University of Ottawa Research Ethics Board, which operates in accordance with the *Tri-Council Policy Statement* (2014) and other applicable laws and regulations, has examined and approved the ethics application for the above-named research project.

Ethics approval is valid for the period indicated above and is subject to the conditions listed in the section entitled "Special Conditions or Comments". The "Renewal/Project Closure" form must be completedfour weeks before the above-referenced expiry date to request a renewal of this ethics approval or closure of the file.

Any changes made to the project must be approved by the REB before being implemented, except when necessary to remove participants from immediate endangerment or when the modification(s) only pertain to administrative or logistical components of the project. Investigators must also promptly alert the REB of any changes that increase the risk to participant(s), any changes that considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project or the safety of the participant(s).

Kim THOMPSON
Responsable d'éthique en recherche / Protocol Officer
Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board**

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Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

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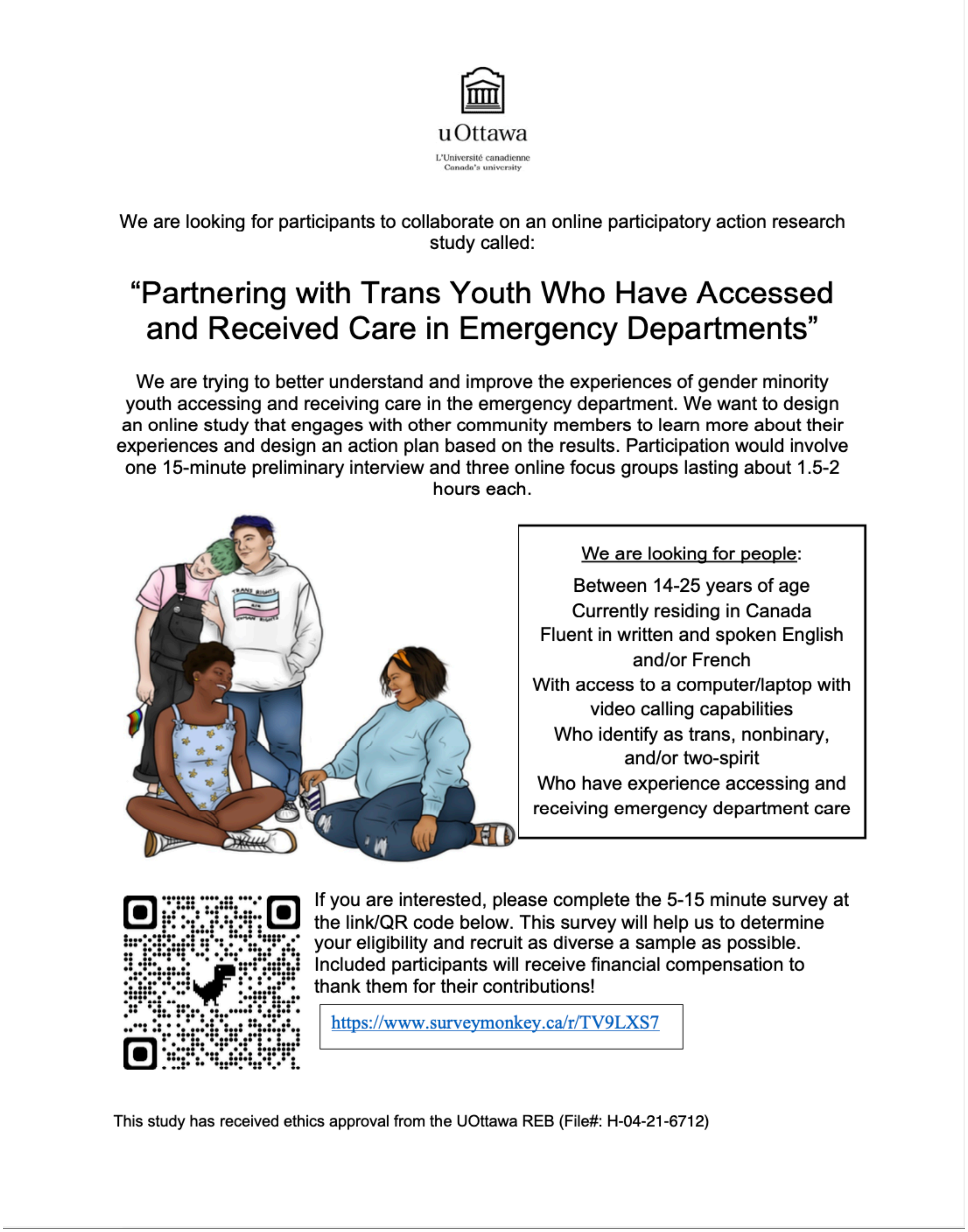
www.recherche.uottawa.ca/deontologie I www.recherche.uottawa.ca/ethics

Appendix D – Recruitment Poster for Focus Groups



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Canada's university

We are looking for participants to collaborate on an online participatory action research study called:

"Partnering with Trans Youth Who Have Accessed and Received Care in Emergency Departments"

We are trying to better understand and improve the experiences of gender minority youth accessing and receiving care in the emergency department. We want to design an online study that engages with other community members to learn more about their experiences and design an action plan based on the results. Participation would involve one 15-minute preliminary interview and three online focus groups lasting about 1.5-2 hours each.

<u>We are looking for people</u>:

Between 14-25 years of age
Currently residing in Canada
Fluent in written and spoken English and/or French
With access to a computer/laptop with video calling capabilities
Who identify as trans, nonbinary, and/or two-spirit
Who have experience accessing and receiving emergency department care

If you are interested, please complete the 5-15 minute survey at the link/QR code below. This survey will help us to determine your eligibility and recruit as diverse a sample as possible. Included participants will receive financial compensation to thank them for their contributions!

https://www.surveymonkey.ca/r/TV9LXS7

This study has received ethics approval from the UOttawa REB (File#: H-04-21-6712)

Appendix E – Recruitment Poster for Focus Groups (French)

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Nous recherchons des participants pour collaborer à une étude de recherche-action participative en ligne appelée:

« Collaborer avec les jeunes trans qui accèdent et reçoivent des soins de santé dans les salles d'urgences »

Nous essayons de mieux comprendre et d'améliorer les expériences des jeunes de minorités de genre qui accèdent et reçoivent des soins de santé aux urgences. Nous voulons concevoir une étude en ligne qui engage d'autres membres de la communauté pour en savoir plus sur leurs expériences et concevoir un plan d'action basé sur les résultats. La participation impliquerait une entrevue de 15 minutes et trois groupes de discussion en ligne d'une durée d'environ 1,5 à 2 heures chacun.

Nous recherchons des personnes :

Entre 14 et 25 ans
Qui résident actuellement au Canada
Qui parlent et écrivent couramment l'anglais et/ou le français
Qui ont accès à un ordinateur (ou un autre appareil) avec des capacités d'appel vidéo
Qui s'identifient comme trans, non binaire et/ou bispirituel
Qui ont de l'expérience dans l'accés et la réception des soins aux urgences

Si vous êtes intéressé, veuillez remplir le sondage de 5 à 15 minutes au lien / code QR ci-dessous. Ce sondage nous aidera à déterminer votre éligibilité et à recruter un échantillon aussi diversifié que possible.
Les participants inclus recevront une compensation financière pour les remercier de leurs contributions!

https://www.surveymonkey.ca/r/XC9J8YR

This study has received ethics approval from the UOttawa REB (File#: H-04-21-6712)

Appendix F - Information Sheet and Consent Form for Focus Groups

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Canada's university

Principal investigator:
Sophie Lightfoot BScN, RN, PhD(c) (she/her)
School of Nursing, Faculty of Health Sciences
University of Ottawa

Supervisors:
Amanda Vandyk RN, PhD (she/her)
Associate Professor
School of Nursing, Faculty of Health Sciences
University of Ottawa
Phone: (613) 562-5800 ext. 6246
Email: Amanda.Vandyk@uottawa.ca

Hannah Kia PhD, RCSW (she/her)
Assistant Professor
School of Social Work
University of British Columbia
Email: Hannah.kia@ubc.ca

Title: Partnering with Trans Youth Who Have Accessed Emergency Departments

Invitation to participate: You are invited to participate in a research study led by Sophie Lightfoot and her supervisors Dr. Amanda Vandyk and Dr. Hannah Kia. The study is part of Sophie's PhD Thesis. This project is not linked to any of the organizations or agencies that may have shared the recruitment poster with you. This means that your relationship with those organizations or agencies will not be affected if you decide to participate. You are able to participate in English and in French.

Why is the study being done?

There is very little research about the experiences of trans*, nonbinary, and/or two spirit youth accessing and receiving care in emergency departments. We would like to team up with you to design a study that explores your experiences, to run the study, and to find a way to use the results to make emergency departments more trans-affirming.

How many people will take part in this study?

In this phase of the study, five to eight youth will work together to create a study, run it, and analyse and share the results.

What will my participation look like?

Participation for this phase will be one 15-minute preliminary interview with Sophie and three focus groups over the course of about two weeks. The interview and the focus groups will be hosted over a secure virtual platform (Microsoft Teams). The sessions will last between 1.5 and 2 hours and will be audio recorded.

What are the risks of participating in this study?

Even though it isn't the focus of this phase of the study, you may end up talking about some of your experiences in the emergency department. If these experiences were negative, you may find talking about them uncomfortable. If so, we would suggest you call a peer support line such as Trans Lifeline (Telephone: 1(877) 330-6366) or a crisis line, such as the Distress Centre crisis line (Telephone: 1(866) 996-0991 or (613) 722-6914 for 24/7 help. You are free to not answer any questions and to take breaks from the focus group as you need them. Because of the focus group format, other group members will see your face and the name that you provide us. This means that there is a risk that someone could recognize and identify you.

What are the benefits of participating in this study?

You may learn new research skills by helping to plan and run a research project. Also, one of the goals of this project is to use the results of the study to benefit your community. We will work together to figure out a way to do so.

What about Confidentiality and Privacy?

Your information will only be used for the this study. Only Sophie and her thesis supervisors will have access to the data. We will use a random code instead of your name on your 'preliminary survey' and on the transcript of the focus groups. There is a risk that someone could overhear what you're saying in the preliminary interview and the focus group. Make sure you are in a place that is private. Anything that is audio recorded will be transcribed, meaning written out. The transcript will not include any names or information that could be used to identify you. The research data (audio recordings, consent forms, focus group transcripts, 'preliminary survey') will be locked in a filing cabinet in Sophie Lightfoot's locked office inside a locked research centre at the University of Ottawa. The research data will be kept for 7 years, until June 2028, and then destroyed and shredded.

The information you share will be kept strictly confidential unless:

(1) You tell us about the abuse of a person under the age of 16. Researchers have to report this type of information but can do it without mentioning your name.
(2) You tell us that you are a risk to yourself or others. Researchers have to facilitate access to emergency services.

Sharing the results

We will give you a summary of the results at the end of the study. Results will be published in scientific journals and will be presented at conferences. We will also collaborate to find ways to share this information in your communities.

Compensation

You will receive 25$ via e-transfer for each of the three focus groups that you participate in, even if you don't complete it. If you choose to withdraw (drop out) during or after a focus group, you will still be compensated for that session.

If I choose, how would I withdraw from the study?

You do not have to participate in this study. You can withdraw from the study at any time without giving us a reason. If you do withdraw, we will still use the data from the focus groups that you participated in because it is too difficult to take out individual comments from a group conversation. Your verbal consent tells us that you understand the information in this consent form and that you agree to participate. By giving us your verbal consent, you are not losing your legal rights as a research participant and the researchers still need to maintain their legal and professional responsibilities.

Ethical aspects of this study

You may contact the principal investigator or her supervisors at any time about this study and your participation. This doctoral thesis study received ethics approval from the University of Ottawa Research Ethics Board. Any question or concern about the ethical conduct of this study may be addressed to the Protocol Officer for Ethics in Research at the University of Ottawa. Phone: (613) 562.5387; Email: ethics@uottawa.ca.

Consent

I, ___________________________________ (name in print), have read and understood this consent form. All my questions and concerns were addressed to my satisfaction. I may contact the researchers at any time for further information.

I understand that the focus groups audio recorded: Yes☐No
I accept to be quoted directly (any identifying information will be removed): Yes☐No☐

Correspondence may be directed to:

I agree to participate in this study.

Principal Investigator's signature: _______________________________ Date: ______________

Appendix G - Information Sheet and Consent Form for Focus Groups (French)

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Canada's university

Investigatrice principale:
Sophie Lightfoot BScN, IA, PhD(c) (elle/la)
École des sciences infirmières, Faculté des sciences de la santé
Université d'Ottawa

Superviseures:
Amanda Vandyk IA, PhD (elle/la)
Professeure agrégée
École des sciences infirmières,
Faculté des sciences de la santé
Université d'Ottawa
(613) 562-5800 ext. 6246
Amanda.Vandyk@uottawa.ca

Hannah Kia PhD, RCSW (elle/la)
Professeure adjointe
École de travail social
Université de la Colombie-Britannique
Hannah.kia@ubc.ca

Titre du projet : Collaborer avec les jeunes trans qui accèdent et reçoivent des soins de santé dans les salles d'urgences

Invitation à participer: Vous êtes invité(e)s à participer au projet de thèse de doctorat, mené par Sophie Lightfoot et ses superviseures de thèse, Dre. Amanda Vandyk et Dre. Hannah Kia. Ce projet n'est pas lié aux organisations et agences qui ont peut-être partagé l'affiche de recrutement avec vous. Cela veut dire que votre relation avec ces organisations ou agences ne devrait pas être affectée si vous décidez de participer. Vous pouvez participer en anglais ou en français.

Pourquoi cette étude est-elle réalisée ?

Il y a très peu de recherches sur les expériences des jeunes trans *, non binaires et / ou bispirituels qui accèdent et reçoivent des soins aux urgences. Nous aimerions travailler ensemble pour créer une étude qui explore vos expériences, pour mener l'étude et pour trouver un moyen d'utiliser les résultats pour rendre les services d'urgence plus trans-affirmatifs.

Combien de personnes participeront à cette étude ?

Dans cette phase de l'étude, cinq à huit jeunes travailleront ensemble pour créer une étude, la mettre en œuvre, analyser et partager les résultats.

À quoi va avoir l'air ma participation?

La participation à cette phase consistera de trois groupes de discussion durant une période d'environ deux semaines. Les groupes de discussion seront sur une plateforme virtuelle sécurisée (Microsoft Teams). Ces sessions devraient durer entre 1,5 et 2 heures et seront enregistrées numériquement.

Quels sont les risques liés à la participation à cette étude ?

Bien que ce ne soit pas l'objet de cette phase de l'étude, vous pourriez finir par discuter de certaines de vos expériences aux urgences. Si ces expériences étaient négatives, vous pourriez vous trouver mal à l'aise d'en discuter. Si tel est le cas, nous vous encouragerons à appeler un service de soutien par les pairs, tel que Trans Lifeline (téléphone: 1 (877) 330-6366) ou une ligne de crise, comme la ligne de crise du centre de détresse (téléphone: 1 (866) 996- 0991 ou (613) 722-6914 pour de l'aide 24h / 7j. Vous êtes libre de refuser de répondre à toutes questions et de prendre des pauses dans le groupe de discussion lorsque vous en avez besoin. En raison du format des groupes de discussion, les autres participants verront votre visage et le nom que vous nous avez fournis. Par conséquent, le risque existe que quelqu'un puisse vous reconnaitre et vous identifier.

Quels sont les avantages de participer à cette étude ?

Vous pouvez acquérir de nouvelles compétences en recherche par aider à planifier et à mettre en œuvre un projet de recherche. De plus, l'un des objectifs de ce projet est d'utiliser les résultats de l'étude au profit de votre communauté. Nous travaillerons ensemble pour trouver un moyen de le faire.

Qu’en est-il de la confidentialité et de la vie privée ?

Vos informations ne seront utilisées qu'aux fins de cette étude. L'accès aux données de recherche sera limité à Sophie et à ses superviseures. Un code sera utilisé pour vous identifier sur votre « enquête préliminaire » et sur la transcription des groupes de discussion. Il y a un risque que quelqu’un puisse entendre ce que vous dites lors de l’entrevue préliminaire et des groupes de discussion. Il est donc important de bien planifier un lieu privé. Tout ce qui est enregistré sera transcrit, c’est-à-dire écrit. La transcription n’inclura aucun nom ni aucune information qui pourraient être utilisés pour vous identifier. Les données de recherche (enregistrements audio, formulaires de consentement, transcriptions des groupes de discussion, « enquête préliminaire ») seront stockées en toute sécurité dans un classeur verrouillé dans le bureau verrouillé de Sophie Lightfoot dans un centre de recherche verrouillé à l'Université d'Ottawa. Les données de recherche seront conservées pendant 7 ans, jusqu'en juin 2028, quand elles seront détruites et déchiquetées.

Les informations que vous partagez resteront strictement confidentielles, sauf si:

(1) Vous divulguez un abus contre une personne de moins de 16 ans. La chercheuse doit le signaler mais peut le rapporter comme provenant d'une source anonyme.

(2) Vous dites que vous présentez un risque pour vous-même ou pour les autres. La chercheuse doit faciliter l'accès aux services d'urgence.

Diffusion des résultats

Un résumé des résultats vous sera fourni à la fin de l'étude. Les résultats seront publiés dans des revues scientifiques et seront présentés lors de conférences. Nous collaborerons également pour trouver des moyens de partager ces informations dans vos communautés.

Compensation

Vous recevrez 25 $ par virement électronique pour chacun des trois groupes de discussion auxquels vous participez. Si vous choisissez de vous retirer pendant ou après un groupe de discussion, vous recevrez toujours une compensation pour cette session.

Si je choisis, comment pourrais-je me retirer de l’étude ?

Vous n'êtes pas obligé de participer à cette étude. Vous pouvez vous retirer de l'étude à tout moment sans justifier votre décision. Si vous vous retirez, vos données des discussions de groupe seront toujours utilisées. Votre consentement verbal indique que vous comprenez les informations dans ce formulaire de consentement et que vous acceptez de participer. En donnant votre consentement verbal, vous ne renoncez pas à vos droits légaux en tant que participant à la recherche et vous ne libérez pas les enquêteurs de leurs responsabilités juridiques et professionnelles.

Aspects éthiques de cette étude

Vous pouvez contacter la chercheuse principale ou ses superviseures à tout moment concernant cette étude et votre participation. Cette étude de thèse de doctorat a reçu l'approbation éthique du Comité d'éthique de la recherche de l'Université d'Ottawa.

Toute question ou préoccupation concernant la conduite éthique de cette étude peut être adressée au responsable du protocole pour l'éthique de la recherche à l'Université d'Ottawa, Tabaret Hall, salle 154, 550 Cumberland St., Ottawa, ON, K1N 6N5. Téléphone : (613) 562.5387 ; Courriel : ethics@uottawa.ca.

Consentement

Je, ____________________________________ (nom en lettres moulées), ai lu et compris ce formulaire de consentement. Toutes mes questions et préoccupations ont été traitées à ma satisfaction. Je peux contacter les chercheurs de l'étude à tout moment pour obtenir de plus amples informations.

J'accepte que les groupes de discussion soit enregistré numériquement: Oui ☐ Non ☐
J'accepte d'être cité directement (toute information permettant de m'identifier sera supprimée) : Oui ☐ Non ☐

Si vous avez des questions ou des préoccupations au sujet de cette étude, vous pouvez contacte:

J'accepte de participer à cette étude.

Signature – Investigatrice principale : ________________________________ Date:___________

Appendix H – Recruitment Poster for Study

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We are looking for participants for an online participatory action research study called:

"Trans, Nonbinary and Two-spirit Youth Experiences in Emergency Departments"

We are a team of trans and nonbinary youth and research partners from the University of Ottawa trying to better understand and improve the experiences of gender minority youth accessing and receiving care in the emergency department. We have created a two-part online study to learn more about your experiences so that we can design an action plan based on the results. Part 1 consists of an online questionnaire (15-20 minutes) designed to learn more about you and your experiences. Part 1 is open to anyone who meets the following criteria:

Between 14-25 years of age
Currently residing in Canada
Fluent in written and spoken English and/or French
Who identify as trans, nonbinary, and/or Two-spirit
Who have been to an emergency department in Canada in the last 2 years

Part 2 of the study involves exploring your experiences in more depth in the way that feels the most authentic to you!

We will be selecting as diverse a group as possible to engage in interviews (1-2 hours), familial focus groups (1.5-2 hours), journaling and/or art-based expression, depending on their preferences. If you are interested in Part 2, please let us know at the end of your questionnaire, which can be accessed at the link/QR code below.
Included participants in Part 2 will receive financial compensation to thank them for their contributions!

https://www.surveymonkey.ca/r/GB7Q2GW

This study has received ethics approval from the UOttawa REB (File#: H-10-21-7370)

Appendix I – Recruitment Poster for Study (French)

uOttawa

L'Université canadienne
Canada's university

Nous recherchons des participants pour une étude de recherche-action participative en ligne appelée:

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence »

Nous sommes une équipe de jeunes trans et non-binaires et de partenaires de recherche de l'Université d'Ottawa qui tentent de mieux comprendre et d'améliorer les expériences des jeunes des minorités de genre qui accèdent et reçoivent des soins dans les services d'urgence. Nous avons créé une étude en ligne en deux parties pour en savoir plus sur vos expériences afin de pouvoir concevoir un plan d'action basé sur les résultats. La partie 1 consiste en un questionnaire en ligne (15-20 minutes) conçu pour en savoir plus sur vous et vos expériences. La partie 1 est ouverte à toute personne répondant aux critères suivants :

Entre 14 et 25 ans
Qui résident actuellement au Canada
Qui parlent et écrivent couramment l'anglais et/ou le français
Qui s'identifient comme trans, non binaire et/ou bispirituel
Qui ont visité une salle d'urgences au Canada depuis les deux dernières années

La deuxième partie de l'étude consiste à explorer plus en profondeur vos expériences de la manière qui vous semble la plus authentique !

Nous sélectionnerons un groupe aussi diversifié que possible qui participera à des entrevues, à des groupes de discussion familiaux, à la rédaction d'un journal et/ou à une expression artistique, en fonction de ses préférences. Si vous êtes intéressé par la partie 2, veuillez nous le faire savoir à la fin de votre questionnaire, qui peut être consulté à l'aide du lien/code QR. Les participants inclus dans la partie 2 recevront une compensation financière pour les remercier de leur contribution !

https://www.surveymonkey.ca/r/GB7TG5H

This study has received ethics approval from the UOttawa REB (File#: H-10-21-7370)

Appendix J – Extended Demographics Questionnaire

https://www.surveymonkey.ca/r/GB7Q2GW

Page 1

“Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments”

Welcome and thank you for your interest!

Through this study, we are aiming to gather qualitative and quantitative data about the experiences of trans, nonbinary and Two-spirit youth in Canadian emergency departments. Ultimately, we hope to inform strategies to improve healthcare for these persons. This study was designed collaboratively by a team of Canadian trans and nonbinary youth and their research partner:

Sophie Lightfoot BScN, RN, PhD(c) (she/her)
School of Nursing,
Faculty of Health Sciences,
University of Ottawa

Sophie is supervised by:

Amanda Vandyk RN, PhD (she/her)
Associate Professor
School of Nursing,
Faculty of Health Sciences
University of Ottawa
Email: Amanda.Vandyk@uottawa.ca

Hannah Kia PhD, RCSW (she/her)
Adjunct Professor
School of Nursing
University of Ottawa
Email: Hannah.kia@ubc.ca

The study contains 2 parts.
Part 1 includes two brief questionnaires (5-15 minutes) to help us learn a bit about you and your experiences. If you are eligible, you will be able to see and fill in the two questionnaires right away. Your answers to Part 1 will help us to select as diverse a group as possible for Part 2.

Part 2 will involve more in-depth explorations of your experiences. If invited, you may participate via an online interview, online focus group, written response, and/or through an art medium that resonates with you.

Please note that you are under no obligation to participate in Part 2. Once you have completed Part 1, you will be asked to let us know if you are interested in being contacted for Part 2.

The three questions on the next page will determine your eligibility for Part 1.

Page 2

"Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments"

Eligibility questions

1. Are you between the ages of 14-25? Yes No
2. Do you identify as trans, nonbinary, and/or Two-spirit? Yes No
3. Have you accessed and received emergency care in a Canadian emergency department in the last two years? Yes No
   (You would be eligible to participate if you have had experiences with a Canadian emergency department in the last two years AND before that. In case this is true for you, we will be open to hearing about any experiences you've had with a Canadian emergency department that you'd like to share with us.)

Page 3

"Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments"

Information and consent – please refer to implied consent form

Page 4

"Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments"

Demographic questionnaire
We are interested in getting to know you better so that we can understand how identity plays a role in healthcare encounters and do our best to capture diverse voices within trans/nonbinary/Two-spirit youth communities.

5. What is your exact age? *Comment box*

6. Please describe your gender, to the extent that you are comfortable. *Comment box.*

7. What are your pronouns? *Comment box*

8. Please describe your sexual orientation. *Comment box*

9. Please describe your race and/or ethnicity. *Comment box*

10. Are you a Canadian citizen? If no, please describe your immigration status. *Comment box.*

11. What is the highest level of education that you have completed? *Comment box.*

12. Which of the following emergency department settings do you have experience interacting with? *Select all that apply:*

General urban emergency department; General rural emergency department; Pediatric emergency department; Mental health emergency department

13. In which cities/regions have you accessed and received emergency department care? *Comment box.*

14. If you believe that there is another aspect of your identity, or how you are perceived, that influences your emergency healthcare experiences (positively, negatively, or both), please describe it here: *(ex. Mental health diagnosis, cis assumed/"passing") 5 short text boxes.*

Page 5

"Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments"

Quantitative questions

These questions are designed to collect much needed statistical data about the experiences of trans, nonbinary and Two-spirit youth accessing emergency departments.

15. In the last two years, approximately how many times have you been to the emergency department? *Multiple choice*

Yearly; Twice a year; Every 3-4 months; Monthly; Weekly; Multiple times per week

If the average number of visits over the last two years is in some way different from your usual usage of the emergency department, please provide further details here: (ex. Family MD retired, crisis situation) Comment box.

16. What are the most common reasons that you go to the emergency department? *5 short text boxes*

(Please rank them from most common to least common. Provide reasons that best describe your experience – you do not need to list 5.)

17. On average, how would you rate the service you receive in the emergency department on a scale of 0 to 10? (10 being the best) *Short text box.*

18. How often do you feel like your concern is addressed after a visit to the emergency department? *Multiple choice.*

A lot of the time; Some of the time; A little of the time; Never

You may add further detail here if applicable. *Comment box.*

19. Have you ever avoided going to the emergency department when you needed care because you are trans/nonbinary/Two-spirit? *Yes No*

You may add further detail here if applicable. *Comment box.*

20. Have you ever had to educate an emergency provider regarding your needs as a trans person? *Multiple choice.*

Yes, provided a lot of education.; Yes, provided a lot of eduation. Yes, provided some education.; Yes, provided a little education.; No

You may add further detail here if applicable. *Comment box.*

Page 6

“Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments”

Discussion questions

For Part 2 of this study, we are hoping to explore your experiences in greater depth guided by questions such as:

1. What is it like for you to go to the emergency department? (Including what it's like before, during, and after the visit.)

2. How do you think your gender identity/expression influences your emergency department experiences?

3. What are the most significant barriers that you've faced when accessing emergency department care?

4. What has contributed to more positive experiences in the emergency department?

5. What are your recommendations for healthcare providers and other people involved in the emergency care of trans, nonbinary, and Two-spirit youth?

21. Are you interested in participating in the Part 2 of the study? Yes No

Page 7

"Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments"

Thank you for your interest in Part 2!

We want to offer you a way to participate that feels authentic to you. As such, options include:

1. Discussion-style online interviews with one or two members of the research team. You are welcome to have a support person join the call if you would like.
2. Online familial focus groups, wherein you can select friends/family who meet the inclusion criteria to join in a group discussion facilitated by one or two members of the research team.
3. Journaling/written response

All three options can be paired with an art-based response that feels authentic to you. These may include visual art, poetry, dance, music, etc...

22. Please enter the name you would like us to address you by: *Comment box*

23. Please enter the email you would like us to contact you by: *Comment box.*

24. How would you like to participate? *Multiple choice.*

Interview; Focus group; Journaling

25. Our research team includes a mix of persons with trans lived experiences, healthcare professionals, and both. If you have selected the interview option, please specify if you would like to request a person of trans lived experience be present at the interview. *Multiple choice.*

Yes, please ensure that a person of trans lived experience is part of my interview.
No, I do not have a preference.
N/A (I did not select the interview option.)

26. Are you interested in adding an art-based option? *Yes No*

If yes, please describe: *Comment box.*

Appendix K – Extended Sociodemographic Questionnaire (French)

https://www.surveymonkey.ca/r/GB7TG5H

Page 1

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence »

Bienvenue et merci de votre intérêt !

Au cours de cette étude, nous visons à recueillir des données qualitatives et quantitatives sur les expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence canadiennes. En fin de compte, nous espérons éclairer les stratégies pour améliorer les soins de santé pour ces personnes. Cette étude a été conçue en collaboration par une équipe de jeunes trans et non binaires canadiens et leur partenaire de recherche :

Sophie Lightfoot BScN, IA, PhD(c) (elle)
École d'infirmières,
Faculté des sciences de la santé,
Université d'Ottawa

Sophie est encadrée par :
Amanda Vandyk IA, PhD (elle)
Professeure agrégée
École d'infirmières,
Faculté des sciences de la santé,
Université d'Ottawa
E-mail: Amanda.Vandyk@uottawa.ca

Hannah Kia PhD, TCSR (elle)
Professeure adjointe
École d'infirmières,
Faculté des sciences de la santé,
Université d'Ottawa
E-mail: Hannah.kia@ubc.ca

L'étude contient 2 parties.
La partie 1 comprend deux brefs questionnaires (5-15 minutes) pour nous aider à en apprendre un peu plus sur vous et vos expériences. Si vous êtes éligible, vous pourrez voir et remplir les deux questionnaires immédiatement. Vos réponses à la partie 1 nous aideront à sélectionner un groupe aussi diversifié que possible pour la partie 2.

La partie 2 impliquera des explorations plus approfondies de vos expériences. Si vous y êtes invité, vous pouvez participer via une entrevue en ligne, un groupe de discussion en ligne, une réponse écrite et/ou via un support artistique qui résonne avec vous.

Veuillez noter que vous n'êtes pas obligé de participer à la partie 2. Une fois que vous avez terminé la partie 1, il vous sera demandé de nous faire savoir si vous souhaitez être contacté pour la partie 2.

Les trois questions de la page suivante détermineront votre admissibilité à la partie 1.

Page 2

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence »

Questions d'éligibilité

1. Êtes-vous entre l'âge de 14 et 25 ans ? Oui Non
2. Identifiez-vous comme trans, non binaire et/ou bispirituel ? Oui Non
3. Avez-vous consulté et reçu des soins d'urgence dans un service d'urgence canadien au cours des deux dernières années? Oui Non
   (Vous seriez admissible à participer si vous avez eu des expériences avec un service d'urgence canadien au cours des deux dernières années ET avant cela. Si cela est vrai pour vous, nous serons ouverts à entendre parler de toute expérience que vous avez eue avec un service d'urgence canadien que vous aimeriez partager avec nous.)

Page 3

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence »

Informations sur l'étude et consentement – SVP consulter le document « consentement implicite »

4. Continuer aux questionnaires ? Oui Non

Page 4

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence »

Questionnaire démographique

Nous souhaitons mieux vous connaître afin de comprendre comment l'identité joue un rôle dans les rencontres avec les soins de santé et de faire de notre mieux pour capter diverses voix au sein des communautés de jeunes trans/non binaires/bispirituels.

5. Quel est votre âge exact ? *Zone de commentaire*

6. Veuillez décrire votre genre, dans la mesure où vous êtes à l'aise. *Zone de commentaire.*

7. Quels sont vos pronoms ? *Zone de commentaire*

8. Veuillez décrire votre orientation sexuelle. *Zone de commentaire*

9. Veuillez décrire votre race et/ou origine ethnique. *Zone de commentaire*

10. Êtes-vous citoyen canadien? Si non, veuillez décrire votre statut d'immigration. *Zone de commentaire*.

11. Quel est le niveau d'études le plus élevé que vous ayez atteint ? *Zone de commentaire.*

12. Avec lesquels des services d'urgence suivants avez-vous de l'expérience en interaction ? *Sélectionnez tout ce qui s'y rapporte:*

Urgences générales urbaines ; Service des urgences rurales générales ; Service des urgences pédiatriques ; Service des urgences en santé mentale

13. Dans quelles villes/régions avez-vous consulté et reçu des soins d'urgence ? *Zone de commentaire*.

14. Si vous pensez qu'il existe un autre aspect de votre identité, ou de la façon dont vous êtes perçu, qui influence vos expériences de soins d'urgence (positivement, négativement ou les deux), veuillez le décrire ici : (*par exemple, diagnostic de santé mentale, cis supposé/ « passing* ») *5 zones de texte courtes.*

Page 5

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence »

Questions quantitatives

Ces questions sont conçues pour recueillir des données statistiques indispensables sur les expériences des jeunes trans, non binaires et bispirituels qui accèdent aux services d'urgence.

15. Au cours des deux dernières années, approximativement combien de fois êtes-vous allé aux urgences ? *Choix multiple*

Annuel; Deux fois par an; Tous les 3-4 mois ; Mensuel; Hebdomadaire; Plusieurs fois par semaine

Si le nombre moyen de visites au cours des deux dernières années est en quelque sorte différent de votre utilisation habituelle du service des urgences, veuillez fournir plus de détails ici : (ex. Médecin de famille à la retraite, situation de crise) *Boîte de commentaires*.

16. Quelles sont les raisons les plus courantes pour lesquelles vous vous rendez aux urgences ? *5 zones de texte courtes*

(Veuillez les classer du plus courant au moins courant. Fournissez les raisons qui décrivent le mieux votre expérience - vous n'avez pas besoin d'énumérer 5.)

17. En moyenne, comment évalueriez-vous le service que vous recevez à l'urgence sur une échelle de 0 à 10 ? (10 étant le meilleur) *Zone de texte courte.*

18. À quelle fréquence avez-vous l'impression que votre préoccupation est abordée après une visite au service des urgences ? *Choix multiple*.

La plupart du temps; Une partie du temps; Un peu du temps; Jamais

Vous pouvez ajouter plus de détails ici, le cas échéant. *Zone de commentaire.*

19. Avez-vous déjà évité d'aller aux urgences lorsque vous aviez besoin de soins parce que vous êtes trans/non binaire/bispirituel ? Oui Non

Vous pouvez ajouter plus de détails ici, le cas échéant. *Zone de commentaire.*

20. Avez-vous déjà eu à informer un fournisseur d'urgence de vos besoins en tant que personne trans ? *Choix multiple*.

Oui, fourni beaucoup d'éducation.; Oui, fourni beaucoup d'éducation. Oui, fourni une certaine éducation.; Oui, fourni un peu d'éducation.; Non

Vous pouvez ajouter plus de détails ici, le cas échéant. *Zone de commentaire.*

Page 6

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d’urgence »

Questions de discussion

Pour la partie 2 de cette étude, nous espérons explorer vos expériences plus en profondeur, guidés par des questions telles que :

1. Comment est-ce pour vous d'aller au service des urgences? (Y compris ce que c'est avant, pendant et après la visite.)

2. Comment pensez-vous que votre identité/expression de genre influence vos expériences au service des urgences ?

3. Quels sont les obstacles les plus importants auxquels vous avez été confrontés lors de l'accès aux services d'urgence ?

4. Qu'est-ce qui a contribué à des expériences plus positives au service des urgences ?

5. Quelles sont vos recommandations pour les prestataires de soins de santé et les autres personnes impliquées dans les soins d'urgence des jeunes trans, non binaires et bispirituels ?

21. Êtes-vous intéressé à participer à la partie 2 de l'étude ? Oui Non

Page 7

« Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence »

Merci de votre intérêt pour la partie 2 !

Nous voulons vous offrir une façon de participer qui vous semble authentique. Ainsi, les options incluent :

1. Entretiens en ligne de type discussion avec un ou deux membres de l'équipe de recherche. Vous pouvez demander à une personne de soutien de se joindre à l'appel si vous le souhaitez.
2. Groupes de discussion familiaux en ligne, dans lesquels vous pouvez sélectionner des amis/de la famille qui répondent aux critères d'inclusion pour participer à une discussion de groupe animée par un ou deux membres de l'équipe de recherche.
3. Journalisation/réponse écrite

Les trois options peuvent être associées à une réponse artistique qui vous semble authentique. Ceux-ci peuvent inclure l'art visuel, la poésie, la danse, la musique, etc...

22. Veuillez spécifier votre nom : *Zone de commentaire.*

23. Veuillez spécifier votre e-mail : *Zone de commentaire.*

24. Comment aimeriez-vous participer? *Choix multiple.*

Entretien; Groupe de discussion ; Journalisation

25. Notre équipe de recherche comprend un mélange de personnes ayant vécu des expériences trans, de professionnels de la santé, et les deux. Si vous avez choisi l'option d'entrevue, veuillez préciser si vous souhaitez qu'une personne ayant une expérience vécue trans soit présente à l'entrevue. *Choix multiple.*

Oui, je veux qu'une personne ayant une expérience vécue trans fait partie de mon entretien.
Non, je n'ai pas de préférence.
N/A (Je n'ai pas sélectionné l'option d'entrevue.)

26. Souhaitez-vous ajouter une option artistique ? Oui Non

Si oui, veuillez décrire : *Zone de commentaires*.

Appendix L – Implied Consent for Extended Demographics Questionnaire

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Canada's university

Title: Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments

Thank you for showing interest in participating in this study and for answering the eligibility screening questions. The following series of questions were designed to create as diverse a sample as possible.

If you wish to participate in this study, please complete the following questions. The two questionnaires should take you approximately 5-15 minutes to complete. You do not have to answer any questions that you do not want to answer. If you are interested in participating in Part 2 of our study, you will be asked for your name and email so that we can contact you to participate if you are selected.

If selected, you will be contacted via the email address that you provide. We will also send you the information sheet and consent form for the study for you to review.

By completing and submitting your answers to the following questions you are consenting to the use of this information in this study. All data will be separated from identifying information (such as name and email address) and summarized in the study. In case you are not selected for Part 2, we will delete all of your identifying information as soon as we finish selecting participants.

The information that you will share will remain strictly confidential and will be used solely for the purposes of this research. The only people who will have access to the research data are Sophie Lightfoot and her supervisors.

In order to minimize the risk of security breaches and to help ensure your confidentiality, we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you are no longer using them / when you have completed the survey.

If you have any questions or require more information about the study itself, you may contact Sophie Lightfoot at the email address mentioned below.

If you have any questions with regards to the ethical conduct of this study, you may contact the Ethics Office at the University of Ottawa by 613-562-5387 or via email at ethics@uottawa.ca.
Thank you,

Sophie Lightfoot BScN, RN, PhD(c) (she/her)
School of Nursing, Faculty of Health Sciences
University of Ottawa

Appendix M – Implied Consent for Extended Demographics Questionnaire (French)

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L'Université canadienne
Canada's university

Titre du projet : Collaborer avec les jeunes trans qui accèdent et reçoivent des soins de santé dans les salles d'urgences

Merci d'avoir manifesté votre intérêt à participer à cette étude et d'avoir répondu aux questions de sélection d'admissibilité. La série de questions suivante a été conçue pour créer un échantillon aussi diversifié que possible.

Si vous souhaitez participer à cette étude, veuillez répondre aux questions suivantes. Les deux questionnaires devraient vous prendre environ 5 à 15 minutes à remplir. Vous n'êtes pas obligé de répondre à des questions auxquelles vous ne voulez pas répondre. Si vous êtes intéressé à participer à la partie 2 de notre étude, il vous sera demandé votre nom et votre adresse e-mail afin que nous puissions vous contacter pour participer si vous êtes sélectionné.

Si vous êtes sélectionné, vous serez contacté par l'adresse e-mail que vous fournissez. Nous vous enverrons la fiche d'information et le formulaire de consentement pour l'étude que vous pourrez examiner.

En complétant et en soumettant vos réponses aux questions suivantes, vous consentez à l'utilisation de ces informations dans cette étude. Toutes les données seront séparées des informations d'identification (telles que le nom et l'adresse e-mail) et résumées dans l'étude. Si vous n'êtes pas sélectionné pour la partie 2, nous supprimerons toutes vos informations d'identification dès que nous aurons terminé de sélectionner les participants.

Les informations que vous partagerez resteront strictement confidentielles et seront utilisées uniquement aux fins de cette recherche. Les seules personnes qui auront accès aux données de recherche sont Sophie Lightfoot et ses encadrants.

Afin de minimiser le risque de failles de sécurité et d'assurer votre confidentialité, nous vous recommandons d'utiliser des mesures de sécurité standard telles que la déconnexion de votre compte, la fermeture de votre navigateur et le verrouillage de votre écran ou de votre appareil lorsque vous ne les utilisez plus / lorsque vous avez rempli le sondage.

Si vous avez des questions ou souhaitez plus d'informations sur l'étude elle-même, vous pouvez contacter Sophie Lightfoot à l'adresse e-mail mentionnée ci-dessous.
Si vous avez des questions concernant la conduite éthique de cette étude, vous pouvez contacter le Bureau d'éthique de l'Université d'Ottawa au 613-562-5387 ou par courriel at ethics@uottawa.ca.

Merci,

Sophie Lightfoot BScN, IA, PhD(c) (elle/la)
École des sciences infirmières, Faculté des sciences de la santé
Université d'Ottawa

Appendix N – Interview Guide

1. What is it like for you to go to the emergency department? (Including what it's like before, during, and after the visit.)

Prompt: How do you prepare yourself?

2. How do you think your gender identity/expression influences your emergency department experiences?

Prompt: How do you feel that you are perceived in the emergency department?

3. What are the most significant barriers that you've faced when accessing emergency department care?

4. What has contributed to more positive experiences in the emergency department?

If no positive experiences, prompt: What is one think that you think could have improved your experiences?

5. What are your recommendations for healthcare providers and other people involved in the emergency care of trans, nonbinary, and Two-spirit youth?

Appendix O – Interview Guide (French)

1. Qu'est-ce que cela vous fait d'aller aux urgences ? (Y compris ce que c'est avant, pendant et après la visite.)

Invite : Comment vous préparez-vous ?

2. Comment pensez-vous que votre identité/expression de genre influence vos expériences au service des urgences ?

Invite : Comment vous sentez-vous perçu au service des urgences ?

3. Quels sont les obstacles les plus importants auxquels vous avez été confrontés lors de l'accès aux services d'urgence ?

4. Qu'est-ce qui a contribué à des expériences plus positives au service des urgences ?

S'il n'y a pas d'expériences positives, demandez : Selon vous, qu'est-ce qui aurait pu améliorer vos expériences ?

5. Quelles sont vos recommandations pour les prestataires de soins de santé et les autres personnes impliquées dans les soins d'urgence des jeunes trans, non binaires et bispirituels ?

Appendix P - Information Sheet and Consent Form for Interviews or Familial Focus Groups

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Canada's university

Principal investigator:
Sophie Lightfoot BScN, RN, PhD(c) (she/her)
School of Nursing, Faculty of Health Sciences
University of Ottawa

Supervisors:
Amanda Vandyk RN, PhD (she/her)
Associate Professor
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Hannah Kia PhD, RCSW (she/her)
Assistant Professor
School of Social Work
University of British Columbia
Email: Hannah.kia@ubc.ca

Title: Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments (TNB2SY-ED)

Invitation to participate: You are invited to participate in a research study that was designed collaboratively by a team of Canadian trans and nonbinary youth and their research partner Sophie Lightfoot who is a doctoral candidate supervised by Dr. Amanda Vandyk and Dr. Hannah Kia. The study is part of Sophie's PhD Thesis. You are able to participate in English and in French.

Why is the study being done?

There is very little research about the experiences of trans*, nonbinary, and/or two spirit youth accessing and receiving care in emergency departments. We would like to learn more about your experiences and find a way to use the results to make emergency departments more trans-affirming.

How many people will take part in this study?

In this phase of the study, 25 to 35 people will be invited to participate.

What will my participation look like?

If you chose the interview option, you participation will consist of a conversation lasting between 1-2 hours. The interview will be hosted over a secure virtual platform (Microsoft Teams) and will be audio recorded.

If you chose the familial focus group option, you participation will consist of a group discussion lasting between 1.5-2 hours. The focus group will be hosted over a secure virtual platform (Microsoft Teams) and will be audio recorded.

If you have chosen to participate in the art-based option, please take pictures of your entries and send us the pictures via email. These pictures will be password protected and saved onto a password protected laptop. You can spend as much time as you would like to create your piece before your interview or familial focus group when you will be invited to introduce your piece and its significance.

What are the risks of participating in this study?

If your experiences in the emergency department were negative, you may find talking about them uncomfortable. If so, we would suggest you call a peer support line such as Trans Lifeline (Telephone: 1(877) 330-6366) or a crisis line, such as the Distress Centre crisis line (Telephone: 1(866) 996-0991 or (613) 722-6914 for 24/7 help. You are free to not answer any questions and to take breaks as you need them.

What are the benefits of participating in this study?

One of the goals of this project is to use the results of the study to benefit your community. We will work together to figure out a way to do so.

What about Confidentiality and Privacy?

Your information will only be used for this study. Only Sophie and her thesis supervisors will have access to the data. We will use a random code instead of your name on your 'extended demographic questionnaire' and on the transcript of our conversation. The team of trans and non-binary youth who collaborated to design this project will analyze the results, and, therefore, will have access to de-identified results so that they can identify themes.

There is a risk that someone could overhear what you're saying in the preliminary interview and the focus group. Make sure you are in a place that is private. Anything that is audio recorded will be transcribed, meaning written out. The transcript will not include any names or information that could be used to identify you. The research data (audio recordings, consent forms, focus group transcripts, 'extended demographics survey', photos) will be locked in a filing cabinet in Sophie Lightfoot's locked office inside a locked research centre. The research data will be kept for 7 years, until November 2028, and then destroyed and shredded.

The information you share will be kept strictly confidential unless:

(3) You tell us about the abuse of a person under the age of 16. Researchers have to report this type of information but can do it without mentioning your name.
(4) You tell us that you are a risk to yourself or others. Researchers have to facilitate access to emergency services.

Sharing the results

We will give you a summary of the results at the end of the study. Results will be published in scientific journals and will be presented at conferences. We will also collaborate to find ways to share this information in your communities.

Compensation

You will receive 25$ via e-transfer for your participation. If you choose to withdraw (drop out) during or after your participation, you will still be compensated for that session.

If I choose, how would I withdraw from the study?

You do not have to participate in this study. You can withdraw from the study at any time without giving us a reason. If you do withdraw, we will still use the data from the focus groups that you participated in because it is too difficult to take out individual comments from a group conversation. Your verbal consent tells us that you understand the information in this consent form and that you agree to participate. By giving us your verbal consent, you are not losing your legal rights as a research participant and the researchers still need to maintain their legal and professional responsibilities.

Ethical aspects of this study

You may contact the principal investigator or her supervisors at any time about this study and your participation. This doctoral thesis study received ethics approval from the University of Ottawa Research Ethics Board. Any question or concern about the ethical conduct of this study may be addressed to the Protocol Officer for Ethics in Research at the University of Ottawa. Phone: (613) 562.5387; Email: ethics@uottawa.ca.

Consent

Verbal consent will be audio recorded.

I, ____________________________________ (name in print), have read and understood this consent form. All my questions and concerns were addressed to my satisfaction. I may contact the researchers at any time for further information.

I understand that the focus groups audio recorded: Yes ☐☐No ☐
I accept to be quoted directly (any identifying information will be removed): Yes ☐☐No ☐☐

I give my consent for the photographs of my art piece to be reproduced for educational and/or non-commercial purposes, in reports, presentations, publications, websites, and exhibitions connected to the TNB2SY-ED project. I understand that no identifying information will be attached to these photographs: Yes ☐ No ☐ N/A ☐

Correspondence may be directed to:
I agree to participate in this study.

Principal Investigator's signature: ________________________________ Date: _____________

Appendix Q - Information Sheet and Consent Form for Interviews or Familial Focus Groups (French)

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Investigatrice principale:
Sophie Lightfoot BScN, IA, PhD(c) (elle/la)
École des sciences infirmières, Faculté des sciences de la santé
Université d'Ottawa

Superviseures:
Amanda Vandyk IA, PhD (elle/la)
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Hannah Kia PhD, RCSW (elle/la)
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Hannah.kia@ubc.ca

Titre du projet : Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence.

Invitation à participer: Vous êtes invité(e)s à participer une étude conçue en collaboration par une équipe de jeunes trans et non binaires canadiens et leur partenaire de recherche Sophie Lightfoot qui est une candidate au doctorat supervisée par Dre. Amanda Vandyk et Dre. Hannah Kia. Cette étude fait partie de la thèse de doctorat de Sophie. Vous pouvez participer en anglais ou en français.

Pourquoi cette étude est-elle réalisée ?

Il y a très peu de recherches sur les expériences des jeunes trans *, non binaires et / ou bispirituels qui accèdent et reçoivent des soins aux urgences. Nous aimerions découvrir vos expériences et trouver des moyens d'utiliser les résultats pour rendre les services d'urgence plus trans-affirmatifs.

Combien de personnes participeront à cette étude ?

Dans cette phase de l'étude, 25 à 35 personnes seront invités à participer.

À quoi va avoir l'air ma participation?

Si vous avez choisi l'option d'une entrevue, la participation consistera d'une conversation qui devrait durer entre 1 et 2 heures. L'entrevue sera sur une plateforme virtuelle sécurisée (Microsoft Teams) et enregistré numériquement.

Si vous avez choisi l'option d'un groupe de discussion, la participation consistera d'un groupe de discussion qui devrait durer entre 1,5 et 2 heures. Le groupe de discussion sera sur une plateforme virtuelle sécurisée (Microsoft Teams) et enregistré numériquement.

Si vous avez choisi de participer à l'option artistique, veuillez prendre des photos de votre œuvre et nous les envoyer par courrier électronique. Ces photos seront protégées par un mot de passe et sauvegardées sur un ordinateur portable protégé par un mot de passe. Vous pouvez consacrer autant de temps que vous le souhaitez à la création de votre œuvre avant votre entrevue ou votre groupe de discussion familial, au cours duquel vous serez invité à présenter votre œuvre et sa signification.

Quels sont les risques liés à la participation à cette étude ?

Si vos expériences aux urgences étaient négatives, vous pourriez vous trouver mal à l'aise d'en discuter. Si tel est le cas, nous vous encouragerons à appeler un service de soutien par les pairs, tel que Trans Lifeline (téléphone: 1 (877) 330-6366) ou une ligne de crise, comme la ligne de crise du centre de détresse (téléphone: 1 (866) 996- 0991 ou (613) 722-6914 pour de l'aide 24h / 7j. Vous êtes libre de refuser de répondre à toutes questions et de prendre des pauses lorsque vous en avez besoin.

Quels sont les avantages de participer à cette étude ?

Un des objectifs de ce projet est d'utiliser les résultats de l'étude au profit de votre communauté. Nous travaillerons ensemble pour trouver un moyen de le faire.

Qu'en est-il de la confidentialité et de la vie privée ?

Vos informations ne seront utilisées qu'aux fins de cette étude. L'accès aux données de recherche sera limité à Sophie et à ses superviseures. Un code sera utilisé pour vous identifier sur votre « questionnaire sociodémographique étendu » et sur la transcription de notre conversation. L'équipe de jeunes trans et non binaires qui a collaboré à la création de cette étude analysera les résultats, et aura donc accès aux résultats dépersonnalisés pour identifier les thèmes.

Il y a un risque que quelqu'un puisse entendre ce que vous dites durant notre conversation, si applicable. Il est donc important de bien planifier un lieu privé. Tout ce qui est enregistré sera transcrit, c'est-à-dire écrit. La transcription n'inclura aucun nom ni aucune information qui pourraient être utilisés pour vous identifier. Les données de recherche (enregistrements audio, formulaires de consentement, transcriptions, « questionnaire sociodémographique étendu ») seront stockées en toute sécurité dans un classeur verrouillé dans le bureau verrouillé de Sophie Lightfoot dans un centre de recherche verrouillé. Les données de recherche seront conservées pendant 7 ans, jusqu'en novembre 2028, quand elles seront détruites et déchiquetées.

Les informations que vous partagez resteront strictement confidentielles, sauf si:

(1) Vous divulguez un abus contre une personne de moins de 16 ans. La chercheuse doit le signaler mais peut le rapporter comme provenant d'une source anonyme.

(2) Vous dites que vous présentez un risque pour vous-même ou pour les autres. La chercheuse doit faciliter l'accès aux services d'urgence.

Diffusion des résultats

Un résumé des résultats vous sera fourni à la fin de l'étude. Les résultats seront publiés dans des revues scientifiques et seront présentés lors de conférences. Nous collaborerons également pour trouver des moyens de partager ces informations dans vos communautés.

Compensation

Vous recevrez 25 $ par virement électronique pour votre participation. Si vous choisissez de vous retirer pendant ou après votre participation, vous recevrez toujours une compensation pour cette session.

Si je choisis, comment pourrais-je me retirer de l'étude ?

Vous n'êtes pas obligé de participer à cette étude. Vous pouvez vous retirer de l'étude à tout moment sans justifier votre décision. Si vous vous retirez, vos données seront toujours utilisées.

Votre consentement verbal indique que vous comprenez les informations dans ce formulaire de consentement et que vous acceptez de participer. En donnant votre consentement verbal, vous ne renoncez pas à vos droits légaux en tant que participant à la recherche et vous ne libérez pas les enquêteurs de leurs responsabilités juridiques et professionnelles.

Aspects éthiques de cette étude

Vous pouvez contacter la chercheuse principale ou ses superviseures à tout moment concernant cette étude et votre participation. Cette étude de thèse de doctorat a reçu l'approbation éthique du Comité d'éthique de la recherche de l'Université d'Ottawa.

Toute question ou préoccupation concernant la conduite éthique de cette étude peut être adressée au responsable du protocole pour l'éthique de la recherche à l'Université d'Ottawa, Tabaret Hall, salle 154, 550 Cumberland St., Ottawa, ON, K1N 6N5. Téléphone : (613) 562.5387 ; Courriel : ethics@uottawa.ca.

Consentement

Le consentement verbale sera enregistré numériquement.

Je, ___________________________________ (nom en lettres moulées), ai lu et compris ce formulaire de consentement. Toutes mes questions et préoccupations ont été traitées à ma satisfaction. Je peux contacter les chercheurs de l'étude à tout moment pour obtenir de plus amples informations.

J'accepte que ma participation soit enregistré numériquement: Oui ☐ Non ☐
J'accepte d'être cité directement (toute information permettant de m'identifier sera supprimée) : Oui ☐ Non ☐

Je consens à ce que les photographies de mon œuvre soient reproduites à des fins éducatives et/ou non commerciales, dans des rapports, des présentations, des publications, des sites web et des expositions liés au projet TNB2SY-ED. Je comprends qu'aucune information d'identification ne sera jointe à ces photographies. : Oui ☐ Non ☐ S/O ☐

Si vous avez des questions ou des préoccupations au sujet de cette étude, vous pouvez contacte:

J'accepte de participer à cette étude.

Signature – Investigatrice principale : ________________________________ Date:___________

Appendix R - Information Sheet and Consent Form for Journaling Option

uOttawa

L'Université canadienne
Canada's university

Principal investigator:
Sophie Lightfoot BScN, RN, PhD(c) (she/her)
School of Nursing, Faculty of Health Sciences
University of Ottawa

Supervisors:
Amanda Vandyk RN, PhD (she/her)
Associate Professor
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Phone: (613) 562-5800 ext. 6246
Email: Amanda.Vandyk@uottawa.ca

Hannah Kia PhD, RCSW (she/her)
Assistant Professor
School of Social Work
University of British Columbia
Email: Hannah.kia@ubc.ca

Title: Trans, Nonbinary and Two-Spirit Experiences in Emergency Departments

Invitation to participate: You are invited to participate in a research study that was designed collaboratively by a team of Canadian trans and nonbinary youth and their research partner Sophie Lightfoot who is a doctoral candidate supervised by Dr. Amanda Vandyk and Dr. Hannah Kia. The study is part of Sophie's PhD Thesis. You are able to participate in English and in French.

Why is the study being done?

There is very little research about the experiences of trans*, nonbinary, and/or two spirit youth accessing and receiving care in emergency departments. We would like to learn more about your experiences and find a way to use the results to make emergency departments more trans-affirming.

How many people will take part in this study?

In this phase of the study, 25 to 35 people will be invited to participate.

What will my participation look like?

Since you have chosen the journaling option, we will send you our interview guide for you to respond to. You may create an electronic document to send to us or handwrite your answers. You can take up to 3 weeks to answer the questions. If you chose to handwrite your answers, please take pictures of your entries and send us the pictures via email. These pictures will be password protected and saved onto a password protected laptop.

If you have chosen to participate in the art-based option, please take pictures of your entries and send us the pictures via email. These pictures will be password protected and saved onto a password protected laptop. You can spend as much time as you would like to create your piece before your interview or familial focus group when you will be invited to introduce your piece and its significance.

What are the risks of participating in this study?

If your experiences in the emergency department were negative, you may find writing about them uncomfortable. If so, we would suggest you call a peer support line such as Trans Lifeline (Telephone: 1(877) 330-6366) or a crisis line, such as the Distress Centre crisis line (Telephone: 1(866) 996-0991 or (613) 722-6914 for 24/7 help. You are free to not answer any questions and to take breaks as you need them.

What are the benefits of participating in this study?

One of the goals of this project is to use the results of the study to benefit your community. We will work together to figure out a way to do so.

What about Confidentiality and Privacy?

Your information will only be used for this study. Only Sophie and her thesis supervisors will have access to the data. We will use a random code instead of your name on your 'extended demographic questionnaire' and on all your submitted documents. The team of trans and non-binary youth who collaborated to design this project will analyze the results, and, therefore, will have access to de-identified results so that they can identify themes.

The research data (consent forms, 'extended demographics questionnaire', journal entries) will be locked in a filing cabinet in Sophie Lightfoot's locked office inside a locked research centre. The research data will be kept for 7 years, until November 2028, and then destroyed and shredded.

The information you share will be kept strictly confidential unless:

(1) You tell us about the abuse of a person under the age of 16. Researchers have to report this type of information but can do it without mentioning your name.
(2) You tell us that you are a risk to yourself or others. Researchers have to facilitate access to emergency services.

Sharing the results

We will give you a summary of the results at the end of the study. Results will be published in scientific journals and will be presented at conferences. We will also collaborate to find ways to share this information in your communities.

Compensation

You will receive 25$ via e-transfer for your participation. If you choose to withdraw (drop out) during or after your participation, you will still be compensated for that session.

If I choose, how would I withdraw from the study?

You do not have to participate in this study. You can withdraw from the study at any time without giving us a reason. If you do withdraw, we will still use the data from the focus groups that you participated in because it is too difficult to take out individual comments from a group conversation. Your verbal consent tells us that you understand the information in this consent form and that you agree to participate. By giving us your verbal consent, you are not losing your legal rights as a research participant and the researchers still need to maintain their legal and professional responsibilities.

Ethical aspects of this study

You may contact the principal investigator or her supervisors at any time about this study and your participation. This doctoral thesis study received ethics approval from the University of Ottawa Research Ethics Board. Any question or concern about the ethical conduct of this study may be addressed to the Protocol Officer for Ethics in Research at the University of Ottawa. Phone: (613) 562.5387; Email: ethics@uottawa.ca.

Consent

I, ____________________________________ (name in print), have read and understood this consent form. All my questions and concerns were addressed to my satisfaction. I may contact the researchers at any time for further information.

I accept to be quoted directly (any identifying information will be removed): Yes No

I give my consent for the photographs of my art piece to be reproduced for educational and/or non-commercial purposes, in reports, presentations, publications, websites, and exhibitions connected to the TNB2SY-ED project. I understand that no identifying information will be attached to these photographs: Yes ☐ No ☐ N/A ☐

Correspondence may be directed to:
I agree to participate in this study.

Participant signature: ____ Date: ______________

Principal Investigator's signature: ________________________________ Date: ______________

Appendix S - Information Sheet and Consent Form for Journaling Option (French)

uOttawa

L'Université canadienne
Canada's university

Investigatrice principale:

Sophie Lightfoot BScN, IA, PhD(c) (elle/la)
École des sciences infirmières, Faculté des sciences de la santé
Université d'Ottawa

Superviseures:

Amanda Vandyk IA, PhD (elle/la)
Professeure agrégée
École des sciences infirmières,
Faculté des sciences de la santé
Université d'Ottawa
(613) 562-5800 ext. 6246
Amanda.Vandyk@uottawa.ca

Hannah Kia PhD, RCSW (elle/la)
Professeure adjointe
École de travail social
Université de la Colombie-Britannique
Hannah.kia@ubc.ca

Titre du projet : Expériences des jeunes trans, non binaires et bispirituels dans les salles d'urgence.

Invitation à participer: Vous êtes invité(e)s à participer une étude conçue en collaboration par une équipe de jeunes trans et non binaires canadiens et leur partenaire de recherche Sophie Lightfoot qui est une candidate au doctorat supervisée par Dre. Amanda Vandyk et Dre. Hannah Kia. Cette étude fait partie de la thèse de doctorat de Sophie. Vous pouvez participer en anglais ou en français.

Pourquoi cette étude est-elle réalisée ?

Il y a très peu de recherches sur les expériences des jeunes trans *, non binaires et / ou bispirituels qui accèdent et reçoivent des soins aux urgences. Nous aimerions découvrir vos expériences et trouver des moyens d'utiliser les résultats pour rendre les services d'urgence plus trans-affirmatifs.

Combien de personnes participeront à cette étude ?

Dans cette phase de l'étude, 25 à 35 personnes seront invités à participer.

À quoi va avoir l'air ma participation?

Puisque vous avez choisi l'option de journalisation, nous vous enverrons notre guide d'entrevue pour que vous puissiez y répondre. Vous pouvez créer un document électronique à nous envoyer ou écrire vos réponses à la main. Vous pouvez prendre jusqu'à 3 semaines pour répondre aux questions. Si vous avez choisi d'écrire vos réponses à la main, veuillez prendre des photos de vos entrées et nous les envoyer par courrier électronique. Ces photos seront protégées par un mot de passe et sauvegardées sur un ordinateur portable protégé par un mot de passe.

Si vous avez choisi de participer à l'option artistique, veuillez prendre des photos de votre œuvre et nous les envoyer par courrier électronique. Ces photos seront protégées par un mot de passe et sauvegardées sur un ordinateur portable protégé par un mot de passe. Vous pouvez consacrer autant de temps que vous le souhaitez à la création de votre œuvre avant votre entrevue ou votre groupe de discussion familial, au cours duquel vous serez invité à présenter votre œuvre et sa signification.

Quels sont les risques liés à la participation à cette étude ?

Si vos expériences aux urgences étaient négatives, vous pourriez vous trouver mal à l'aise d'en discuter. Si tel est le cas, nous vous encouragerons à appeler un service de soutien par les pairs, tel que Trans Lifeline (téléphone: 1 (877) 330-6366) ou une ligne de crise, comme la ligne de crise du centre de détresse (téléphone: 1 (866) 996- 0991 ou (613) 722-6914 pour de l'aide 24h / 7j. Vous êtes libre de refuser de répondre à toutes questions et de prendre des pauses lorsque vous en avez besoin.

Quels sont les avantages de participer à cette étude ?

Un des objectifs de ce projet est d'utiliser les résultats de l'étude au profit de votre communauté. Nous travaillerons ensemble pour trouver un moyen de le faire.

Qu'en est-il de la confidentialité et de la vie privée ?

Vos informations ne seront utilisées qu'aux fins de cette étude. L'accès aux données de recherche sera limité à Sophie et à ses superviseures. Un code sera utilisé pour vous identifier sur votre « questionnaire sociodémographique étendu » et sur la transcription de notre conversation. L'équipe de jeunes trans et non binaires qui a collaboré à la création de cette étude analysera les résultats, et aura donc accès aux résultats dépersonnalisés pour identifier les thèmes.

Il y a un risque que quelqu'un puisse entendre ce que vous dites durant notre conversation, si applicable. Il est donc important de bien planifier un lieu privé. Tout ce qui est enregistré sera transcrit, c'est-à-dire écrit. La transcription n'inclura aucun nom ni aucune information qui pourraient être utilisés pour vous identifier. Les données de recherche (enregistrements audio, formulaires de consentement, transcriptions, « questionnaire sociodémographique étendu ») seront stockées en toute sécurité dans un classeur verrouillé dans le bureau verrouillé de Sophie Lightfoot dans un centre de recherche verrouillé. Les données de recherche seront conservées pendant 7 ans, jusqu'en novembre 2028, quand elles seront détruites et déchiquetées.

Les informations que vous partagez resteront strictement confidentielles, sauf si:

(1) Vous divulguez un abus contre une personne de moins de 16 ans. La chercheuse doit le signaler mais peut le rapporter comme provenant d'une source anonyme.

(2) Vous dites que vous présentez un risque pour vous-même ou pour les autres. La chercheuse doit faciliter l'accès aux services d'urgence.

Diffusion des résultats

Un résumé des résultats vous sera fourni à la fin de l'étude. Les résultats seront publiés dans des revues scientifiques et seront présentés lors de conférences. Nous collaborerons également pour trouver des moyens de partager ces informations dans vos communautés.

Compensation

Vous recevrez 25 $ par virement électronique pour votre participation. Si vous choisissez de vous retirer pendant ou après votre participation, vous recevrez toujours une compensation pour cette session.

Si je choisis, comment pourrais-je me retirer de l'étude ?

Vous n'êtes pas obligé de participer à cette étude. Vous pouvez vous retirer de l'étude à tout moment sans justifier votre décision. Si vous vous retirez, vos données seront toujours utilisées.

Votre consentement verbal indique que vous comprenez les informations dans ce formulaire de consentement et que vous acceptez de participer. En donnant votre consentement verbal, vous ne renoncez pas à vos droits légaux en tant que participant à la recherche et vous ne libérez pas les enquêteurs de leurs responsabilités juridiques et professionnelles.

Aspects éthiques de cette étude

Vous pouvez contacter la chercheuse principale ou ses superviseures à tout moment concernant cette étude et votre participation. Cette étude de thèse de doctorat a reçu l'approbation éthique du Comité d'éthique de la recherche de l'Université d'Ottawa.

Toute question ou préoccupation concernant la conduite éthique de cette étude peut être adressée au responsable du protocole pour l'éthique de la recherche à l'Université d'Ottawa, Tabaret Hall, salle 154, 550 Cumberland St., Ottawa, ON, K1N 6N5. Téléphone : (613) 562.5387 ; Courriel : ethics@uottawa.ca.

Consentement

Je, ____________________________________ (nom en lettres moulées), ai lu et compris ce formulaire de consentement. Toutes mes questions et préoccupations ont été traitées à ma satisfaction. Je peux contacter les chercheurs de l'étude à tout moment pour obtenir de plus amples informations.

J'accepte que ma participation soit enregistré numériquement: Oui ☐ Non ☐
J'accepte d'être cité directement (toute information permettant de m'identifier sera supprimée) : Oui ☐ Non ☐

Je consens à ce que les photographies de mon œuvre soient reproduites à des fins éducatives et/ou non commerciales, dans des rapports, des présentations, des publications, des sites web et des expositions liés au projet TNB2SY-ED. Je comprends qu'aucune information d'identification ne sera jointe à ces photographies. : Oui ☐ Non ☐ S/O ☐

Si vous avez des questions ou des préoccupations au sujet de cette étude, vous pouvez contacte:

J'accepte de participer à cette étude.

Votre signature ici: ____ Date:___________

Signature – Investigatrice principale : ________________________________ Date:___________

Appendix T - Information Sheet and Consent Form for Analysis Focus Groups

uOttawa

L'Université canadienne
Canada's university

Principal investigator:

Sophie Lightfoot BScN, RN, PhD(c) (she/her)
School of Nursing, Faculty of Health Sciences
University of Ottawa

Supervisors:

Amanda Vandyk RN, PhD (she/her)
Associate Professor
School of Nursing, Faculty of Health Sciences
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Phone: (613) 562-5800 ext. 6246
Email: Amanda.Vandyk@uottawa.ca

Hannah Kia PhD, RCSW (she/her)
Assistant Professor
School of Social Work
University of British Columbia
Email: Hannah.kia@ubc.ca

Title: Trans, Nonbinary and Two-Spirit Youth Experiences in Emergency Departments (TNB2SY-ED)

Invitation to participate: You are invited to participate in the analysis phase of the research study that you co-designed with Sophie Lightfoot who is a doctoral candidate supervised by Dr. Amanda Vandyk and Dr. Hannah Kia. The study is part of Sophie's PhD Thesis. You are able to participate in English and in French.

Why is the study being done?

There is very little research about the experiences of trans*, nonbinary, and/or two spirit youth accessing and receiving care in emergency departments. We would like to learn more about your experiences and find a way to use the results to make emergency departments more trans-affirming.

How many people will take part in this study?

In this phase of the study, all 8 people from the original focus groups will be invited to participate.

What will my participation look like?

You are invited to participate in three approximately three-hour focus groups where we will analyze the data gathered in the study.

What are the risks of participating in this study?

If your experiences in the emergency department were negative, you may find talking about them uncomfortable. If so, we would suggest you call a peer support line such as Trans Lifeline (Telephone: 1(877) 330-6366) or a crisis line, such as the Distress Centre crisis line (Telephone: 1(866) 996-0991 or (613) 722-6914 for 24/7 help. You are free to not answer any questions and to take breaks as you need them.

If you were also a participant in the study, you may be worried about how you might feel about focus group members discussing your data. Please note that Sophie will de-identify all the data and only present key messages for thematic analysis during the focus groups so your raw data will not be revealed.

What are the benefits of participating in this study?

By participating in data analysis, you will learn important research skills. One of the goals of this project is to use the results of the study to benefit your community. We will work together to figure out a way to do so.

What about Confidentiality and Privacy?

Your information will only be used for this study. Only Sophie and her thesis supervisors will have access to the data. We will use a random code instead of your name on your ‘extended demographic questionnaire’ and on the transcript of our conversation. The team of trans and non-binary youth who collaborated to design this project will analyze the results, and, therefore, will have access to de-identified results so that they can identify themes.

There is a risk that someone could overhear what you’re saying in the preliminary interview and the focus group. Make sure you are in a place that is private. Anything that is audio recorded will be transcribed, meaning written out. The transcript will not include any names or information that could be used to identify you. The research data (audio recordings, consent forms, focus group transcripts, ‘extended demographics survey’, photos) will be locked in a filing cabinet in Sophie Lightfoot’s locked office inside a locked research centre. The research data will be kept for 7 years, until November 2028, and then destroyed and shredded.

The information you share will be kept strictly confidential unless:

(1) You tell us about the abuse of a person under the age of 16. Researchers have to report this type of information but can do it without mentioning your name.
(2) You tell us that you are a risk to yourself or others. Researchers have to facilitate access to emergency services.

Sharing the results

We will give you a summary of the results at the end of the study. Results will be published in scientific journals and will be presented at conferences. We will also collaborate to find ways to share this information in your communities.

Compensation

You will receive 25$ via e-transfer per focus group. If you choose to withdraw (drop out) during or after your participation, you will still be compensated for that session.

If I choose, how would I withdraw from the study?

You do not have to participate in this study. You can withdraw from the study at any time without giving us a reason. If you do withdraw, we will still use the data from the focus groups that you participated in because it is too difficult to take out individual comments from a group conversation. Your verbal consent tells us that you understand the information in this consent form and that you agree to participate. By giving us your verbal consent, you are not losing your legal rights as a research participant and the researchers still need to maintain their legal and professional responsibilities.

Ethical aspects of this study

You may contact the principal investigator or her supervisors at any time about this study and your participation. This doctoral thesis study received ethics approval from the University of Ottawa Research Ethics Board. Any question or concern about the ethical conduct of this study may be addressed to the Protocol Officer for Ethics in Research at the University of Ottawa. Phone: (613) 562.5387; Email: ethics@uottawa.ca.

Consent

Verbal consent will be audio recorded.

I, ____________________________________ (name in print), have read and understood this consent form. All my questions and concerns were addressed to my satisfaction. I may contact the researchers at any time for further information.

I understand that the focus groups audio recorded: Yes ☐☐No ☐
I accept to be quoted directly (any identifying information will be removed): Yes ☐☐No ☐☐

Correspondence may be directed to:
I agree to participate in this study.

Principal Investigator's signature: ________________________________ Date: _____________