

CONSENT AS A CONTESTED RELATIONSHIP: RESEARCH ETHICS IN PRACTICE

WITH PEOPLE ENGAGED IN SEX WORK

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

AUGUST 2018

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Consent as a Contested Relationship: Research Ethics in Practice with People Engaged in Sex Work

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the degree of Masters of Science

in Nursing _____

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ABSTRACT

Increasingly, ethical issues in health research that focus on people engaged in sex work (PESW) are highlighted as a growing concern. The purpose of my thesis was to analyze research participants' experiences of data collection and consent processes among PESW. Utilizing qualitative data drawn from the *Ethics Project*, I conducted a secondary analysis of 15 interviews. Data were analysed using thematic analysis informed by a relational ethics framework. Findings illustrate interrelated ethical concerns situated within the power dynamics and relationships between researchers and participants. Participants have several strategies to navigate and mitigate harms associated with data collection and consent, and had important recommendations concerning what constitutes ethical research. The harms identified by participants were largely preventable and are unacceptable in the context of research. Prevalent ideologies of deviance impacted how research was conducted in data collection, contributing to omissions in relational engagement, and the perpetuation of stigma and discrimination towards PESW. Recommendations for research, education, and ethical practice include: encouraging mental health supports in research, trauma- and violence-informed care education for researchers, and increased reflexivity and community-based research methods to address power dynamics between researchers and participants.

LAY SUMMARY

Ethical issues in health research focused on people engaged in sex work (PESW) have been highlighted as a growing concern. More research is needed to understand how PESW experience research, and what ethical concerns participants as PESW may have. With a focus on ethical concerns, this study explores the experiences of PESW in data collection. Study findings demonstrate that power dynamics between researchers and participants impact and influence ethical concerns in research. Participants experience harms in research in areas of consent, autonomy, respect and engagement. Participants expressed many ways in which they navigated and reduced the harms of their engagement. Additionally, participants had many recommendations for ways in research could be safer and more ethical in practice. Study findings illustrate that more support is needed to improve research, education and practice for researchers in order to improve participant safety and dignity when participating in research.

PREFACE

This thesis was a collaboration between my supervisory committee and myself. I completed the work of data analysis with input from my primary supervisor, Dr. Vicky Bungay. The writing of the thesis was completed with the guidance and input from all committee members including Dr. Victoria Bungay, Dr. Colleen Varcoe and Dr. Adrian Guta. The thesis received ethics approval from the Human Ethics Board of UBC Research Ethics. The ethics ID is H14-00372.

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ACKNOWLEDGEMENTS

First, thank you to the participants for without their shared experiences, this research would not be possible - deep respect to your courage, resilience and dedication to your community.

I would like to extend significant gratitude to Dr. Vicky Bungay. Your guidance and encouragement have been critical from the beginning. I would not be here without your support and have learned so much from working with you. Thank you for your sharp eye, fierce character and kind heart. You have been an incredible mentor.

To my committee members, Dr. Colleen Varcoe and Dr. Adrian Guta, thank you for asking really important questions, your enthusiasm, and challenging me to do better. I have learned so much from you and truly appreciate the time you spent reviewing the work.

Thank you to my fellow students: Sunny Jiao, Fin Gareau, Jenny Woo and Max Ferguson for enriching my graduate school experience with your kindness, laughter, and joyful cynicism. This journey would also not have been possible without the early encouragement from Dr. Leanne Currie, Dr. Kathleen Stephany and Heather MacMillan.

And last, but certainly not least... a special thank you to my family: sisters Lauren, Naomi and Emily, to my parents Karin and Peter, and to some of my besties: Kat, Jocelyn, Julie, Maja, Dani and Jesse. Without you, what a boring world this would be – thank you for your love, silliness, shoulders, and food.

DEDICATION

For my Oma.

CHAPTER ONE: SITUATING THE ISSUE

Introduction

Ethical concerns within health research focused on people engaged in sex work (PESW) have been highlighted as a growing concern. In particular, there is growing interest in understanding how research participants experience research engagement and the effectiveness of ethical guidelines in practice (Cox & McDonald, 2013). Ethical issues in research pertaining to sex work, including methodological challenges in research design, have been identified in the literature. Some of the ethical concerns include: a lack of representativeness, sample biases, bias in research focus, concerns with maintaining privacy and confidentiality, and concern for the welfare of participants, especially regarding safety and incentives (Allman, Ditmore & Kaplan, 2014; Bell & Salmon, 2011; Bowen & Bungay, 2016; Bowen & O’Doherty, 2014; Bungay, Oliffe & Atchinson, 2016; Lyons, Krusi, Pierre, Kerr, Small & Shannon, 2017; Shaver, 2005; Socias, 2015). With the multiplicity of ethical concerns, little is understood about PESW experiences of research engagement. In this study, I explored the ethical dimensions of research participation during data collection and consent processes, with a focus on how the social and structural conditions interplay within the research-participant relationship.

Research Ethics

Research ethics are integral to ensuring the protection of human participants through guiding research conduct (Tri-Council Policy Statement [TCPS], 2014). Through ethical frameworks, such as the Tri-Council Policy Statement (2014), research ethics provide moral guidance informing how participants are to be respected, how research is to be conducted and the ethical standards intended to uphold the integrity of research as an institution and thus, promote public trust (TCPS, 2014). Research ethics are informed by social norms, significant historical

events such as the Tuskegee Syphilis Study, and through dominant ethical paradigms (Sherwin, 1992). Thus, research ethics are integral in shaping research and research conduct.

Principle-based ethics (PBE) inform the major principles of the TCPS. Three interdependent ethical principles make up the TCPS research ethics framework: respect for persons, concern for welfare, and justice (TCPS, 2014). Respect for persons includes the concepts of autonomy and consent. Autonomy is defined in the TCPS (2014) as: “the ability to deliberate about a decision and to act based on that deliberation (p.2).” Further, it includes the person’s right to exercise choice without interference in their research participation (TCPS, 2014). Informed consent is constructed as free, ongoing and meaningful. That is, participation in research is maintained as a choice, and in order to be meaningful, participants are given the opportunity to understand the full breadth of research involvement (TCPS, 2014). Concern for welfare is described as balancing the risk and benefits of research for potential participants. At an individual level, the TCPS (2014) states that researchers should consider the impact of the research on the participants’ holistic well-being, including their social and economic circumstance. Beyond the individual, the TCPS recommends consultation with communities who may be impacted by the research, to understand the impact and potential unintended consequences of the research (TCPS, 2014).

Lastly, the principle of justice encompasses the interrelated concepts of fairness and equity. In the TCPS (2014), the application of justice extends to participants being treated equitably, with researchers needing to account for power relations and participant vulnerability, which when abused, can result in participant harm. The TCPS (2014) suggests that people who may experience marginalization as a result of their social locations may require special attention in order to receive just treatment in research, as an effort to prevent harms that have been

perpetuated in the past. Ultimately, these principles are intended to serve as broad moral guidance for researchers.

Relational ethics extends our understanding of PBE through the expansion of ethics beyond the individual, to a conceptualization that includes the social, political and structural conditions which shape ethics at a structural and interpersonal level (Sherwin, 1992, 1998; Kenny, Sherwin & Baylis, 2010). Further, Sherwin (1998) argues that principles such as autonomy are enacted within the relational space, rather than being an individualistic experience. Thus, social, structural, and relational circumstances can constrain and expand a person's agency, as well as construct the opportunities and choices people are presented (Sherwin & Winsby, 2011). In attending to the welfare of participants, Sherwin (1992, 1998) argues that researchers have a duty to attend to the larger structural conditions of participants' lives in order to relieve the constraints which impact participant oppression, including autonomy and choice.

Bergum and Dossetor (2005) describe relational ethics as comprised of four main concepts: embodiment, environment, respect and engagement. Rather than a transactional experience, relational ethics involve attending to the whole person, with presence, and ethics enacted within the relational space. Overall, relational ethics contribute greater depth to an ethical analysis through the inclusion of structural and relational lenses to how PESW experience research engagement in data collection and consent. In this study, both PBE and relational ethics informed my analysis of participants' experience in data collection and consent, in how ethics in practice occurred both relationally and mediated by broader social-structural conditions.

State of the Research: PESW and Research Ethics

PESW are frequently characterized as vulnerable in research; yet, little data exists evaluating their engagement in research, particularly within an ethical framework. Anecdotally,

there have been concerns voiced regarding PESW welfare in participating in research (Agustin, 2004; Bowen & O’Doherty, 2014; Jeffreys, 2007; Maggies Toronto, N.D). In studies investigating sex workers’ experience in research, participants expressed concerns with confidentiality and privacy, particularly with having their identity disclosed to the public (Goldenberg et al., 2015; Reed, Khoshnood, Blankenship & Fisher, 2014; Reed, Fisher, Blankenship, West & Khoshnood, 2017; Urada & Simmons, 2014). Further, some participants feared violence if their involvement in sex work was exposed (Reed et al., 2014; Reed et al., 2017). Relatedly, participants described trust as a key factor in deciding whether or not to participate in research (Brown, Davtyan & Fisher, 2015; Ditmore & Allman, 2011; Urada & Simmons, 2014). Gaps remain in understanding the ethical concerns of participants in greater depth.

In research exploring other communities characterized as ‘vulnerable’ and who experience significant marginalization¹ (Andrighetti, Semaka, & Austin, 2017; Guillemin et al., 2016; Newman et al., 2011), including people who use drugs (PWUD) (Barratt, Norman & Fry, 2007; Bell & Salmon, 2011; Boyd & Association of Naomi Patients [ANP], 2013; Fry, & Dwyer, 2001; Singer et al., 2008); and people with mental health conditions (Roberts, Warner & Brody, 2000; Taylor et al., 2010); participants’ shared ethical concerns similar to those expressed by PESW. The main ethical concerns included themes of trust and respect, experiences of consent, and privacy and confidentiality. The core principles of trust and respect played a significant role

¹Marginalization: “involves systematic limitations on access to institutions, resources, and privileges within a group or society that often leads to feelings of alienation, disenfranchisement, and isolation.” Hayes, 2017

in their decision making to participate in research, and how they felt about their research engagement.

Likewise, researchers' experiences of undertaking sex work focused research shared similar themes of concern regarding privacy and confidentiality and trust, as well as, issues of representativeness in research design (Agustin, 2004; Bungay, Oliffe & Atchinson, 2016; Jeffreys, 2009; Sanders, 2006; Shaver, 2005; Sinha, 2017). However, these analyses were retrospective in design and did not include participants' perspectives on their research engagement. Additionally, the studies did not use an explicit ethical analysis in their research design, highlighting the need for a purposeful analysis of research participants' experience of research, how ethics are enacted – including the impact of structural and relational influences in research and the research-participant relationships.

In recent years, PESW and not-for-profit sex work advocacy organizations' involvement in research and knowledge production in community-based research and participatory research methods has grown (Bowen & O'Doherty, 2014; Jeffreys, 2006; Sanders, 2006; Sex Work Exiting and Transitioning Consortium [SWETC], 2014; Shaver, 2005; The SPACES Team, 2016). This involvement has also developed from grassroots advocacy, as organizations have critiqued researchers and academia for over-researching sex worker communities, a lack of inclusion throughout the research process, a bio-medical focus which has ignored PESW priorities related to occupational health and safety, and a lack of research results returning to the community (Bungay, Oliffe, & Atchinson, 2016; Jeffreys, 2006; SPACES Team, 2016; SWETC, 2014; Van der Meulen, Durisin, Love, & Elya, 2013). In response, several sex worker not-for-profit organizations have created materials to support PESW in research engagement, for example: outlining their rights in terms of informed consent, incentives, knowledge sharing, and

questions to ask prior to participation (Bowen, Davis, Kiselbach, & Broden, 2006). This discordance is further identified by researcher critiques of research ethics boards for institutional discrimination including ignorance towards PESW and their diverse realities (Sanders, 2007; Sanders & Campbell, 2007; Sinha, 2016). Thus, the work addressed in my thesis can contribute to understanding how researchers and ethics review boards can improve their research design, ethics applications, and support and engagement of research participants.

Because some of the main aims of research ethics are to ensure the safety and voluntariness of research participants, inquiry into participants' experiences of ethical engagement is crucial to understanding how ethics in practice occur, especially within populations who experience varying levels of oppression and marginalization. Through this inquiry, research ethics in practice can be informed, thus improving the experiences of PESW who participate in research, and hopefully, extend to the improvement of their overall health and well-being

Study Purpose

Through an investigation of the accounts of PESW about their experiences with data collection and consent processes during research participation, I sought to unpack the ethical issues embedded in their research engagement; including inquiry into the social-structural contexts and ethics within the researcher-participant relationship. This research attends to gaps in the literature concerning how PESW experience research participation and how ethics are enacted in the day-to-day research setting.

Research Question

The research question guiding the analysis was: "What are research participants' experiences throughout data collection and consent processes in studies concerned with sex work and health?"

Thesis Overview

In this chapter, I presented the need for the research by introducing the current state of inquiry into research ethics in health research involving PESW. Additionally, I described the research purpose, question and aims. In Chapter 2, I present the current literature on PESW perspectives on research engagement and research ethics, researchers' perspectives on research ethics in sex work related research, and lastly, literature exploring the perspectives of research ethics and research participation from participants who experience marginalization as a result of their social location. In Chapter 3, I describe my analytical framework and research methods, and their relation to the research aim and purpose. Further, I describe the ethical considerations and limitations of my research approach. In Chapter 4, I impart the research findings from my analysis. First, I provide an overview of the participants and their research engagement. Following this, I present themes identified from data analysis, which include how participants' ethical issues in data collection are impacted by power dynamics, including experiences with consent, respect and justice. I then share the harms of participants' research engagement, and how participants navigated and mitigated research harms. Lastly, I share participants' recommendations for ethical data collection. In chapter 5, the findings are contextualized within the current literature on PESW and research ethics, and I discuss their implications and make recommendations for future research.

CHAPTER TWO: LITERATURE REVIEW

Introduction

In this chapter, I present a review of the current state of research literature on PESWs' experience of data collection, research ethics, and research participation. In addition to addressing the primary research question, literature concerning researchers' perspectives on research ethics in sex worker related research is included, and literature exploring the perspectives of research participants who may have experienced marginalization as a result of their social location(s), on research ethics in research participation. To begin, I describe my process in conducting the literature review. Next, I describe the major themes of how research participants experience research engagement, including the benefits of research participation, structural constraints and consent, trust and respect, and confidentiality and privacy. I then describe the literature on researchers' perspectives regarding ethical and methodological challenges in research with PESW. Lastly, I discuss the literature on research participants' experiences of research, focusing on their experiences in research engagement and research ethics. As a whole, this review situates my study in the literature on what is understood regarding PESWs' experience of research and research ethics.

To develop a comprehensive understanding of the current state of research on PESW experience research and research ethics, I conducted a thorough search of Medline, Pubmed, CINAHL, and Web of Science. To address my overarching research question and understand a wide perspective of participants' experiences of research engagement from an ethical lens, I conducted three different literature searches: 1) investigating PESW perspectives on research

engagement and research ethics, 2) researchers' perspectives on research ethics involved in conducting health and social research with PESW, and 3) investigating the perspectives of people who may experience marginalization as a result of their social location, on research participation and research ethics. In conducting my first literature search, my key words included "sex workers," "perspectives," "research ethics," "ethics," "experience," and "sex work." In conducting the second search, my additional terms included "researcher" and "method*." Lastly, in searching question number three, my keywords included: "perspectives," "research ethics," "ethics," "experience," "human subjects," "research subjects," "marginal*," "vulnerable," "mental health," "African American," "racialized," "women," and "Indigenous." The literature included for review in this chapter was primarily conducted outside of North America. I could locate very little literature within a Canadian context that investigated the application of research ethics in research inquiring on PESW. As adult experiences were the focus of my thesis, my review of the literature focuses on adult research participants.

Following this process, the review of the literature is divided into three sections. The first section discusses what is known about PESW experiences of research ethics and research participation. The second includes the perspectives of researchers on ethical challenges in health and social research involving PESW. Lastly, literature including the perspectives of research participants who may experience marginalization as a result of their social location on research ethics and research engagement is discussed.

PESW Experiences of Research Engagement

There is a dearth of research exploring PESW experiences of research participation and research ethics, especially specific to data collection. In review of the literature, six studies were located; these all were retrospective and qualitative in nature. Five of the six studies focused on

female sex workers' (FSW) experience engaging in HIV prevention research, while the sixth was a retrospective design inquiring about participants' experience participating in an HPV vaccine study (Brown et al., 2015; Ditmore & Allman, 2011; Goldenberg et al., 2015; Reed et al., 2014; Reed et al., 2017, Urada & Simmons, 2014). Additionally, the research was primarily conducted outside of North America, taking place in the Philippines, Guatemala, Peru and India (Brown et al., 2015; Goldenberg et al., 2015; Reed et al., 2014; Reed et al., 2017; Urada & Simmons, 2014) with the exception of an online survey, open to PESW globally with 54% of participants responding from North America (Ditmore & Allman, 2011). Demographically, the research participants were mostly FSW, migrant workers, and managers of brothels, with small sample sizes (n=16-74) (Brown et al., 2015; Ditmore & Allman, 2011; Goldenberg et al., 2015; Reed et al., 2017; Reed et al., 2017; Urada & Simmons, 2014). The primary data collection methods ranged from semi-structured 1:1 interviews, surveys (online and in person), and focus groups. None of the studies utilized an explicit ethical theory or framework in their data analysis. The results were primarily contextualized in a principle based ethics (PBE) approach, prioritizing ethical principles of autonomy, beneficence and justice. A number of the studies also engaged community advisory boards in the development of research questions, recruitment, and validating the research results (Brown et al., 2015; Urada & Simmons, 2014).

The research aims of the studies reviewed were quite variable. Three of the studies explored ethics in research engagement with FSW (Goldenberg et al., 2015; Reed et al., 2014; Urada & Simmons, 2014). Reed et al. (2014) explored the motivations of FSW in research participation while also investigating the rights of participants in HIV prevention-focused research in Andhra Pradesh, a state in India. In contrast, Urada and Simmons (2014) explored structural and contextual factors influencing FSW research participation in the Philippines. The

researchers were interested in understanding research participation in HIV prevention research, including condom use and education related to sexual health. Urada and Simmons (2014) also explored the role of managers of FSW worksites, in how they influenced and facilitated research participation of PESW. Their methods included sharing detailed vignettes with participants to explore their feelings about research engagement with the intention of facilitating participant sharing without explicit disclosure of personal experiences (Urada & Simmons, 2014). The vignettes highlighted ethical issues such as the lack of knowledge of ethics review boards, issues of consent and respect for persons. In Brown et al.'s (2015) Sunflower Study, 16 past participants of an HPV vaccine study in Peru were interviewed regarding their intentions for participating, levels of trust throughout the research engagement, consent, privacy and confidentiality, and incentives. Lastly, Ditmore and Allman (2011) sought the perspectives of PESW on improving communication in HIV prevention studies. As a whole, the studies sought research participant experiences, with diverse research purposes.

Benefits of Research Participation

Reflecting on past research involvement, participants described numerous benefits to research engagement. Participants expressed enjoying learning about the research process, gaining more knowledge about their health, the financial compensation, and found interviews therapeutic (Brown et al., 2015; Reed et al., 2014; Reed et al., 2017). Other benefits included access to health care services, developing relationships with participants and research team members, feeling heard, and being able to give back to their communities (Brown et al., 2015; Goldenberg et al., 2015; Reed et al., 2014). Overall, most participants described research as a social good; that is, a process valued by the public and intended to benefit the public. This theme

of research as a social good was further reflected in participants' beliefs that their research contributions were intended to improve the health and well-being of their communities.

Constraints on Autonomy and Consent

Participants shared numerous structural and interpersonal constraints impacting their autonomy and consent within research participation. Structural factors such as perceived government involvement, immigrant or migrant status, criminalization, and poverty including financial need provided a backdrop of participants' livelihood, mediating their autonomy and involvement in research (Goldenberg et al., 2015, Reed et al., 2014; Reed et al., 2017; Urada & Simmons, 2014). Within the study by Reed et al. (2014), several participants reported feeling the consent process was rushed, with researchers focused on recruiting more survey participants versus a detailed informed consent process. In Brown et al. (2015) and Urada and Simmons (2014), participants expressed they appreciated the informed consent process, stating it was helpful in understanding their rights, but noted that they did not necessarily establish trust with the person collecting the data. Alternatively, Reed et al. (2017) found participants expressed personal challenges with consenting to research, including being coerced to participate in studies by senior PESW and their managers, in order to split the research incentive. Overall, participants experienced multi-level challenges with consent in research.

Similarly, participants expressed constraints on consent when describing their experiences of research engagement. In Reed et al.'s (2017) study of FSW motivations to engage in research, participants shared that they would not decline answering intrusive questions as they felt it would be perceived as disrespectful, stating it was their duty to follow through with the study regardless

of the difficulty endured. Intertwined with this experience, participants feared a loss of resources if they declined to participate, specifically, a loss of income. Similarly, Ditmore and Allman (2011) reported participants felt they did not have the resources to self-advocate when they felt the research was conducted poorly. Thus, participants experienced a number of constraints, impacting their ability to self-advocate, negotiate consent, and share authentically with researchers.

Trust and Respect

Concepts of trust and respect were also significant themes in participants' reporting on research engagement (Goldenberg et al., 2015; Urada & Simmons, 2014). Trust was viewed as a necessity for participants to share authentically during interviews, especially with questions pertaining to sex, sexual health, substance use and experiences of violence (Brown et al., 2015; Ditmore & Allman, 2011; Reed et al., 2017; Urada & Simmons, 2014). With a more developed understanding of the study and established rapport, some participants shared they would be more inclined to be detailed and authentic in their responses (Urada & Simmons, 2014; Reed et al., 2014). Establishing trust and maintaining confidentiality were key factors in addressing fears surrounding research engagement, which were interrelated with participants' concerns regarding maintaining their privacy in research (Reed et al., 2014). In Reed et al. (2014), participants described intimate partner violence as moderating their involvement and disclosure in research. Some participants described their partners as suspicious of their research engagement and felt their partners were concerned about what they as participants might share with the research team (Reed et al., 2014).

In Tecum Ulum, Guatemala, the socio-structural context of migration, deportation, and criminalization of FSW contributed to participants fear and reluctance to engage in HIV-focused

research. The risk of deportation as a result of a positive HIV status contributed to distrust with researchers, including the perception that researchers may be colluding with government organizations (Goldenberg et al., 2015). Thus, confidentiality, trust, and privacy were interrelated priorities for the participants to engage with research.

Establishing trust and rapport was crucial in establishing relationships between researchers and participants (Reed et al. 2014; Urada & Simmons, 2014). Participants described a number of occasions when the interviewers avoided eye contact, laughed when asking questions, or asked intrusive questions regarding their motivations to engage in sex work, condom use, and sexual health practices (Reed et al., 2014; Urada & Simmons, 2014). Participants from the Philippines noted distrust as a barrier to engagement and disclosing personal information (Urada & Simmons, 2014). Further, some participants did not believe the results of the research would positively impact their livelihood (Urada & Simmons, 2014). Alternatively, participants stated having an existing relationship and trust was a mediating factor in lessening the negative impact of personal questions (Urada & Simmons, 2014). Thus, trust played an integral role in the research process, mediating what was shared, how people engaged in research, and thus, impacting the authenticity of the research data.

Confidentiality and Privacy

Even with the variety of the research contexts and locales, ethical concerns regarding privacy and confidentiality by research participants were commonplace. Fear of being outed, that is, having their involvement in the sex industry made public to family, police or others - was a primary concern (Brown et al., 2015, Goldenberg et al., 2015; Reed et al., 2014, Reed et al., 2017; Urada & Simmons, 2014). As a result, participants feared a loss of work, jail time, potential deportation, shame, violence, and a loss of family support (Goldenberg et al., 2015;

Reed et al., 2017; Reed et al., 2014; Urada & Simmons, 2014). In some studies, participants described being approached by researchers in their “hotspots”, specifically places where they would be solicited for work. This action would draw attention to their space, potentially putting the person at risk of being outed – that is, they feared their involvement in the sex industry being made public, or that participation may deter potential customers, resulting in a potential jail time and a loss of income (Goldenberg et al., 2015; Reed et al., 2017).

In Reed et al. (2014), some participants shared that their husbands were suspicious regarding the amount of time spent with the research team, and were not aware the participants were engaged in sex work – thus, interviews for participants needed to be discrete and brief in order to preserve their privacy and safety. Additional privacy concerns arose in being visible while accessing health, research or community-based buildings thereby increasing their risk of being outed through research activities (Reed et al., 2014; Reed et al., 2017). As a whole, structural and social contexts were crucial in mediating research participation, and presented a significant concern and challenge for research participants who were engaged in sex work.

Summary

The studies reviewed provide insight into the current state of the research; however, several areas require attention. Firstly, there is a need for an analysis in a Canadian context, as the selected studies reflect a diverse geography of settings. Secondly, further knowledge is needed to understand participants’ experience of data collection, as the research primarily focused on participants’ motivations for engaging in research. Further, we do not know how effective ethical safeguards are in practice with PESW. Relatedly, the studies reviewed utilized a PBE framework for analysis; while valuable, this framework lacks an analysis of the larger social-structural context, which is integral for understanding ethics in practice. Lastly, the

literature review reflected safety concerns in research participation, however, little is known about what participants need to feel safe in research and how effective the current ethical guidelines are at ensuring their rights and dignity are respected. To address these gaps, I analyzed Canadian data with a relational ethics analytical framework, investigating participants' experiences engaging in data collection to unpack the ethical dimensions of their research engagement.

Researchers' Perspectives Regarding Ethical and Methodological Challenges

A number of researchers who have conducted research with PESW have written about their reflections on ethical and methodological challenges related to research on PESW. This literature provided an important framing of larger academic ethical issues, which impact how both researchers and participants experience research engagement and research ethics. In this review, the geographical contexts were diverse, including locations in India, the United States (US), Canada, the United Kingdom (UK), and Australia (Agustin, 2004; Bungay et al., 2016; Jeffreys, 2009; Sinha, 2017; Shaver, 2005; Sanders, 2006). The primary foci of the studies were retrospective reflections of qualitative methods in sex work-related research and the associated ethical challenges. Most authors discussed their research within the ethical context of PBE. The participant samples focused on FSW who are street involved. Within this body of literature, the common ethical themes were privacy and confidentiality, trust and developing relationships, ethical guidance, sampling strategies to increase the representativeness, and developing community-based research methods to improve relationships with communities involving PESW (Agustin, 2004; Bungay et al., 2016; Jeffreys, 2009; Sinha, 2017; Shaver, 2005; Sanders, 2006). In addition to the themes above, Agustin (2004) and Jeffreys (2009) argued for greater

meaningful involvement of PESW in the development of research, and improved attunement to power dynamics between researchers and participants.

Privacy and Confidentiality

Similar to the literature concerned with the perspectives of PESW regarding research participation, researchers also identified privacy and confidentiality as primary ethical concerns (Agustin, 2004, Bungay et al., 2016; Jeffreys, 2009; Sanders, 2006; Shaver, 2005; Sinha, 2017). Developing research designs that protect participant privacy and confidentiality were considered particularly important. The authors discussed specific strategies as going beyond typical participant protections, to prevent ‘outing’ participants, thereby working to ensure participants’ safety (Bungay et al., 2016; Jeffreys, 2009; Sanders, 2006; Shaver, 2005; Sinha, 2017). Strategies included keeping participants’ identities and work locales confidential, undertaking field work in spaces and times set by the participants, and offering choice in whether participants want to be interviewed by a peer or research assistant (Bungay et al., 2016; Shaver, 2005). Further strategies included being respectful of the neighborhoods that PESW frequent, including how and when researchers approach potential participants, consulting with and providing training on research and research ethics for not-for-profit sex work support and advocacy organizations when developing research, and spending significant time in the field to ensure rapport with community gatekeepers is maintained to reinforce trust between the researcher and community (Sanders, 2006; Shaver, 2005; Sinha, 2017).

In a narrative on conducting ethnographic research in India, Sinha (2017) shared challenges in maintaining participant privacy when working with the local not-for-profit sex work support and advocacy organizations. During Sinha’s research, community workers asked for the participant identities and often spoke about the participants with each other. This

presented a number of ethical concerns in compromising participant privacy and confidentiality, was disrespectful to the clients and indicated a need for ethics education for the community workers. Sinha (2017) also highlighted the consequences for participants in being outed, with women being disowned, at risk for violence and homelessness, and arrest in India. Through her engagement with participants, Sinha (2017) shared that participants were fearful of being reported in the media and were reluctant to engage. Thus, participants shared with Sinha that creating a private space for an interview was important for the participants to feel safe to share their experiences. Thus, researchers recognized that designing studies with privacy and confidentiality in mind was paramount to ensure not only that recruitment occurs, but also to ensure participant safety, and that the methods are contextualized to the participants' environment and livelihood.

Trust and Relational Engagement

Researchers articulated trust as an important principle and method in designing and engaging in research. In discussions regarding improving the veracity of research data on PESW, Agustin (2004) and Jeffreys (2009) reinforced the importance of rapport and relationship building with communities involving PESW. Trust and relational engagement were argued as integral in developing research relationships to access participants, understand potential research priorities, and also, ensure that data is meaningful and representative of the communities' needs (Sanders, 2006; Shaver, 2005; Sinha, 2017). Agustin's (2004) analysis emphasized that the different motives between researchers and participants can result in discordant ethics and motivations. In particular, Agustin (2004) argued that some participants might not be truthful in what they disclose for fear of judgment or for fear of being viewed as distrustful if their answer

does not align with the assumptions the researchers may hold regarding participants' involvement in sex work.

Similar to Agustin's (2004) narrative that participants may share what they perceive the researcher wants to hear, Sinha (2017) observed that participants' narratives changed as the trust in their relationship grew. During several interviews, participants initially described being forced to work in the sex industry. However, as the research-participant relationship developed in parallel with increased contact, participants described their work as autonomous and self-driven, sharing how sex work benefitted their livelihood. In another observation, Sinha (2017) observed participants' discomfort when being interviewed in the not-for-profit sex worker support space. As the participants received referrals from the not-for-profit to access research and thus, the related resources – Sinha (2017) suggested that participants may be catering their responses to appease the not-for-profit, highlighting the power differentials in different research spaces and how it may impact the veracity of the data. As a whole, trust was viewed as critical throughout the research process, including the inter-personal, at the community level, and within the academic – researcher space.

Representativeness

Researchers also discussed how ethical issues and research methodologies presented challenges for sample representativeness. In a study discussing sampling methods in conducting research on sex work, Bungay et al. (2016) argued that sampling strategies needed to be intentional to develop inclusive recruitment methods. In doing so, the diverse needs of PESW could be better represented, particularly for men, transgender persons, and people who work indoors. Without intentional sampling methods, Bungay et al. (2016) argued that the results become skewed towards particular populations, primarily street-involved FSW, thus, potentially

producing policy and health promotion strategies that overlook the diversity of sex workers needs and issues and thereby potentially harmful to PESW.

Jeffrey's (2009) articulated a similar argument, who stated that, a lack of representativeness and inclusion of PESW in the development of research had contributed to harmful policy development and outcomes, which reinforced narratives supporting the criminalization and victimization of PESW. Further, research has highlighted the over-focus on HIV/STI in research as contributing to the stigma of PESW as 'vectors of disease' (Bungay et al., 2016; Jeffreys, 2009). Lastly, Jeffreys (2009) argued that greater meaningful involvement of PESW throughout the research process to center their lived experience would improve policy, and overall, improve health and social outcomes for PESW.

Researchers also discussed the emotional burdens of designing and implementing research (Sanders, 2006; Sinha, 2017). Some of the hurdles included navigating ethical challenges with research ethics boards, community organizations, and with participants. Sanders (2006) reflected that sex work has been characterized as a "problematic area of inquiry" with "stereotypes and misunderstandings about the research setting exacerbate these generic concerns about the methods often employed when studying the sex work field (P.452)." As such, both Sanders (2006) and Sinha (2017) argued that guidance from research ethics boards has been limited in addressing nuanced ethical situations in practice. In summary, researchers articulated a diverse set of ethical challenges in developing social and health research.

Summary

As a whole, the limited literature available revealed a broad set of ethical challenges for researchers when conducting research on sex work. The majority of the literature was based on researchers' experience, and focused on research design and methodology and related ethical

challenges. Additionally, these reflections were framed within a PBE framework, rather than a relational ethics framework, leaving a gap in understanding how the social- structural conditions shape research ethics within the researcher and participant relationship, and the impact on ethics in practice. The ethical issues identified in the literature by the researchers highlight a need for understanding PESW experience of research engagement. In this thesis, I will provide an in depth analysis of these processes.

Experiences of Participants who Experience Marginalization

With the limited research available in understanding PESW experiences in data collection and on research ethics, I expanded my review to include literature investigating research participants whose social location may result in them experiencing marginalization, to understand if there are similar or diverging ethical issues in their research experiences, and what the gaps are in this research. As there was little research available within each subgroup, this review represents a broad sample of participants with a variety of research topics. The research selected includes samples from Australian Indigenous communities; people at risk for HIV, including bisexual and gay participants; women with post partum disorder (PPD); two studies of people with schizophrenia, and five studies that included people who use drugs (PWUD) (Andrighetti et al., 2017; Barrett, 2011; Bell & Salmon, 2011; Fry & Dwyer, 2001; Guillemin et al., 2016; Newman et al., 2011; Roberts et al., 2000; Taylor et al., 2010; Singer et al., 2008). The majority of the research designs were qualitative, with two studies utilizing mixed methods in their study design (Newman et al., 2011; Roberts et al., 2000). Similar to research with PESW, the studies investigated participants' experiences and motivations to engage with research. Data collection methods included surveys, focus groups, and one to one interviews. The studies did not utilize any explicit ethical frameworks or approaches, with the qualitative studies using

grounded theory, content or thematic analysis and contextualizing the results with an implicit PBE approach.

Motivations to Participate

Reflecting perceptions of research as a social good, research participants expressed altruistic motivations to engage with research. Most participants expressed feeling motivated to give back to their communities, wished to help others, and see research as an opportunity to learn about their health or develop different skills (Fry & Dwyer, 2001; Barrett, 2011; Bell & Salmon, 2011; Guillemin et al., 2016; Newman et al., 2011; Roberts et al., 2000; Taylor et al., 2010). For example, participants in an experimental HIV vaccine trial described feeling helpless when their friends died during the HIV epidemic, and saw participation as an action and opportunity to prevent future harms (Newman et al., 2011). For Australian Indigenous participants, the opportunity to improve research experiences and the health of their communities was a significant motivator (Guillemin et al., 2016). On a personal level, many participants described being curious about clinical trials and the opportunity for participation, or sought out research as a means to access health care and engage in their own self care (Boyd & ANP, 2013; Fry & Dwyer, 2001; Newman et al., 2011; Singer et al. 2008).

A number of participants were motivated by incentives, reflecting a need for additional income (Barratt et al., 2007; Bell & Salmon, 2011; Fry & Dwyer, 2001; Singer et al., 2008). In Fry and Dwyer's (2001) study, 22% of participants reported solely engaging in research for the incentive. However, this also reflected the needs of their participants, with 40% under the age of 25, and most of the participants homeless. In contrast, participants in Bell and Salmon's (2011) study described engaging for the incentives while also describing an interest in giving back to the community and improving the health of women and PWUD, reflecting nuanced motivations for

research engagement. Similar to participants with mental health conditions, PWUD equally shared hope that their contributions would be meaningful and improve the well being of others (Andrighetti et al., 2017; Barratt et al., 2007; Bell & Salmon, 2011; Boyd & ANP, 2013; Dwyer & Fry, 2001; Singer et al., 2008; Taylor et al., 2010).

Decision Making

Another theme identified in the literature was participants' decision making concerning the risk-benefit to determine if the research was safe to participate in. For example, Singer et al. (2008) found that participants balanced the risks of potential confidentiality and privacy concerns with the benefit of incentives and access to health care, when deciding to participate in research. In contrast, participants in the Guillemin et al. (2016) study wanted to know more about the researchers, their commitment to Indigenous communities, including past research and how researchers planned to utilize the data collected before agreeing to participate. Within Andrighetti et al.'s (2017) study, people were open to sharing if they felt the impetus of the research would benefit the greater community.

Similar to research participants who engaged in sex work, trust was key in people's decision-making processes for research participation (Andrighetti et al., 2017; Bell & Salmon, 2011; Boyd & ANP, 2013; Guillemin et al., 2016; Singer et al., 2008; Taylor et al., 2010). Participants with PPD shared that their established relationships with the research centre as patients and knowledge of the research institution as reputable, increased their confidence in deciding to engage. In comparison to non-Indigenous participants, Guillemin et al. (2016) described Indigenous participants as more deliberate in their assessment of the pros and cons of

research, before agreeing to participate in research. Indigenous participants shared that their trust of particular Indigenous agencies and researchers was a key factor in deciding if they would participate in the research. In comparison, Non-Indigenous participants were more inclined to trust the researcher rather than feel that the researcher needed to earn their trust (Guillemin et al., 2016). In another study which evaluated the efficacy of an HIV vaccine trial, participants described initially having high levels of trust with the study; however, at the unblinding stage, where participants found out if they had received the placebo or the actual vaccine, participants predominantly expressed being left vulnerable and feeling distrust with the study, citing sporadic communication by the research team regarding the termination of the trial and the risks involved with receiving the vaccine (Newman et al., 2011). Following participation, participants described feeling reluctant to engage in future studies (Newman et al., 2011).

Trust was also integral to participants' ability to consent to research, and to feeling confident that their confidentiality and privacy would be respected. Bell and Salmon (2011) reported that participants described researchers as "talking down and being condescending" in their research engagement (p.7). Participants described feeling "pigeon-holed", being asked the same questions repeatedly, and being treated as a "guinea pig" because they had a substance use disorder (Bell & Salmon, 2011, p.7). Participants shared preferring to be interviewed by someone "who understands you...is on your level (p.7)." Underlying both sentiments was a desire to be treated with respect, in which the participants preferred community-based research methods as they were provided with a greater opportunity to be heard and participate, and felt that the results would be utilized to improve their communities well being (Bell & Salmon, 2011). Similar to research with PESW, PWUD often feared being outed as a result of research participation (Singer et al., 2008). Fear of stigma and discrimination, particularly among family

members was a significant concern (Singer et al., 2008). When people felt they could trust that their privacy would be maintained, they were more inclined to participate (Barratt et al., 2007; Bell & Salmon, 2011; Singer et al., 2008).

Several studies explored the impact of the cessation of research within an ethical context. In a study by Boyd and ANP (2013), the research team examined research participation in a clinical trial investigating the impact of injectable opioid therapy. In their findings, some participants described feeling misled by the researchers when their medication was discontinued upon completion of the study (Boyd & ANP, 2013). Participants reported feelings of being used and having mistrust with research, as they were informed in the beginning of the trial that studies were usually successful in having continuation of the clinical trial medication, following the conclusion of the study (Boyd & ANP, 2013). Similarly, participants in an HIV Vaccine trial felt poorly prepared for an early closure of their study. Participants were informed that the vaccine was not only ineffective, but those who received the actual vaccine were now at more risk of becoming HIV positive (Newman et al., 2011). Some participants expressed they felt that they were not adequately informed of the potentially adverse outcomes, stating in hindsight they felt they put their health and sexual partners health at risk (Newman et al., 2011). In both situations, participants felt they were oversold the benefits of the research and unprepared for the potential adverse effects, which had significant impact on their well-being (Boyd & ANP, 2013; Newman et al., 2011).

Benefits of Research Engagement

In reflection of motivations to participate in research, some participants described research engagement as a therapeutic activity (Andrighetti et al., 2017; Roberts et al., 2000; Taylor et al., 2010). Research engagement provided a place to explore meaning of their illness, developing

relationships, social connection, and to feel like a member of the team or a part of something potentially innovative (Andrighetti et al., 2017; Barratt et al., 2007; Bell & Salmon, 2011; Boyd & ANP, 2013; Newman et al., 2011; Taylor et al., 2010). It was also seen as a place to share personal stories they may not share otherwise feel comfortable sharing (Andrighetti et al. 2017; Taylor et al., 2010). Research also provided important financial resources for women who use drugs (Bell & Salmon, 2011). In some cases, participants described that research participation provided a sense of hope for participants, with possibility for new treatments or improved care (Newman et al., 2011; Roberts et al., 2000) As a whole, research engagement provided the possibility of a therapeutic engagement, a space to reflect and share about their life.

Challenges within Data Collection

In addition to participants' articulating benefits of research participation, some studies exploring participants' experiences with research reported challenges with research engagement, particularly with interview questions (Bell & Salmon, 2011; Barratt et al., 2007; Dwyer & Fry; Singer et al., 2008; Taylor et al., 2010). Some difficulties in research engagement included: questions that were too personal, repetitive questions, describing interviews as embarrassing or inconvenient or being 'triggered' by the questions –that is, experiencing a negative emotional-physical response, potentially resulting in a fight or flight nervous system response (Bell & Salmon, 2011; Barratt et al., 2007; Dwyer & Fry, 2001; Singer et al., 2008.). In one study, participants described questions regarding their psychosis and suicidality resulted in triggering difficult feelings; however, this was not a deterrent for them to participate in future research (Taylor et al., 2010). As such, participants shared finding research participation difficult at times, with numerous challenges during the research process, yet most participants expressed interest in future participation.

Summary

To develop a greater understanding of participants' experience of research, particularly from communities who may experience marginalization, this literature review provided insight into ethical challenges experienced during the research process. With the exception of PWUD, limited analysis was provided on the impact of research questions and data collection methods on research participants. PWUD shared some similar themes with PESW in regards to trust, privacy and confidentiality and data collection. Further research is needed to understand how these ethical principles are enacted within the research-participant relationship and impacted by larger socio-structural constructs. Overall, there is limited research available investigating how participants experience research, with the limited literature available focusing on their motivations and decision making when participating in research.

Chapter Summary

In this review of the current literature, several key gaps have been identified. First, there is a dearth of Canadian literature exploring research participants' experiences of research and research ethics, particularly PESW. This is important as PESW are routinely engaged in research, and yet, we have limited data exploring the efficacy of ethical safeguards for participants. Key ethical themes of trust, privacy and confidentiality, and consent were identified in the literature review, and pointed to some safety and ethical concerns in participant engagement. These ethical themes were largely analyzed within a bioethical framework, which related ethical concerns as largely individualistic and localized to their specific research experience. Thus, the larger socio-structural conditions of participants' lives and how they shape and influence their experiences in research were often absent in the discussion. To add more depth to the analyses, a relational ethics framework will provide greater insight into how the

larger context and relational engagement with the research team influenced their experiences of research participation and research ethics. Lastly, in understanding what participants' experiences of research ethics and engagement, this study seeks to include recommendations on what would improve ethics in practice for research participants, informing researchers and research ethics boards on how to support PESW in research.

CHAPTER THREE: RESEARCH DESIGN AND APPROACH

Introduction

As noted previously my research question was: “What are research participants’ experiences throughout data collection and consent processes in studies concerned with sex work and health?”

My aim was to analyze participants’ experience of data collection and consent processes from an ethical perspective, to unpack the ethical issues embedded in research engagement. This analysis focused on the social-structural conditions impacting participant engagement, and the ethical issues experienced within the research-participant relationship.

To address this research question and aim, I used secondary analysis as my research approach, drawing on a subset of data from a larger project examining the ethical and methodological challenges within health research on PESW. To guide my analysis, I utilized relational ethics as analytical framework. In undertaking this approach, I sought to deepen my ethical analysis of the participants’ experiences of data collection and consent processes. In this chapter, I detail my research design, elaborating on the larger study and methods of sampling for my project and locate myself specifically within this work. I provide an overview of relational ethics as a conceptual framework to guide analysis and discuss how the analytic approach was applied during analysis. Finally, I conclude with a discussion of the ethical considerations for this project and how I maintained ethical integrity throughout.

Situating the Study

As noted previously, my project involved secondary analysis of a sub-set of data that was collected as part of a larger, Canadian Institutes of Health Research (CIHR) funded, 3-year empirical inquiry into the ethical context of health research that included PESW as research

participants. This project, known as the Ethics Project, received ethics approval from the University of British Columbia (UBC) Behavioral Ethics Research Board. Informed by the guidance of experiential experts in roles as co-investigators and advisors, the project included an analysis of current CIHR funding for research concerned with PESW health, content analysis of research guidance materials used by not for profit sex worker support and advocacy organizations, and qualitative interviews with 53 people with current or previous sex work experience who reported being a research participant in the previous 10 years; 16 people who work for not-for-profit sex work service community organizations who regularly participated in research activities including as partner organizations and/or sites of recruitment, and 17 researchers identified in the analysis of CIHR funding data base as being a primary or co-investigator on research funded between 2008-2013 that included sex work as a topic of interest in the study design. The study utilized critical ethical inquiry (CEQ) as an analytical framework, applying concepts of social justice and equity in the analysis.

Within the larger project, research participants were eligible to participate if they were 18 years of age or older; had participated in research that included them acknowledging their sex work participation within the past 15 years; were able to communicate in English; and were geographically located in Canada. The interviews were conversationally oriented and explored with the participants the types of research methods they had engaged with, their decision making to participate in research, the focus of the studies, and the actual experience of being involved in research as a participant. Probes specific to consent, incentives for participation, and recommendations to improve research with PESW were included. Based on the guidance of the advisors, structured demographic questions were not asked and instead people were offered the opportunity to share information about themselves that they felt

comfortable providing. Recruitment and sampling were purposeful. The research team travelled to cities across Canada in which researchers held the largest number of CIHR funded grants identified in the analysis of the CIHR funding history. Consequently, the bulk of recruitment occurred in British Columbia, Ontario, and Manitoba, with participants from dense urban and less urban centres participating.

Situating Myself

As a nurse working in community health and a volunteer with several not-for-profit agencies, I have worked with PESW over the past 10 years. While this has provided me with some knowledge as an outsider, I do not make any claim to being an expert on PESW experiences in research or otherwise. As part of the Ethics Project, I worked as a research assistant from September 2016 to June 2017. During this time, I reviewed transcripts from multiple participant interviews to check for accuracy of the transcript and to remove any identifying information from the text. Following the transcription review work, my responsibilities included the coding of interview data, using QSR NVIVO 11 and the established codebook to organize data, first with broad thematic categories and following with coding for sub-categories within each category. Through this work, I spent many hours immersed in the data, developing familiarity with participant narratives and the emerging ethical themes. During this time, I took notes, and wrote down questions for further discussion with the research team. In discussions with the research team, I explored how certain data should be coded or if particular information needed to be removed for confidentiality purposes. As a whole, this experience provided a strong foundation for initiating my secondary analysis.

Research Design

Secondary Analysis

Over the past twenty years, secondary analysis has grown as research method in qualitative research (Heaton, 2008). However, consensus is lacking on a common approach to conduct a secondary analysis on qualitative data (Heaton, 2008; Thorne, 2008). Debates persist on what a rigorous approach might look like, as numerous approaches exist. As others have identified in the literature, a secondary analysis provides an opportunity to explore and utilize existing data (Heaton, 2008). Thus, researchers seeing increased benefit and efficiency in knowledge production, to ask additional research questions and share data with other research members (Thorne, 2008). This has also been echoed as an alternative methodology for researching hard to research and hidden populations (Heaton, 2008). In this circumstance, secondary analysis provided the opportunity to conduct an ethical analysis on the experiences of PESW during data collection. I utilized existing data that had not been analyzed, and was collected by other researchers. Additional benefits from this approach include accessing data from communities who may be hidden, or preventing participants from being asked the same questions asked multiple times, which has been a frequent criticism of research from some sex worker community members (Bell & Salmon, 2011; Urada & Simmons, 2014).

Theoretical Perspectives

Introduction

The ethical analysis of the experiences of PESW participating in data collection was significantly informed by the guiding principles of the TCPS (2014): autonomy, justice and respect for persons, as well as, the theoretical approach of relational ethics. The TCPS (2014) provides ethical guidance for research conducted on human subjects and informs research ethics

boards (REB) practice. Understanding the ethical underpinnings of the TCPS is integral to understanding how these principles shape participants experiences of research engagement. To provide a deeper analysis, the addition of a relational ethics framework facilitated inquiry into how social, political and environmental conditions shape ethics in practice, including ethics within a relational space, and how core relational concepts influence ethical decision making in day to day to research engagement (Bergum & Dossetor, 2005; Sherwin, 1998).

Relational Ethics

Relational ethics are well suited for analyzing the experiences of PESW in data collection. Relational ethics situate ethics within the relationship, expanding on PBE to include the relational and socio-structural context in ethical analysis (Bergum & Dossetor, 2005; Pollard, 2015). Bergum and Dossetor (2005) articulate several interdependent tenets of relational ethics: mutual respect, engagement, embodiment and environment. Bergum and Dossetor (2005) argue that mutual respect is integral to relational ethics and described as a reciprocal relationship demonstrating care and regard for each-other, including acceptance of difference. In describing engagement, relational ethics includes manifesting elements of presence with the participant, through demonstrating responsiveness and empathy. Underlying engagement is the impetus for authentic connection, which is exhibited through respect, sensitivity to the participant, and the aforementioned presence (Bergum & Dossetor, 2005).

Furthermore, Bergum and Dossetor (2005) described embodiment and environment as two major tenets central to relational ethics. Embodiment refers to the mind-body connection. Where attention to feeling and emotional domains in relation to ethics are given equal privilege to scientific knowledge, thus decision making is an amalgamation of different ways of knowing, rather than limited to rational decision making, excluded from context (Bergum & Dossetor,

2005; Pollard, 2015). Lastly, environment is defined as where the social environment and personal identity are intrinsically connected, where values, beliefs and perceptions are socially constructed and mediated (Bergum & Dossetor, 2005). This is discussed further by Sherwin and Winsby (2011), who argues: “Rather than theorizing about abstract individuals, conceived of simply as rational deliberators, we recognize that persons are essentially social beings, whose distinct identities are developed and maintained within a complex web of social relations (p.184).” Thus, ethics in practice are conceived as relational and enacted on structural, environmental and relational levels (Bergum & Dossetor, 2005; Sherwin, 1998; Sherwin & Winsby, 2011).

Further, I expand on this definition of relational ethics to include the analysis and impact of social and structural contexts, including oppression and its impact on relational autonomy (Baylis, Kenny & Sherwin, 2008; Sherwin & Winsby, 2011). As PESW are a diverse group of people, relational ethics as an analytical framework highlight how ethical principles such as autonomy and consent are enacted through layered experiences of social, political and interpersonal contexts (McLeod & Sherwin, 2000; Sherwin, 1998). Thus, members of oppressed groups are not homogenous and do not experience the same vulnerabilities. Rather, people have variable oppressions and privileges, influencing their self-capacity and self-trust, influencing their ability to express agency and autonomy (McLeod & Sherwin, 2000; Sherwin, 1992). Sherwin (1998) argues that participants are not to be denied access to research as a result of their perceived vulnerability; rather, researchers are challenged to address structural barriers and oppressions that impede participant autonomy and choice. Thus, in this paper, ethics in practice are not conceptualized within a series of individualized experiences; they are seen within dynamic processes, structurally mediated, layered, and relational (Baylis et al., 2008; Sherwin,

1998). Lastly, how the relational ethics approach was applied during analysis is discussed in the Data Analysis section below.

Methods

Data Collection: Developing the Sample

Drawing in the central tenets of secondary analysis and the overarching aim of my study, I selected a total of 15 transcripts as the study sample (Heaton, 2008). Because of the focus on the experiences of PESW as research participants, all community organization members and researchers were excluded from the possible list. Using NVivo 11TM I created a subset of all data that had been coded for the broad analytic categories of experiences of data collection and consent within the context of the larger study as a starting point for transcription selection. Although all of the 53 possible data sources had some mention of consent and/or data collection experiences, 25 had detailed descriptions of their experiences of both data collection and consent to warrant further review. Sufficient data was determined by the breadth and depth of the content of text within the transcripts, including for example, discussion of consent process, explanation of how they experienced data collection and their interpretations of these experiences. With the guidance of my supervisor, I selected transcripts from 14 individual, one-on-one interviews and one focus group. These 15 data sources permitted diversity from each province where data had been collected in the original study, provided consistency in the level of street-level sex work as the majority of CIHR funded research has emphasized street-based marketplaces, and included primarily women, who based on the analysis of funding within the larger project (see Appendix A for coding structure in the larger Ethics Project), represent the majority of participants in health research concerned with sex work funded in Canada (Bungay, 2017).

A number of participants were street involved during their research participation. Street-involved is defined as being involved in street life; being homeless, couch surfing or living on the street; or precariously housed, including living in a motel or single room occupancy (SRO) (McCreary Report, 2015).

Data Analysis

Thematic Analysis

For the data analysis, I utilized thematic analysis. Thematic analysis “is a form of pattern recognition within the data, where emerging themes become the categories for analysis,” (Muir-Cochrane & Fereday, p. 82, 2006). Paired with a theoretical framework, this method of analysis involves breaking down the text into smaller parts, analyzing for patterns and themes, and then co-constructing meaning of the themes from larger categories (Sparker, 2005). Thematic analysis also provides a methodology in which theoretical frameworks can function, providing a larger context for analysis. Thus, I utilized relational ethics as my analytical framework with a thematic analysis to facilitate a critical and nuanced analysis of participant experiences in data collection.

During each transcript review, I documented potential codes and took notes on patterns I identified and observations I made. The initial descriptive themes included respect within relationships, informed consent, and disrespectful questions and the impact on participants.

Moving from descriptive coding into a theoretical approach, I closely analyzed the data from a relational ethics perspective, with an incorporation of the TCPS guidelines into my analysis. Furthermore, I analyzed participants’ relational, social and environmental context when coding. In consideration of the interrelated nature of the themes, I created a thematic map to chart the patterns and emerging themes (Braun & Clarke, 2006). This was conducted with a reflexive intention that research participants’ perspectives were represented as authentically as

possible in their experience of ethical research engagement in data collection (Thorne, 2008).

With informed consent identified as an early theme, I delved deeper into the relational ethics analysis to understand how consent was enacted as a relational process. As such, relational engagement and research related harms were noted as later themes. Furthermore, following re-reading and comparison of the codes and memos, themes of the physical environment as a space for consent were identified. Following further analysis, subthemes included managing harms and lapses in relational engagement.

However, with further discussion of the major themes with my supervisor and committee, the major themes were revised into four main categories: power dynamics and consent processes in data collection, the harms of research, how the harms of research were navigated and mitigated, and lastly, participant recommendations on what ethical research could like.

Ethical Considerations/ Limitations of Study

In designing this study, a number of ethical considerations were made. First, I employed guidelines and protocols from the Tri-Council Policy Statement (TCPS, 2014), following completion of the TCPS 2 online course. My study application was reviewed and approved by the Ethics Project advisory board for research. In a secondary analysis, this is particularly significant, as the advisory board is comprised of members of the community who were engaged in sex work and provided oversight on the Ethics Project study. In review of my study proposal, they consented to the re-use of data for purposes beyond the original study, including sharing data with people outside of the original study and ensuring study fit within the parameters of the original study aims (Heaton, 2008). I also received ethics approval from UBC to conduct the study. Further, to protect client confidentiality in conducting the data analysis, the data analyzed was de-identified data, thus protecting client privacy.

Rigour

This study sought to provide an ethical analysis on the experiences of PESW during data collection in research. In conducting the research, I established methods to ensure rigour throughout my research process. Rigour is established as a method to ensure trustworthiness of the data and encompasses principles of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985; Sandelowski, 1993). To address trustworthiness, my sampling strategy involved identifying transcripts that had good data fit – demonstrating relevance to my research question and maintaining close relevance to the original research (Thorne, 2008). Additionally, the transcripts included were full of thick, rich description of the phenomena of study (Heaton, 2008). Thus, these strategies supported confirmability and dependability of the research. In addition to credibility, I focused on strategies such as reflexivity to improve the trustworthiness of my analysis and thus, ensure the descriptions of participants' experiences were as genuine as possible.

Reflexivity

In addressing the subjective nature of qualitative research, reflexivity has increasingly been recognized as a critical activity in qualitative knowledge production (Berger, 2013). Reflexivity is defined as a continuous, iterative practice of critical self-reflection, including the researchers' positionality in acknowledgement that the self may impact the research process (Berger, 2013; Guillemin & Gillam, 2004). Further, Guillemin & Gillam (2004) argue that reflexivity can be used “for understanding both the nature of ethics in qualitative research and how ethical practice in research can be achieved (p. 263, 2004).” Thus, as researchers in the qualitative tradition are active in the process of constructing interpretations of knowledge, it is critical to reflect on how the knowledge is both produced and generated (Guillemin & Gillam, 2004).

To begin my process of reflexivity, including the active process of critical reflection of my own positionality – my values, beliefs and biases and how they have impacted my research process. My critical reflection began as I started my journey in developing my research question, and throughout my research design process. I documented my reflections, reactions, and inquiry into certain assumptions and positions on my research. I acknowledge that I have my own lens and bias that require constant reflection and thoughtfulness in drawing forward themes and patterns. For example, acknowledging my role as a nurse who has worked with PESW and my current role as a researcher, and how those positions and experiences can influence my interpretation and understanding of the data. Journaling and discussions with my supervisor were spaces where I was able to actively reflect on how these orientations influenced my data analysis, writing process and ongoing thinking. Another example includes deciding which excerpts to include and exclude in the findings section, and what impact that may have on the interpretation of the participants' experience in research. Privileging narratives over others has implications on what issues are prioritized and intertwines with my own values, beliefs and orientation (cite). As a whole, these results add value to the limited knowledge available on the experiences of PESW during research engagement, within an ethical context.

Representativeness

In conducting a qualitative secondary analysis, representativeness presents several challenges. In this secondary data analysis, there is a risk of misrepresentation of the data. To address the lack of representativeness, immersion in the data was critical, including close reflection on how the data was analyzed and interpreted (Thorne, 2008). Additionally, I frequently consulted with my supervisor, the principal investigator of the original study, on my interpretation to facilitate my reflexivity and analysis. Critical reflection of how my own

positionality impacted the research was pivotal to ensuring the research remains relevant to the interests and perspectives of the original data sources (Thorne, 2008). However, I acknowledge that as a person who did not collect the data, and who is not a part of the community of study, there remains a risk of misrepresentation of the data.

Chapter Summary

This study sought to understand how PESW experienced data collection through a relational ethics framework. With a qualitative secondary analysis research design, ethics in practice were analyzed with a particular interest in how systems of power related to and influenced participants' ethical concerns and experiences in research. Analyzing rich participant narratives, using a thematic analysis and relational ethics approach provided a descriptive and interpretive approach to understand the major themes of participants. Ultimately, 15 interviews with participants were sampled from the original Ethics Project data. The findings of this analysis are articulated in Chapter Four.

CHAPTER FOUR: FINDINGS

Introduction

In this section, I detail the study findings following the ethical analyses of PESW experiences as research participants in data collection and consent processes. First, I describe the participants and provide a general overview of the types of data collection that they have been involved in. Then, I describe the context in which the research occurred. Afterwards, I present four major interrelated themes concerning ethics and participants' research experience. The first is a theme of how power dynamics mediated participants' experience of consent and methods within data collection. The second theme was the experience of research related harms, particularly, from a lack of shared knowledge and expectations regarding research participation. The third theme is how participants navigated and mitigated the harms of research. In the last theme, I illustrate participants' recommendations for more ethical research. Within these themes are illustrations of ethical concerns within the researcher – participant relationship, but also encompassed in the broader context participants' lives.

Participants

In this study, there were 15 data sources (i.e., transcripts) including 22 people's experiences as a research participant. Of the 22 participants, 19 identified as female, 1 as a trans female, 1 as gender fluid, and 1 as male. The predominance of female participants is reflective of my literature review, where FSW were the predominant sample of participants. Most of the participants had significant experience with a wide variety of research and data collection methods; however, the most common methods were qualitative interviews, surveys, and research involving blood and/or tissue sample collection for HIV and sexually transmitted infection testing.

Participant Experiences of Data Collection: Consent and Methods

Participants described experiencing multiple ethical concerns during research engagement including violations of consent, trust and respect. The harms they experienced in research participation were harms perpetuated by power dynamics related to socio-structural conditions such as gender, class and race. While participants described their experiences of research engagement primarily in the context of the research-participant relationship, the larger social context of both the researcher and participant shaped their interpersonal dynamics in research, and thus, the ethical concerns brought forward in this data. Space and social environments also contributed to oppressive relational contexts, perpetuating participant harms in research through omissions in consent and power relations. In what follows, I illustrate the complexity of the participants' experiences and the interrelationship between the social context of their lives and the inequitable relations of power situated within the research process.

Ethical issues pertaining to consent were reflected in the disconnect between what participants experienced in research and what they initially agreed upon, with personal, intrusive interview questions being the most common concern among the participants. A resounding issue within the interviews was how surprised participants felt by the nature of the questions, sharing they felt assumptions were made about what topics they might be comfortable discussing. The following excerpts from two participants demonstrate for example, how they felt after being asked about their experience of personal trauma:

“And how some of us are blaming ourselves for what happened and stuff. And there was a lot of anger around those issues and... it was a really touchy subject because some of us didn't know how to handle the reaction that we'd be getting from these certain questions.”

“Like with the testing thing, they didn’t explain... Well, and I’ve been diagnosed now for almost 15 years, but they didn’t explain to me any of the reasons why they needed to know how many partners I had been with, unprotected sex within a month. They didn’t explain none of that to me.”

The common types of questions participants were asked reflected dominant ideologies of sex workers as social deviants, victims, and lacking personal agency. Participants described feeling unprepared for the types of interview questions asked, consistently describing the questions as ‘invasive,’ ‘personal,’ or ‘intrusive.’

“I think questions are very triggering and intrusive; like asking people how much money they’re making, what [sex work] are they doing for that money, that amount of money. It’s sickening a little bit, and I don’t see, like after being on the other side of it and doing and participating in the research with [name] I don’t see how those questions are very valid, you know to their research”

Additional questions considered to be intrusive included: the types of sexual acts they engaged in; if the types of sexual acts changed if they were high or were paid more; condom use; and drug use.

“Okay. Well, how many blowjobs did you do today? And how many condoms did you use? And out of those 10 blowjobs, how many of them spoofed in your mouth?”

Additionally, participants were often asked about their histories of violence, sexual and partner abuse, sexual assault and work related violence. Participants frequently expressed not being emotionally or mentally prepared for such interview questions as a direct result of not being fully informed about the types of questions they were expected to answer prior to the onset of data

collection. Participants found some interview questions irrelevant to the nature of the research, and suggested the questions were asked because the participant was engaged in sex work.

“It was, and even sex they asked about how much sex people were having and if they were having unprotected sex and it was like why would you, what does this have to do with taking vitamins?”

Some participants found the questions reinforced prejudice towards PESWs, identifying they felt they were treated differently from other social groups during the research process.

“It’s almost like this, yeah we’re sex workers but it’s like asking, go and take that question and ask some very wealthy lady who lives in the West End, somewhere in North Van, ask her that question and ask her how she feels; how offended and how holy cow how could you ask that question?”

Omissions in informed consent on the potential harms of personal questions during data collection contributed to mistrust, feelings of disrespect and were described as harmful. Consequently, a number of ethical issues intersected in participants’ experiences of data collection, including voluntariness; consent, autonomy and the overarching power dynamics, which mediated their research engagement. Overall, participants felt researchers should have not only informed participants of the risk of harm from the interview questions, but also have been aware of the potential harmful impact on the participant, reflecting the larger social and environmental conditions that impact PESW on a regular basis.

During data collection, participants shared experiences of direct consent violations that contributed to re-traumatization, feelings of disrespect, and damage to trust. Participants expressed feeling a lack of agency in these processes, often in economic situations where they felt they needed the cash research incentive, and at times, expressed that they were unsure of

their rights during research participation. In one example, a participant shared how the focus group participants were not informed that they could leave the study at any time, violating informed consent in the TCPS guidelines (2014).

“They didn’t leave us an option to say, okay, you can drop out at any time. You can withdraw at any time. It was, once you say this, it’s being archived... and it really hit me like a ton of bricks. I was, like, oh, my god...”

Nor was this participant aware of the nature of the questions to be asked in the research, which had a significant impact once the research started.

“Well, I think that would have been a little bit more respectful on their part to kind of prepare us better for what was coming. Not just say, oh, here’s some money. We’re going to ask you some questions. It’s going to be short and sweet. That was all bullshit.”

Overall, issues of respect, concern for participant well-being and informed and ongoing consent were key issues – with participants being considerably triggered by the questions, and some may have felt as though they were required to stay in the research.

“I said, “Do you guys not realize you’ve just opened a new can of worms for these participants?” And they’re, like, “Oh, well, we’ve been to other places and it didn’t seem to affect anybody like this.” And I’m, like, “Well, come on, how can you sit there and say that?” I said, “You guys are dealing with street people. How can you sit there and say it didn’t affect any of them the way it affected us?” Because if it affects us like this, then there’s got to be others that were affected the same way but didn’t want to show it.”

This participant drew attention to the interplay of the socio-economic status of the group, the social locations of participants and the potential vulnerability of participants as being street-involved. The participant also highlighted how silence does not necessarily reflect a lack of harm

for participants – but may have been missed by the researchers. The participant also alluded to the shame produced by bringing forward traumatic experiences and the impact on participant welfare. Without explicit and ongoing consent processes, participants’ expressed a belief that researchers downplayed the significance of the everyday exposure to violence, stigma and discrimination participants experienced.

Poverty was an important aspect of voluntariness and ultimately consent for research participation. Participants expressed feeling internal and external pressures to engage with research in which they may not otherwise participate exacerbating the potential for undue influence. For example, some participants shared how their economic need (external pressure) trumped their self-protection from research harms (internal pressure). Several participants shared participating in research primarily to obtain the research incentive. As one participant expressed: “I was just thinking about the ten bucks. I didn’t even care.”

Cash incentives also played out in the amount of information participants’ received about expectations for research participation. A number of participants shared “being told to come in for a few bucks and a quick interview.” At times, participants were later asked to be involved in in-depth research, with having little time to ask questions and truly understand and prepare for the research. Some participants remarked not remembering their engagement, not being sure of the research purpose, or of the possible risks of the research. This resulted in feelings of confusion, distress and at times, harm related to participation. This was a particularly important issue for participants who were street-involved and experiencing multiple and competing demands for survival.

In some instances, participants relied on relationships and trust with not-for-profit sex worker support service agencies to gauge whether or not the research was safe or worthwhile.

Participants described learning about research by engaging with a sex worker space (i.e, agency) to participate in a study. This sometimes backfired however in that participants were told the study would be good for them (i.e., they would receive money) and enrolled without really knowing what the study was about. They ended up participating without a clear sense of what they were doing, thereby negating a fully informed consent process. Consequently, social environments and trust were important factors for participants in deciding to participate in research.

Participants who were street-involved frequently discussed the socio-structural conditions that were external to their research participation including homelessness or being under-housed, mental health and substance use, interpersonal and structural violence, transitions from recovery centres or jail, and experiences with acute and chronic illness. Research engagement was often focused on income generation in exchange for the participants' story. Thus, some street-involved participants described exchanging significant amounts of personal information without adequate informed consent regarding the nature of the study, how the data would be used, or the required supports to cope with the potential harms of engagement. Participant voluntariness was notably compromised by the social locations of participants and the urgent nature of their poverty was a key determinant in decision-making. As a whole, the context of participants' lives is integral to their involvement in research, their decision-making, and welfare.

In addition to the socio-structural conditions mentioned above, social and physical environments were ethical spaces mediating relational engagement. Consent and respect were negotiated in the context of the actual methods for data collection and the social milieu where data collection occurred. For example, participants shared feeling respected when given the opportunity to choose the interview location. In being given greater control over their physical

environment, participants felt seen for their value of privacy and confidentiality, as well as, personal safety.

“Okay, with [name], yeah. With [name], it was always choice. She’d come right to your home. I don’t know if she’s allowed to do that anymore, but she would always give me the choice. I could go meet her any place in the city and she would come. For me, I’m most comfortable in my home, and if interviewer or surveyor is allowed to come to my home, then I’d sooner have them come to my home because I’m in my comfortable zone.”

In a broader social context, the home also provides safety and confidentiality from the larger criminalized and stigmatized social environment for PESW. When researchers prioritized the participants’ choice, they supported agency, and facilitated safer engagement in research. At home, participants shared feeling in charge of their own space.

Fears of compromised confidentiality and privacy by being outed were amplified by research contact in public spaces. Participants were interviewed on the street, in shelters, in tent encampments, and in cafes. In one example, a participant described the shame and fear associated with being exposed during an interview in a café:

“I was waiting for her to be done and we were meeting at a coffee shop that she’s meeting other women there and she’s asking these women questions about sex work and the woman’s got her head down and she’s just like yeah and she’s got her sunglasses on and she’s got her head down. She’s not even looking at her or anybody. Then when she finally gets up she looks around and everyone in the coffee shop was looking at her. When she got up and looked at everybody finally everyone looks at her at that point with their judgmental, moral eyes. ”

The social dynamics interplayed with the lack of privacy, feelings of shame, impacted participants' abilities to suggest a private space or cease the interview. While participants may agree to meet in a public space, ethical concerns remain for the consequences of violating participant privacy and confidentiality.

The intersections of public vulnerability, precarious housing, incentives, substance use, and the participants' experiences of being street-involved contributed to a lack of voluntariness in research engagement. People who had lived in tents during a time of intense media coverage about homelessness and tents as a source of housing recounted stories of being approached with incentives to engage in research or media interviews with no sense of what they were actually participating in. The publicized nature of tents and/or other living spaces raised the visibility of the participant and thus, compromised their privacy and safety and contributed to a sense of being on display. Yet the participants' need for the incentives trumped their privacy and discomfort. Ultimately, participants who were street involved raised numerous ethical concerns for research participation, with complex layers of structural and social conditions mediating their research involvement

Harms of Research Engagement

As a result of research engagement, participants expressed experiencing multiple ethical violations within respect for personhood, consent in terms of the research process and within the relationship, and in denial of participants' opportunities to participate in decision-making in data collection processes. As a result, the harms within research perpetuated oppressive circumstances within the relationship. Participant experienced harms through ethical violations of their confidentiality, privacy and safety – resulting in triggering experiences, feelings of shame, and a loss of trust.

In response to feeling re-traumatized by interview questions, participants described themselves as being 'triggered,' dissociating, feeling depressed and isolating themselves.

'Triggered' refers to eliciting a negative emotional response, which is often paired with flashbacks, sadness, panic and in many cases, physical manifestations such as shaking, fainting and fatigue (Friedman, Keane & Resick, 2014). The symptoms and severity can vary – but this experience is common in survivors of trauma – however, people do not need to experience trauma to be triggered (Friedman, Keane & Resick, 2014).

“It was more wicked questions and questions you wouldn't want to answer. Taking it home and no one to talk about after, because it brings back all the memories.”

In response to interview questions, participants conveyed triggering experiences during data collection as a mental and physical phenomenon. As one participant shared,

“The questions were so triggering and harsh that afterwards I needed the money. Even now just thinking about it and talking about it I'm getting a sensation a little bit.”

In addition to the emotional experience and labour involved in being re-traumatized, participants described bodily responses as: feeling tingles throughout their limbs, heart pounding sensations, dissociating from their body, feeling faint, and “sobbing uncontrollably.” A participant within a focus group for example, described members being triggered collectively, with the research “opening old wounds.”

“A lot of the participants, by the middle of it, they were crying, because it touched a nerve that hasn't been touched in so many years, that some may have thought they had forgotten about up until that point in time. You know, and then all of a sudden it's, like, okay, here's a scab, let's rip it off and start it all over again. That's not fair to anybody.”

The visceral language used to describe the triggering experience is indicative of the depth of the trauma and pain invoked during data collection.

Following research engagement, participants described being left to manage their trauma on their own, whether without emotional support or formal counseling resources. Some participants felt there was little concern by researchers for their overall welfare. Numerous participants recognized their own histories of trauma and clearly articulated the need for mental health supports during research engagement. Several participants shared having mental health issues, and that the research exacerbated their symptoms. As a result of their poor experiences, participants shared disengaging from research, or being more discerning in their future research participation.

In experiencing harms during research, participants expressed feeling “stressed out”, “hurt”, “violated”, “humiliated”, and “betrayed” following data collection. These descriptors reflect participants feeling a violation of their relationship with the researcher, including a lack of compassion and sensitivity to their well-being. As one of the participants described:

“I also notice an insensitivity to the questions that are asked. And I’m not talking everyone, right. I’m just talking the negative things that I have experienced, which unfortunately have sort of dominated it right.”

Additionally, participants discussed accepting a degree of vulnerability in research engagement; however, it was important that their feelings and daily realities were not minimized in participation.

“I know now why they need to know, but had they explained it, maybe I could have answered their questions more specifically instead of just wanting to get the questionnaire

part over and done with and get the hell out of there. Because it's hard enough... And this is totally irrelevant to what we're discussing now, it's hard enough to take in the fact that I just found out I'm positive and then I got to deal with all these humiliating kind of questions, you know what I'm saying?"

Considering the broader context of participants' lives, these violations were deeply felt. Research engagement was described as something happening to them, rather than a reciprocal, engaged relational process. Some participants described this power dynamic as feeling extractive, where they felt a part of them was taken, with little benefit in return.

"That should be like... Way heads up, because a lot of research... I'm not discriminating or whatever. You're just doing this research on us. You don't first-hand know what it's like to be a sex trade worker on the street, in-house, you know? So you don't know what kind of stuff, feelings and emotions you're inflicting on us by asking us these questions. Do you know [what]I mean? Do you understand?... "You're just textbook. We are the book."

Participants illustrated the impact of power dynamics inherent in research being conducted on them – rather than with them. To mediate the power imbalances, participants emphasized being recognized and respected for their experience, resilience and contributions to the research community.

In another example of harms, participants' described clinical and cubicle spaces as sterile and uncomfortable for interviews. Participants shared feeling as outsiders in the sterile spaces, where power differentials between the researcher and participant were amplified. In contrast, some participants described feeling comfortable being interviewed in not-for-profit sex worker support agencies; however, some spaces were critiqued for lacking privacy and confidentiality as

a result of interviews being conducted in shared spaces as reflected in the following excerpt:

“There was no confidential space to talk in; it made it a huge issue for me.”

While the use of community agencies facilitated greater access to participants by researchers and helped participants learn about research opportunities, some participants felt they over-shared when a trusted community member was present in the interview. Thus, being interviewed in participant based locations provided both a sense of safety through leveling power dynamics, but also presented risk for participants in how it affected their sense of agency, confidentiality, privacy and safety.

Navigation and Mitigation of Research Harms

Participants expressed a variety of approaches to navigating and mitigating the harms of research. Some participants self-advocated by informing the researcher of the harmful questions, whereas others removed themselves either emotionally or physically from the context in order to cope with their feelings. Moreover, participants demonstrated skillfulness in learning from past experiences and requesting more information up front prior to consenting to research participation, for example, during an interview one participant shared: “That’s why I asked you [for more information]. I don’t feel like crying today.”

In managing their emotions, some participants expressed suppressing their own feelings to maintain the researchers comfort, prioritizing the researchers’ needs over the participants’. In addition, some participants responded in what they thought the researcher wanted to hear, adjusting their responses to quickly end the interview. In some circumstances when participants attempted to address disrespectful behavior by the research team, they were met with resistance. This resistance was described as a lack of presence and emotional attunement, or outright dismissal of the participant’s concerns. These experiences were underscored by the existing

power dynamics and broader social context, shaping how participants perceived their feedback would be received:

“The first research I have ever been through is about using and whatnot, and I just felt like the lady had no, she wasn’t really listening to the words that were coming out my mouth and she was texting on her cellphone. It seemed like she wasn’t listening ...She asked me to turn off my cell or mute it or whatever, and she kept interrupting me and she’s like oh this is very important. I’m like well you’re here to talk to people that are on the streets and whatnot. Is my input, the questions you’re asking, does that not matter?”

In another case, a participant overheard a researcher talking behind her back with an employee, compromising mutual respect through a lack of confidentiality and trust. However, the participant felt nothing would be done if she complained, so she disengaged from the research project, impacting her trust with future research studies. At times, participants described instances of internalizing the relational slight, and feeling undervalued, that their contribution did not matter.

Participants also described feeling afraid of consequences of self-advocating or not knowing if there were mechanisms in place for complaints. To highlight the difficulties participants experienced in navigating power in their relational dynamic with a researcher one participant described a scenario of over sharing personal details. Initially, the participant felt very comfortable with the researcher and in hindsight, attributed their comfort to over-sharing. When they asked to retract specific data, the researcher declined, citing that the participant consented to giving this data for the book purposes and “knew what she was getting into.” In order to successfully have the data retracted, the participant required significant personal ability, self-trust and confidence. However, the researcher resisted, using their power and privilege, to challenge

the participants request; as they felt they did their due diligence in gaining the participants informed consent. This extended to the participants request to have the writing shared with the participant, which was perceived as a challenge.

Mirroring other examples, the personal interests of the researcher overshadowed the participants' emotional and personal integrity and potentially, the safety and well-being of the participant. While the researcher may have clearly articulated how the data was to be used and owned in advance, this interaction highlights how informed consent can be insufficient in supporting research participants to fully understand the implications of research and the power dynamics intertwined in their research engagement.

In addition to navigating the relational landscape of their research engagement, participants utilized a variety of strategies to cope with being triggered by interview questions. One approach was disengagement, which included leaving the interview, dissociation, or passing on particular questions or increasing the brevity of their responses to complete the interview as quickly as possible.

“I went and they paid me \$150 for a two hour long session... I walked out an hour and a half into it because I just couldn't handle the questioning anymore.”

In some circumstances, participants attended the interview intoxicated, which functioned as a buffer to the personal nature of the questions. Several participants discussed needing psychoactive substances following interviews in order to manage the activation of deep emotional pain and distress. Moreover, using substances interplayed with how participants negotiated the harms of research, where they acknowledged they were willing to share difficult experiences and potentially be triggered in order to obtain the much-needed incentives.

In other cases, participants utilized internal and external resources to manage the impact of research engagement. During one focus group, participants relied on each other for support, providing safe touch and active listening to support each other. The active sharing of each other's pain was critical to processing their experience. Several participants shared spending several days alone in their own space, isolating from others in order to recuperate. Participants also utilized grounding techniques, engaged with friends, or a counselor provided in the study. "You got to try and re-ground yourself and that's what I have to do after I'm done here." In order to be safe for support, participants required counselors to be trustworthy and understand the unique realities of sex work, or were able to engage in a culturally safe manner. Thus, research participation involves significant emotional preparation, personal and social resources, for participants to feel safe and be able to sufficiently cope with emotional expenditure.

For a few research participants, past negative research experiences socialized them to inquire further about the potential harms and benefits. Thus, suggesting that under different circumstances, and in past experiences, the participants would have engaged in research with less discernment. In contrast, other participants shared that the incentive was not worth invoking past traumas or that they were unable to cope if they did engage with the research. However, a few participants managed engagement by leaving the research as soon as they received the incentive. As a whole, participants demonstrated varying levels of agency when navigating the harms and challenges within in data collection and in the research-participant relationship.

Participant Recommendations for Ethical Data Collection

Many participants shared recommendations on how to improve data collection and consent processes with the aim of preventing harm and improving the research experience of participants. The participants frequently voiced how the context of their lives impacted their

research engagement, especially their experiences of trauma and day-to-day street involvement. The priority recommendation was to increase transparency to improve informed and ongoing consent, and thus reduce the potential harms of data collection. Suggestions included using plain language and facilitating longer informed consent sessions, or having a couple of visits to discuss the research. As one participant shared:

“But I think right at the get go, if you’re going a survey on that kind of stuff, you should make the participant well aware. Like “I’m going to be asking you some very graphic questions, and they may be triggering or traumatizing, and you need to know this right up front. Don’t just throw it out at me halfway through the interview. You’re going to traumatize me and bring back all these bad memories.”

Having a transparent and more comprehensive explanation was described as facilitating a better understanding of the rationale behind the interview question selection, including the value added to their community well-being. Participants shared that having a longer and detailed informed consent session, provides a space of comfort and trust, and also demonstrates respect through ensuring the client’s choice and safety. Another strategy was improving the frequency of check-ins; as a check-in provides an opportunity for genuine feedback and support, validating the participant’s time, emotions, and expertise in the research topic. A check-in would also facilitate opportunities for renegotiating consent, an imperative in research engagement. As one participant shared, asking: “Well, what did you think about that? How did it affect you?” following an interview provides space for ethical engagement.

Through having more time and a safe space to ask questions, one participant saw the consent process as a place to also provide education to the researchers, to understand who they are and what has shaped their interest in sex work research. Through an understanding of the

researcher's personhood, the participant felt more at ease in participation – cultivating respect and thus, building a relationship. As well articulated here:

“Probably what I've sort of mentioned before and how I tend to do it now, which is get a lot of information from them, ask them about their advisory, like how that's working, how the questions were picked, and why they're doing the research? Why are they doing this particular research? Because some research benefits our community more than others.

Some research, as you know, can be shaped in different ways as well, which is important to recognize I think too. That's what I would say... with that answer, would be... just finding out more information from them in that exchange, try to also educate in a way, which is not usually what research participants would do.”

As a whole, these recommendations focus on not only having knowledge and comprehension of the research study, but also attending to the relationship and personhood of the research participants.

Another recommendation was for PESW to be engaged throughout the research process to improve the safety, relevance and quality of research. One participant shared that they were more likely to participate in research knowing that PESW were part of the development of interview questions, as they trust that the research question would be less triggering, as they have insider knowledge. Participants recognized the value of their insider knowledge and how their contributions are integral to developing meaningful research.

Many participants identified the need for mental health support due to the triggering nature of the questions, to prevent and ameliorate harms. Some participants suggested having counselors, psychologists and/or elders to be available for support. Debriefing was considered an

important strategy and participants noted that researchers could help participants debrief after interviews or surveys. As one participant noted:

“So you make sure that you have a back-up when you’re done and to debrief and then smudge. Go home and light a candle and that can make you feel relaxed... Yeah, and really try to ground yourself after.”

Activities such as having a person to walk them to the bus, providing coffee and food, and having private spaces for research were also concrete actions reported to demonstrate relational engagement. Additionally, participants’ noted that people doing data collection need to attend to the individual in the moment and not ignore the discomfort felt in the relational space between the participant and researcher. Participants described attending to the individual and the relationship between the researcher and participant as being present.

Participants highlighted the value of acknowledging discomfort in the moment and attuning to communication basics of eye contact, body language, social support and active listening. “Be mindful of the person. Look at them, be mindful of their body language,” were shared as methods to address perceived stigma and judgment within the interviews. Additional suggestions focused on participant safety such as having familiar outreach workers present, providing crisis line phone numbers, follow up calls post research, and the creation of a safety plans for triggered participants.

However, underlying this engagement is the moral impetus to truly understand the lived realities of the participants, to be present in their pain, and to be active in addressing the power dynamics present in their research engagement, and daily lives. It is integral that researchers are emotionally and mentally engaged to be well prepared in their interviews to ensure participant dignity is upheld and even further, the greater community benefits from research engagement.

Chapter Summary

Participants described multiple ethical concerns shaped by structural and interpersonal power dynamics in their research engagement. Participants illustrated how power dynamics were inherent in their navigation of interrelated ethical issues of problematic consent and voluntariness, in expressing numerous violations of respectful engagement. Furthermore, participants' stories within the research context demonstrated how, at times, their research engagement reproduced oppressive social and structural conditions, contributing to personal harms. Moreover, participants were impacted by research harms on physical and emotional levels, particularly for street-involved participants – where the impact of structural oppressions mediated their research engagement, raising significant ethical concerns. Participants' demonstrated agency and skillfulness in navigating and mediating the research related harms, by sharing the nuances of their decision-making in how and what their participation looked like. Further, participants shared numerous recommendations on what ethical research could look like in practice. Ultimately, participants requested greater psychological and social support, and shared knowledge regarding research expectations and ongoing respect from researchers, honoring the wealth of knowledge and experience they bring to research participation.

In the next chapter, I situate my findings in the context of current research on the ethical dimensions of PESW in research. This includes discussing the contributions of my thesis research, the significance of the findings, and comment on the strengths and limitations of my research. I then describe my recommendations for further research, practice and education.

CHAPTER FIVE: DISCUSSION

Introduction

In this chapter, I discuss the findings of this study that undertook an ethical analysis of PESW experiences of data collection in research. The primary aim of the research was to examine how participants' experienced data collection and consent processes to unpack the ethical dimensions of their research engagement. During data analysis I utilized the TCPS and a relational ethics framework to analyze participants' experiences of data collection, while situating their ethical concerns in a broader socio-structural and relational context. In this chapter, I summarize the key findings shared in Chapter Four. Following this, I discuss the key contributions of the study's findings situated within the current literature. Finally, I conclude the chapter with recommendations for future research, education and practice.

Summary of Key Findings

This study analyzed the ethical context of PESW experiences as research participants during data collection and consent processes. Research participants articulated research engagement as fraught with ethical concerns and harms, which were amplified and mediated by complex layers of socio-structural conditions such as poverty, stigma and discrimination. Analysis of participants' narratives demonstrated how power differentials between by researchers with participants perpetuated oppressive socio-structural harms, including stigma and discrimination. Within the structural and relational contexts, ethical violations of privacy, consent, voluntariness, justice and respect were described throughout participants' engagement with research. Participants demonstrated agency and strength through how they navigated and managed the harms within their larger social context. Finally, participants shared important recommendations

for improving the application of research ethics, involvement of PESW in research, and what ethical research could look like.

In building upon PBE, the use of relational ethics as an analytical framework informed my understanding of how ethics were enacted within broader social-structural relations of power (Sherwin, 1998). PBE emphasizes ethical principles such as concern for welfare and respect for persons, which reference relational concerns, which are often conceptualized as individual concerns. In contrast, relational ethics situates our understanding of ethics within the research relationship itself and the broader community, acknowledging that ethics are shaped and mediated by relationships and social environments (Sherwin, 1992; TCPS, 2014). Relational ethics provided a theoretical background to understand how these conditions shape participant and researcher engagement, specifically with enacting power, expressing choice and agency. As a whole, this theoretical framework was integral to providing a nuanced view of ethics in participant engagement in research.

Contributions to the Literature

The study findings illustrated that much of the harms reported by participants' in research were preventable. Harms included a lack of voluntariness during consent processes, shame and re-traumatization during the interview process (with participants being provided minimal support during and after research engagement), participants' emotional disengagement and distancing from the researchers as a way to protect themselves from re-traumatization, and violations of privacy and confidentiality. Further, the harms experienced by participants were reinforced by oppressive social and structural harms such as stigma and discrimination. These findings build on recent literature exploring PESW experiences of research, where participants shared discomfort with interview questions regarding sexual health practices (Bell & Salmon, 2011;

Urada & Simmons, 2014). However, this research adds depth to our understanding of what types of questions are harmful and how they impact participant welfare. Recent literature has shared participants reporting experiences of stigma and exclusion in research participation (Bell & Salmon, 2011; Bowen & O'Doherty, 2014). PESW and researchers have also identified privacy and confidentiality as a significant ethical concern, especially regarding risk and the impact of being outed (Bungay & Guta, 2018; Goldenberg et al., 2015; Sinha, 2017). Conversely, no literature has reported the depth of ethical concerns in research participation for PESW. As a whole, the harms experienced by participants in this research identify a need for further research to understand this gap in ethical practice in research.

Ultimately, these harms occurring through research and identified in this study are unacceptable in the context of research. Researchers have an ethical responsibility to attend to the welfare and dignity of participants, expanding the often individualistic perspective of ethics in practice to a systems view analyzing how power impacts the conditions of their research and thus, participant well-being (Bergum & Dossetor, 2005; Sherwin, 1998; TCPS, 2014). In doing so, researchers can work towards addressing oppressive conditions tied to social, legal and economic contexts which impact participant livelihood (Sherwin, 1998; TCPS, 2014). As noted in the TCPS (2014), researchers require knowledge of the communities they are investigating and are encouraged to meet with them in advance of conducting research. In meeting, communities can share their ideas for research, give feedback on research ideas, and is one approach for researchers to demonstrate respect to the communities of interest. Further, through consultation, communities can identify harmful discourse, language and give feedback on what research methods have and have not worked in the past (Bowen & O'Doherty, 2014). In the absence of this work, researchers risk perpetuating harmful ideologies and stereotypes regarding

PESW as victims, deviants, or vectors of disease, which have significant influence on current policy and research (Bowen & O’Doherty, 2014).

Community-based research and participatory action research are methods that have been used to address power relations in research with PESW (Bungay et al., 2012, Bowen & O’Doherty, 2014). Bowen and O’Doherty (2014) reported on the use of PAR with PESW as a ‘politic act’ and strategy to reduce power relations in research. Methods included employing PESW in leadership positions and research roles throughout research design. Bowen and O’Doherty (2014) described the intentional employment and involvement of PESW as a means to improving the quality of knowledge production regarding PESW, challenging the dominant discourse on sex workers as victims and deviants. Academic literature has been critiqued for reinforcing these narratives, harmfully influencing social policy and the associated resources made available to PESW (Bungay et al. 2016; Bowen & O’Doherty, 2014; Sanders, 2007; Woffers, 2004). These suggestions echo participant recommendations to for greater inclusion of PESW in research design, with the intention of reducing harmful questions and increasing the relevance of the research. Further, participants’ experiences of power differentials in research participation contributing to ethical violations in practice represent a need for research methods and practice that decrease oppressive practices. To prevent further harms, researchers have an obligation to attend to the context of participants and their community context in consideration of research ethics.

The harms involved in PESW's research participation reflect a perpetuation of ideologies of deviance in how the research is conducted with participants. Narratives of deviance, which suggests moral culpability for their engagement in sex work (Scambler & Paoli, 2008) result in

PESW being disrespected and treated as disposable, yet their sexual activities and traumas are deemed appropriate for public consumption. For example, omissions in relational engagement manifested in patterns of inquiry without appropriate informed consent for participants. Participants shared feeling humiliated and disrespected in many of their research encounters where they were asked questions about their sex work or trauma, without their consent or the appropriate supports in place. These examples add to our understanding of how ideologies of deviance reflect structurally embedded stigma and discrimination towards PESW in the research context (Bowen & Bungay, 2015; Sanders & Campbell, 2007). In response to this treatment, participants have reported answering interview questions with what they thought researchers wanted to hear (Agustin, 2004; Sinha, 2017), or expressed feeling used by researchers for their knowledge or treated like “guinea pigs” (Salmon & Bell, 2011, p.7). This research reinforces participants’ concerns with how their experiences as sex workers are constructed in the literature, particularly with a discourse of victimization (Jeffreys, 2009; Bowen & O’Doherty, 2014). As the discourse of deviance and victimhood is widely entrenched, further knowledge is needed to understand how to challenge this dominant discourse in research practice and ensure PESW are treated with dignity and humanity.

Recommendations

Research

Study participants experienced multiple ethical violations throughout the course of their participation in research. To date, little research exists investigating PESW research participation, and thereby, there is minimal research investigating effective methods to support ethical research practice with PESW. To address this gap, future research could explore PESW experiences in research in different Canadian communities. Additionally, intervention based

studies exploring the efficacy of advanced ethics education or trauma informed practice education for researchers could benefit our understanding of effective supports. As there is limited research utilizing a relational ethics lens, future research investigating these topics would benefit from a structural lens to incorporate an analysis of power relations.

To prevent further harms to research participants, stakeholder engagement – that is, engagement of PESW and related not for profit community agencies, throughout the research process is crucial to preventing and understanding potential ethical concerns and research harms. Involvement of stakeholders can highlight areas of research where stigma and prejudice have influenced assumptions regarding PESW, and how the harms of research in relation to PESW have been conceptualized (Bowen & O’Doherty, 2014; Sanders, 2006; Sanders & Campbell, 2007). In the findings, participants highlighted the importance of community consultation as a means to increase ethical research and improve the quality of their experience as participants. In taking up a relational ethics stance, strategies that aim to address power relations in research include engaging with PESW from the beginning of research. In establishing early involvement, PESW can inform research priorities, how the community would like to be involved, support rapport building with community members and provide a space for capacity building. The hiring of PESW in research positions, alongside education and training is another strategy to share power, improve the quality of research data, and challenge harmful discourse in research and policy (Bowen & O’Doherty, 2014; Sherwin, 1998; Sherwin & Winsby, 2011; SPACES Team, 2016). Importantly, community consultation is also a space where language and respectful questions in research can be addressed, together with increasing the relevance and safety of research.

Practice

Further attention needs to be paid to increasing reflexivity of the researcher, such as opportunities for reflection and feedback during research. Reflexivity is considered a core process of qualitative research – however, more is needed to understand what the impact of reflexivity as a research team is collectively (Tilley, 2016). Further, in research, areas to focus reflexivity can extend to considerations on research purpose, biases, language, fears and judgment (Tilley, 2016). How researchers conceptualize and operationalize vulnerability, risk and deviance in relation to sex work also requires attention in practice.

Omissions in relational engagement in this study emphasize the need for greater emotional attunement between researchers and participants. Attunement involves aspects of respect, presence, and concern for the welfare of the participant demonstrated through check-ins, follow-up, and appropriate resourcing in the research setting (Bergum & Dossetor, 2005; Tilley, 2016). This could be enacted in practice through scheduled or regular intervals for check-ins with participants to discuss research engagement. Through applying these strategies, there is also the opportunity for authentic engagement and fulsome ongoing consent. Optimal conditions for feedback include research members being open to learning, having established trust and respect with participants, and working from an anti-oppression framework (Bergum & Dossetor, 2005; Sherwin, 1992; Sherwin, 1998; Tilley, 2016). This also includes recognition that participant in research can require significant emotional capacity and strength, especially in sharing personal information. Acknowledging researchers' place of privilege and power and working towards decreasing the power differential can create a space for authentic engagement and safety for participants (Sherwin, 1992; Sherwin, 1998; Tilley, 2016).

In addition to reflexive practice and emotional engagement, more resources are needed to support participants' mental health and well-being during and following research engagement. Participants spoke of numerous occasions where they were re-traumatized during data collection and were left to cope with their trauma on their own, or the support provided was not adequate for the severity of their experience. Participants shared rushing through the research, dissociating, passing on questions, and some participants chose not to return to continue participating in the study. Some participants recommended having cultural and spiritually-relevant supports in place, including a counsellor and/or elder available as needed during interviews, with access following interviews. Additionally, REB and research institutions have an important role supporting researchers in making considerations for the inclusion of mental health supports when developing their research design.

The factors mentioned above could contribute to the quality of research provided and raises questions about the value of the research to the greater community. The study findings also suggest that feedback mechanisms may be inadequate during the research process, as many participants did not share with the research team when they were triggered. While participants demonstrated resiliency and skilfulness in navigating their experiences, these harms are preventable. If harms do occur, supports should be provided through the research team.

More work is needed to facilitate understanding of the nuances of vulnerability of PESW in the larger context of social, legal and economic contexts and how that relates to research ethics. Additionally, as we don't know why these lapses in ethical practice occurred, more research is needed to understand the gaps in research ethics in practice in research conducted on and with PESW. Furthermore, these research findings reflect the need for the concept of participant vulnerability as a spectrum of considerations, rather than a binary concept of risk and

harm (Sanders & Campbell, 2007; Bowen & Bungay, 2015).

Notions of procedural and ongoing consent need to be examined in practice. While the TCPS (2014) defines consent as “free, voluntary, and ongoing” – in practice, consent appeared to happen once and was over once the participant agreed to participate. Further concepts of autonomy and consent need to be expanded to incorporate a relational ethics lens, to reflect how systems of power impact individual experiences of ethics and participants ability to express agency and choice (Sherwin, 1992; Sherwin, 1998; Sherwin & Winsby, 2012). Within the researcher- participant relationship, consent needs to be explicit, ongoing and continuously negotiated. Further examination of how consent is enacted in practice in research is needed to understand where the gaps in practice are occurring and how to address the gaps.

Education

Trauma and violence informed care (TVIC) is an approach to safely working with people who have experienced trauma and structural violence, acknowledging the impact of trauma on their health (Browne et al., 2012; Levine, 2016). Through training of research staff, there is an opportunity to improve relational engagement and reduce re-traumatization with participants, and thus, preventing harm. TVIC can improve safety in relational engagement, through preventing re-traumatization and supporting participants through recognizing their own physical and mental responses for trauma. Additionally, this training supports self-awareness for vicarious trauma and personal trauma responses, as it focuses on self-regulation of emotional responses. As participants shared frequent experiences of re-traumatization, TVIC training for researchers could be a valuable and effective strategy to prevent future harm.

Relatedly, education for researchers on power and privilege is an approach that could be used to reflect on power relations in research practice. While the TCPS provides ethical guidance

on protecting human subjects, facilitated training on examining relations of power and privilege can provide a space for researchers to analyze and reflect on their own social location and privileges and how they mediate their relationships and engagement with participants (Wood & McActeer, 2017). Training on power and privilege focuses on how systems of power impact different communities as well as impacts on the individual, while providing a reflective space for a person to analyze their social location, their values, and how their privilege manifests in their daily interactions. With reflection, engaged learners can become attuned to how their power and privilege manifest in their interactions with participants, and think about what they can do to actively mediate power in their interactions. As power plays a significant role in ethical practice, this training could support skill development in navigating ethical issues as they arise. Furthermore, it can develop researchers skillfulness in working with communities who experience varying levels and intersecting forms of oppression.

Limitations

This study has a number of limitations related to the research design. First, this study uses secondary data analysis; there were not primary interviews conducted with participants. Secondly, this analysis is based on a small sample across multiple settings. However, qualitative studies often include small sizes, with the intention of discovering the richness and nuances of participants' experiences. Moreover, the type of design used in this analysis is impacted by sample bias; however, the sample reflects current research with a predominance of street-involved, female, urban participants engaged in sex work. Additionally, participants who have more research experience or positive research experiences may have been more motivated to participate.

Conclusion

This study brings to light a number of ethical concerns regarding PESW experience of research engagement in data collection. While this study includes a small number of participants, the study addresses gaps in our understandings of how participants experience research, how they navigate and manage harms in research, and showcases how participants have insight and skillfulness in understanding ethical issues in research engagement. Many of the ethical issues participants experienced could have been prevented through following ethical guidelines, including recommendations focused on community engagement, consultation which are rooted in PAR and CBR methods, and focused on preventing unintended harms to communities who experience structural and social oppressions.

Furthermore, this study raises questions about how stereotypes regarding PESW influence research design and ethical concerns in research, highlighting a need for changes in how vulnerability, victimization and agency are conceptualized at the structural level of research design and a need for greater involvement of PESW at all levels of research design and knowledge production related to sex work.

Lastly, but importantly, PESW can experience significant violence, trauma and mental health conditions – yet, little resources are available to support their mental health. From a system perspective, there are opportunities to integrate training for researchers on trauma-informed practice and power and privilege to reduce ethical violations in research practice. Additional mental health supports for PESW when participating in research is an important consideration. To demonstrate concern for welfare in research, researchers and REBs should consider the provision of such supports prior to engaging with PESW as participants.

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Appendix A

Code Book

As part of the coding for the larger Ethics Project, the investigative team met to review data and map their analytic questions across data. Each team member read six transcripts and presented summaries to the team that included the main themes identified in the data. These themes were then collectively grouped into broader analytic categories that captured key research questions about ethical and methodological issues. A code book and coding instructions was developed and members of the research team, including research participants, uploaded the data into QSR NVIVO 11, an unstructured data management software. All transcripts with the 91 participants were read and re-read by members of the team and coded according to broad analytic categories and their respective sub-categories. The parent nodes of data collection and consent were of primary concern to my secondary analysis.