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TOWARD A BETTER UNDERSTANDING OF THE CHRONIC PAIN EXPERIENCES OF
INDIGENOUS WOMEN WHO EXPERIENCE VIOLENCE: IMPLICATIONS FOR
NURSING EDUCATION, PRACTICE AND RESEARCH

by

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A SPAR PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF

MASTER OF SCIENCE IN NURSING

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

(School of Nursing)

THE UNIVERSITY OF BRITISH COLUMBIA

Vancouver

April/2018

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*Preamble**Research*

I have struggled,
 with how to describe
 and how to measure
 the immeasurable strength and incalculable power
 of women in pain,
 living within systems
 that fail them,
 and in doing so,
 fail us all,
 women who transcend description
 women who exist, endure, survive
 women who flourish.

-A. Heino, 2018

“What, then, does it mean to break the formalities of academic and scholarly writing, in part by evoking poetic traditions, so that language/word/sentence (space silence gap between words) become tools unto themselves for unsettling the very means by which we (especially non-Indigenous settler geographers) produce knowledge about colonial violence? How do geographers—particularly Canadian geographers in a post-TRC time and place—re/form the stories that need to be told and untold and told/not-told about decolonization, anti-colonialism, colonial violence, reconciliation, and truth?”

-S. de Leeuw (2017, p. 316)

Abstract

Problem/Issue and significance: Intimate partner violence [IPV] is a critically urgent public health issue worldwide. Violence and trauma have multiple short- and long-term health effects including pain, which is a complex, highly subjective experience that can have profoundly negative impacts on both “body and soul.” Untreated pain can become chronic and debilitating, leading to a lower quality of life, decreased employment opportunities, and increased mental health concerns. Addressing pain is an important aspect of the health care professional’s role, and the failure to do so can exacerbate existing health disparities and worsen health outcomes. Current approaches to understanding and managing pain are primarily based on a Westernized view of health and illness. Diversity in knowledge and perspectives is missing from clinical practice, nursing education, and research, and is needed to improve pain assessment and management practices.

Approach or innovation: While health care practitioners recognize that more holistic approaches to understanding, assessing, and treating pain are required, the significance of women’s chronic pain experiences in the context of IPV has been largely unexplored. This paper proposes the creation of “pain profiles” using an approach that draws of multiple sources of information and types of knowledge to gain new insights and to develop a richer understanding of women’s pain experiences. The unique circumstances and experiences of Indigenous women are used to illustrate the usefulness of the pain profiles as a case in point. In Canada, Indigenous women experience higher levels of violence and trauma as a result of interpersonal violence, historical trauma, and ongoing socio-economic inequities and systemic racism than non-Indigenous women. When Indigenous women seek health care for pain, they often report a lack of culturally safe and appropriate services and are often labeled as “drug-seeking” which can

cause further delays or avoiding seeking care. Few existing health services address pain arising from violence and trauma for women, especially services that focus on cultural safety and trauma-and-violence informed care.

Lessons and implications: Pain profiles provide a novel and more nuanced approach to understanding, and addressing, pain in women who have experienced violence by using a holistic approach that draws on various perspectives and multiple sources of information, including the women's own words. This approach may help to guide the implementation of more culturally safe, trauma-and-violence informed health practices and services, strengthen nursing curriculum around pain assessment and management, and help improve the overall well-being and quality of life of all women who have experienced violence.

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Acknowledgements

A graduate project is never a solitary endeavor and this work would not have been possible without several people to whom I would like to extend my sincerest thanks.

I would like to express my gratitude to my project committee chair Dr. Colleen Varcoe, who has been a wonderful and incredibly patient mentor over the past several years. I have been profoundly changed both personally and professionally through this journey and through our collaboration. Her tireless dedication to addressing violence in its many forms and her passion for teaching are an inspiration. I will take the many lessons I have learned through this experience forward with me. Thank you for everything.

I would also like to thank my second committee member, Dr. Annette Browne, for her helpful, kind, and insightful feedback, and her encouragement and support. I am inspired by her amazing work and by her dedication to addressing health inequity in its many forms.

I am thankful for:

- The Grant Funded CIHR masters trainee fellowship I received through the “Reclaiming our Spirits:” Aboriginal Women’s Intervention study,
- The IMPART program for the masters trainee fellowship funding and the opportunity to learn from both mentors and peers,
- The Irene Goldstone HIV/AIDS and Social Justice Graduate Scholarship I received from the University of British Columbia,

All of which helped make it possible for me to do this work.

I am grateful to Drs. Vicky Bungay, Madeleine Dion-Stout, Marilyn Ford-Gilboe, Koushambhi Khan, Bernadette Pauly, and Vicki Smye as well as Elder Roberta Price whose work I admire and who have been role models for the kind of nurse, scholar, and person that I would like to be.

To the women with whom I collaborated as a graduate student on the “Reclaiming our Spirits” study, it was an honour and a privilege to meet you and to hear your stories. I am humbled by your strength and by your resilience. Thank you also to the nurses, for their commitment to the women and to the study, and for helping me to see the “how” of this important work.

To my colleagues at Douglas College, thank you for your stories, humor, wisdom and understanding and for all of the extra cups of coffee as I wrote this paper. I am grateful to the Dean of Health Sciences, Pamela Cawley, for her support, encouragement and flexibility as I adjusted my work schedule to make it all fit over these past few weeks.

To my family and friends, thank you for being understanding, positive, and encouraging through all of the ups and downs of the past few years. Your love keeps me going and I am grateful. And to Petr, thank you for being such a caring and devoted dad to our girls.

Dedication

To my two amazing daughters, Athena and Evangeline, you are more precious to me than I could ever describe. I dedicate this project to you both.

and

To my mother, Claudette Landry, for teaching me about courage and resilience in the face of adversity. *Tu m'inspires et je t'aime.*

“Nurses support oppression when they actively participate in oppression; deny or ignore oppression; or recognize oppression, but take no action. Noticing or witnessing oppression, and taking the moral stance that it is none of our business, or that it is someone else’s responsibility to speak up, is the same as not doing anything in the face of need – silence is assent.”¹

Clinical Anecdote

Early on in my nursing career, I travelled to Uganda on three separate occasions to volunteer as a registered nurse in two rural health care clinics over a span of nearly eight months. One late afternoon in 2009, a young woman presenting with concerns about chronic pain disclosed to me through a translator that she was experiencing ongoing violence at the hands of her husband. She wanted to take her children somewhere safe and start over, even if it meant risking being marginalized by her community and almost certain financial hardship. The translator kept frowning and shaking her head, no, as I asked about possible resources that might be available to her. Because of lack of community supports in the particular area where I was working, I was unsure as to how to help her and felt frustrated about not being able to provide her with more information. Before leaving, the young woman turned to me and said: “What happens now?” then looked sadly and resignedly out into the darkening sky before giving a little shrug and a slight shake of her head. She grasped my hand and smiled gently while thanking me profusely. She then headed out into the night.

The moment the young woman walked out of the clinic I felt a strong emotional stirring from deep within me. My interaction with her galvanized me and ignited a passion for trying to do what I could to better understand and help to address violence against women. The impacts of violence, of which I had been developing a gradual awareness, suddenly had a very real human face.

¹ (McGibbon, Mulaudzi, Didham, Barton & Sochan, 2014, p. 187)

Through my nursing work abroad, I slowly began to realize how trauma and violence profoundly affect the physical, mental and emotional health of women all over the world. I also started to recognize how these health effects are compounded by poverty, oppression, stigma, racism, substance use, as well as pervasive systemic and interpersonal violence. My understanding of what I had previously perceived as the individual effects of violence became much more socially positioned and embedded.

Upon returning to Canada I found myself becoming more and more uneasy by the labeling and stigmatization of patients, and particularly of women dismissed as “drug-seekers.” It was my frustration and confusion with this very term, and my gradual awareness of the harmful discourses that are deeply embedded and normalized within health care practice environments (Doane & Varcoe, 2015) that became the catalysts in my pursuit of graduate studies.

Preface

This paper is divided into six sections. In the first section, I provide background information and a review of the literature to contextualize the research questions and purpose of the SPAR, which I describe in detail in the second section. In the third section I explain theoretical lenses and frameworks that guided this work. In the fourth section I describe the ways that women’s experiences of pain are currently accounted for, and I suggest the creation of pain profiles which draw on multiple types of knowledge and sources of information to enrich the understanding of clinicians and educators on women’s pain experiences in the context of violence. I outline some of the potential approaches to creating pain profiles and discuss a few of the considerations and potential limitations of doing so. In the fifth section I review the clinical

and educational implications of this work, including pain education and assessment of pain, before providing the recommendations for nursing education, health care, and research guided by this project. I conclude this paper in section six. A number of appendices attached to this paper also provide additional information and reference materials.

Section I: Background and Literature Review

Chronic Pain is Poorly Understood and Managed

Pain is a highly subjective, complex, universal phenomenon that remains shrouded in mystery despite ongoing research on both animal subjects and human participants. Acute pain serves a useful purpose as a warning system and helps to protect an organism from further injury, while chronic pain is generally defined as pain that persists or recurs for more than 3 to 6 months after “normal” healing time (Julien, Lacasse, Labra, & Asselin, 2018; Treede et al., 2015). Chronic pain can be further divided into various categories and subtypes, but consistency regarding its definition and classification systems has proven elusive in the literature.

Despite the lack of agreement and consistency in defining chronic pain, it is widely recognized that unrelieved pain is an important and serious health issue. Chronic pain has an estimated lifetime prevalence of approximately 18-20% and it exacts tremendous physical, psychological and financial impacts on a global scale (Schopflocher, Taenzer, & Jovey, 2011; Volders, Boddez, de Peuter, Meulders, & Vlaeyen, 2015). The most common causes of chronic pain in Canadians include arthritic and joint pain, spine pain including the neck, thoracic region and lower back, and trauma including osteoporosis (Schopflocher et al., 2011). In Canada, estimated costs of unrelieved pain range between \$43 and \$60 billion per year in health care expenses and lost productivity, which exceeds the cost of cancer, heart disease, and HIV

combined (Canadian Institutes of Health Research [CIHR], 2016). The highest prevalence of chronic pain occurs among Canadian women over the age of 65 years (Reitsma, Tranmer, Buchanan, & Vandenkerkhof, 2011).

Chronic pain is associated with decreased quality of life, and increased mental health concerns such as depression, anxiety, and suicidal ideation (Choinière et al., 2010; Choinière et al., 2014). Individuals with chronic pain describe feeling stigmatized by health care providers, and by friends and family (CIHR, 2016). In health care settings, stigma and discrimination related to chronic pain can be exacerbated by the intersections of various factors including violence and trauma, substance use, poverty, chronic illness, and mental health issues as well as a lack of provider awareness, knowledge and training (Pauly, McCall, Browne, Parker, & Mollison, 2015; Salmon, Livingston, & Browne, 2009).

In 2016, a Canadian pain research summit brought together researchers, clinicians, citizens and policy makers to identify and prioritize research gaps, strengthen pain research and promote collaboration (CIHR, 2016). An executive summary of the outcomes of the summit identified that despite the prevalence of pain and its negative impact on overall health and the quality of life of Canadians, less than 1.5% of health research funding is currently allocated to pain research (CIHR, 2016). Globally, restrictive drug policies to controlled medications limit the ability of billions of citizens to access pain medication with 92% of the global morphine supply being consumed by countries where only 17% of the world's population reside (Burke-Shyne et al., 2017).

In nursing, the assessment and treatment of pain is recognized as an ethical imperative that has profound impacts on the health and quality of life of clients (American Association of Nurse Practitioners, 2016; Bernhofer, Hosler, & Karius, 2016; Chow & Chan, 2015) and yet pain

remains undertreated and under-assessed in clinical settings, especially in women (Bailey & Bernstein, 2013; Pierik, Ijzerman, Gaakeer, Vollenbroek-Hutten, & Doggen, 2017; Vickers, Wright, & Staines, 2014). Studies have identified concerning disparities between actual and perceived pain management knowledge, the fragmented nature of pain education in nursing curricula, and the tendency to privilege outward and observable manifestations of pain that fit with a nurse's own beliefs related to pain over a patient's self-report on their pain experience as factors influencing pain under-assessment and under-treatment (Duke, Haas, Yarbrough, & Northam, 2013; Vickers et al., 2014).

Chronic Pain is a Significant Problem for Women Who Have Experienced Violence

Intimate partner violence [IPV] remains a global problem exacting overwhelming physical, psychological, social and financial costs. The World Health Organization [WHO] estimates that 1 in 3 women will experience physical and/or sexual violence by an intimate partner in their lifetime making it a critically urgent, and pervasive, public health issue (Garcia-Moreno et al., 2006; Shrivastava, Shrivastava, & Ramasamy, 2016). Violence against women is a widespread, often culturally sanctioned behavior, with proven short- and long-term adverse impacts on the health and wellbeing of women worldwide (Andrews, Cao, Marsh, & Shin, 2011; Becker, Stuewig, & McCloskey, 2010; Beckerman & Auerbach, 2010; Black, 2011; Bosch, Weaver, Arnold, & Clark, 2017; Dutton et al., 2006; Ellsberg et al., 2008; Engstrom, El-Bassel, & Gilbert, 2012; Haskell & Randall, 2009; Humphreys, Cooper, & Miaskowski, 2011; Illangasekare et al., 2012; MacIntosh, Wuest, Ford-Gilboe, & Varcoe, 2015; Mitchell & Anglin, 2009; Sarkar, 2008; Wong, Fong, Lai, & Tiwari, 2014).

The extensive negative consequences of violence on the health and safety of women have been clearly established in the literature (Black, 2011; Ellsberg et al., 2008; Ford-Gilboe,

Merritt-Gray, Varcoe, & Wuest, 2011; Karakurt, Patel, Whiting, & Koyutürk, 2017; Pigeon et al., 2011; Wuest et al., 2009; Zieman, Bridwell, & Cárdenas, 2017). Violence and trauma are specific and important causes of chronic pain. Women who have experienced violence and trauma have higher levels of pain than the general population, pain that can be profoundly limiting and debilitating (Bailey & Bernstein, 2013; Beck & Clapp, 2011; Dillon et al., 2013; Ellsberg et al., 2008; Humphreys et al., 2011; Wong et al., 2014; Wuest et al., 2010; Wuest et al., 2008), and such women tend to have poorer health outcomes, and more frequent and severe chronic physical symptoms requiring the increased use of services (Ellsberg et al., 2008; Mitchell et al., 2009; Varcoe et al., 2011).

The traumatic stress related to IPV can result in permanent neuroendocrine changes which include chronic pain (Beck & Clapp, 2011; Bosch et al., 2017; Bosco, Gallinati, & Clark, 2013; Dillon et al., 2013; Gutierrez, 2003; Humphreys et al., 2011; Kwako et al., 2011; McEwen, 2007; Sarkar, 2008; Solomon & Heide, 2005; Wuest et al., 2009; Wuest et al., 2008). The pathophysiological effects of stress can persist for long periods because of *intrusion*, an unwanted interference from both internal and external sources (Ford-Gilboe et al., 2011). As stated by neuroscientist Dr. Gillian Einstein “the world writes on the whole body” with the body, brain, and society all in relationship and mutually affecting one another (Bluhm, Jacobson, & Maibom, 2012, p. 160)

Pain is inextricably linked, and exacerbated, by mental health conditions such anxiety, hypervigilance, depression, as well as the chronic fatigue and sleep disturbances reported by many survivors of IPV; these constellations of symptoms can lead to worsening physical health effects and severe mental health concerns such as suicidality (Beck & Clapp, 2011; Bosco et al., 2013; Ellsberg et al., 2008; Humphreys et al., 2011; Pigeon et al., 2011; Wuest et al., 2010). A

history of child abuse and other forms of trauma may further compound the health consequences of IPV and the dose-response effect of abuse means that women experiencing higher levels of violence and multiple forms of abuse often exhibit more severe health consequences (Anda et al., 2006; MacIntosh et al., 2015; Scott-Storey, 2011) including chronic pain (Humphreys et al., 2011).

Women who experience violence are at risk of chronic pain from patterns of injuries that include the head, neck, and face, which are areas of the body that are most likely to be injured during IPV, and as many as half of women experiencing IPV may sustain blunt force trauma or attempted strangulation, which increase the risk of traumatic brain injury [TBI] with studies estimating a prevalence of TBI as high as 30-74% (Kwako et al, 2011). Postconcussive syndromes may go undetected, or be considered an expected aspect of violence by providers, and these syndromes can have detrimental effects on cognition including memory, higher order reasoning, decision-making, which can lead to mental concerns such as depression and anxiety, and can cause other debilitating neurological sequelae such as dizziness and painful chronic headaches (Karakurt et al., 2017; Kwako et al, 2011; Wong et al., 2014). The effects of postconcussive syndromes on mood can also exacerbate sleep problems, which can lead to a worsening of chronic pain conditions in a perpetual cycle that has ongoing negative effects on a woman's quality of life (Humphreys et al., 2011; Pigeon et al., 2011). Research on the types of neurological and neuropsychological damage to the brain in the context of IPV is lacking and is urgently needed to help guide effective health interventions (Wong et al., 2014).

Despite some of the progress made in understanding aspects of chronic pain management, it remains poorly recognized, addressed and managed in women who have experienced violence (Bernhofer et al, 2016; Chow & Chan, 2015; Mitchell et al., 2009;

Schreiber et al., 2014). A more robust understanding of women's chronic pain experiences in the aftermath of IPV and their experiences of navigating the health care system are needed given the multiple negative impacts of pain on the lives and on the health of women (Wuest et al., 2010; Wuest et al., 2008); impacts that could perhaps be mitigated through interventions and policies that help women receive the care and services that they need.

Current Approaches to Understanding Chronic Pain

Current approaches to understanding chronic pain are shaped by current research and evidence-based literature. Research examining the relationships between chronic pain, violence, and substance use have predominantly focused on the extrapolation of animal models to humans, and have tended to privilege the use of quantitative data. While quantitative studies and traditional pain assessment instruments provide important insights into an individual's perception of their pain and its impact on their functioning, there has been an increased recognition that a more complete picture is needed to more fully understand an individual's experience of pain, including the use of pain profiles to provide insights not otherwise available (Davies et al., 2015; Johnson, Pittsley, Becker, & Young, 2015; Matteliano, Scherer, & Chang, 2014).

A small body of literature has used qualitative methods to explore women's experiences of violence, sometimes linking these experiences to chronic pain and substance use. However, quantitative analyses tend to decontextualize women's experiences, and while qualitative approaches attend to context, they have rarely centered on women's pain experiences. A more comprehensive approach to understanding pain drawing on multiple sources of information is needed to assist clinicians and educators in caring for women who have experienced violence.

Section II: Purpose of the SPAR project**Overview and Research Questions**

The purpose of this Scholarly Practice Advancement Research Project [SPAR] is to provide recommendations regarding the essential questions and domains of analysis to consider in relation to the chronic pain experiences of women who have experienced violence, using the experience of Indigenous women as a case in point. These questions and domains of analysis are particularly important when planning programs or interventions aimed at supporting women experiencing chronic pain in the context of IPV. Because Indigenous women experience the highest levels of violence, and higher levels of chronic pain, the imperative for a comprehensive approach to pain assessment and management becomes all the more urgent and pressing. Considering the particular circumstances of Indigenous women's lives in which as a population they face high levels of discrimination, policy enforced poverty and threats to their human and reproductive rights, underscores the importance of understanding pain related to IPV within a wider context for all women.

The specific questions that were used in the analysis undertaken for this SPAR project were as follows. To better understand women's experiences of the intersecting issues of chronic pain and violence:

- What are the key elements of women's experience that should be taken into account?
- What are the unique considerations for Indigenous women?
- How might individual historical factors that shape individual's women's experiences be taken into account?

- What are the implications with respect to clinical practice and/or interventions aimed at supporting women?
- What are the implications with respect to the types of data needed to study and/or evaluate clinical practice and interventions aimed at supporting women? What are the implications for clinical practice and for nursing education?

Section III: Theoretical Lenses and Indigenous Epistemologies

Theoretical Lenses

This project is informed by a feminist and Indigenous lens to situate women's experiences of pain as a result of violence within a broader context of patriarchal and colonial structures that continue to perpetuate many forms violence and inequity against women, with particularly pernicious effects for Indigenous women. In this project I also drew on an intersectional approach which generates understandings of women's experiences by examining the interactions between different social identities such as race, gender, class and how their positioning within oppressive, inequitable social structures have negative effects on a person's wellbeing, and on their health outcomes (Kelly, 2011). A feminist, intersectional approach is motivated not only by seeking a more comprehensive understanding of women's experiences but also by the pursuit of social justice, which can therefore guide recommendations around research and interventions to help address health disparities (Kelly, 2011).

In a book on neurofeminism, Dr. Gillian Einstein stated that using a feminist lens "...opens the doors of real discovery about that which is unknown, ignored, or silenced...the politics of feminist approaches allows a questioning of why we do not know something..." (Bluhm et al., 2012, p.169). Writing about the silences becomes as important aspect of research

in an effort to address the various reasons as to why phenomena with such important and detrimental effects on the health and wellbeing of large population groups, including women, are not being investigated more fully, and why.

An Indigenous lens is crucial in broadening our understanding of the intersecting traumas and intrusive harms that undermine resources and relationships for Indigenous women, both in the context of IPV and other forms of violence (Dion Stout, 2012; Varcoe et al., 2017). Using a feminist, intersectional perspective assists in situating how the multiple dimensions of sex, gender, race, and class interact and shape the chronic pain and violence-related experiences of women. This allows an understanding of how women who experience violence are located within ongoing oppressive, colonial structures that perpetuate various forms of inequity, thereby contributing to poorer overall health outcomes (Brown, Strega, & Xwi7xwa, 2005; Browne & Varcoe, 2009; Browne & Fiske, 2001; Kelly, 2011; Varcoe, 1996; Varcoe et al., 2017).

While acknowledging and critiquing how ongoing colonization shapes Indigenous reality, some Indigenous scholars also maintain that a focus on resilience, on building on existing strengths and capacities, as well as reorienting public discourse and using decolonizing strategies are all crucial in moving forward towards the regeneration and restitution of Indigenous consciousness, voice, and identity (Alfred, 2009; Battiste, 2008; Brown et al., 2005; Smith, 1999).

As a nurse trained within a traditional binary “Westernized” health care system, using an intersectional and feminist framework helped me to unpack and explore the fluid inter-relatedness of trauma, violence, substance use, mental health and poverty and which may lead to a broader understanding of how Indigenous women understand their own health and wellness which will benefit women more generally (Bourque Bearskin et al., 2016; Brown et al., 2005).

This has allowed me to generate recommendations in my project on how to inquire about and address pain in women using a culturally safe and trauma-and-violence approach that builds on multiple sources of information and types knowledge, while acknowledging the tremendous strengths and resilience of women who have experienced violence (Doane & Varcoe, 2015; Varcoe et al., 2017).

Indigenous Epistemologies

A reductionist perspective is inadequate for capturing complex, varied, dynamic, and holistic Indigenous knowledge (Bourque Bearskin et al., 2016; Kovach, 2009), and it has been suggested that the use of non-Indigenous, and colonial language, by a White settler may present a challenge in attempting to interpret Indigenous reality (Battiste, 2008; Battiste & Henderson, 2000). In order to address this potential bias, I have reflected on my unique social location, perspective, and lens as a graduate student (Brown et al., 2005) and the need for creating ethical space (Ermine, 2007) to engage more fully and perspicaciously in the work.

When suggesting an approach that takes into account the unique pain experiences of women, it is vital to consider how research and “the pursuit of knowledge is deeply embedded in the multiple layers of imperial and colonial practices” (Smith, 1999, p.2). Indigenous epistemologies involve ways of knowing that are fluid, experiential, derived from storytelling passed from generation to generation, and emerge from traditional languages that are verb-based instead of noun-based (Brown et al., 2005). These ways of knowing also value the subconscious, including dreams and visions, and acknowledge the complex interrelationships between the human, spirit, and natural worlds, as well as people’s connections to place (Brown et al., 2005; Gladu, 2016), and this includes finding new and innovative ways of addressing pain (CIHR, 2016) while also more broadly helping to support efforts at cultural renewal (Hall et al., 2015).

When using an Indigenous lens, it is necessary for a researcher to recognize the tremendous diversity among Indigenous peoples. Research approaches that over-generalize and do not distinguish between the experiences of diverse Indigenous women, for example: Inuit, Metis and First Nations, on and off-reserve, could potentially conceal important differences in needs, priorities, capacities, experiences, interests, and views (Gladu, 2016) as within Inuit, Metis, and First Nations communities, there exists tremendous diversity in cultural identities, core knowledge, traditions, ways of life and collective consciousness (Statistics Canada, 2016). During the Canadian pain research summit of 2016, participants concluded that the process of engagement related to pain management research needs to support Indigenous leadership and “should be multi-directional, multi-lateral, and in the absolute spirit of multi-engagement” (CIHR, 2016, p.33).

In the words of Dr. Madeleine Dion Stout, an Indigenous researcher and scholar, and a Cree-speaker (2012):

Scant acknowledgement is given to whether and how the responses, *naskomowēnā*, and the human reserves, *sōhkātisiwinā*, of Indigenous people with lived experience might inform new thinking about ancient ideas while drawing on new interventions from old actions. (p.4)

Therefore an enhanced understanding of the chronic pain experiences of Indigenous women through feminist, intersectional and Indigenous frameworks may help provide to a more effective platform from which to make recommendations on education, practice and policy, and help to guide future research.

Section IV: Ways of Accounting for Women's Pain Experiences

This section offers an analysis of the kinds of data, measures and information that can be useful to more adequately account for the complexity of women's chronic pain in the context of IPV. Specific implications for the kinds of understandings, data and information that might be well suited to evaluating or studying practice or health interventions aimed at supporting Indigenous and non-Indigenous women are reviewed. The importance of drawing on multiple types of knowledge and sources of information to gain a more complete and comprehensive of women's pain experiences is highlighted through an examination of the particular circumstances of Indigenous women as a case in point.

Approaches Drawing on Multiple Forms and Sources of Information

A comprehensive approach to understanding women's pain experience requires multiple sources of information and types of knowledge - including both quantitative and qualitative data to enrich areas of inquiry, deepen understanding, and provide new insights with practical and pragmatic implications for praxis (Polit & Beck, 2012). The use of various kinds of knowledge and information has numerous advantages including: the complementarity of different approaches that thus avoids the limitations of a single approach, the practicality of answering questions that may not be answerable by only qualitative or quantitative approaches, the incrementality of generating questions or hypotheses that can then be further examined through the other sources of information, the enhanced validity of the findings, and the collaboration between researchers, clinicians, and educators with varied kinds of backgrounds and experiences (Polit & Beck, 2012). This section will offer examples of current pain-related research based on the current literature.

Researchers have discussed how collecting information from multiple sources can offer unique insights into the complexity of trauma, violence, and pain experiences. For example, studies have used a variety of quantitative and qualitative approaches to gain new insights and generate novel hypotheses on the sexual victimization of women (Testa, Livingston, & VanZile-Tamsen, 2011), on the pain experiences of individuals with pressure ulcers (Gorecki, Closs, Nixon, & Briggs, 2011), on the perceptions of individuals with chronic pain on pain rehabilitation (Wideman et al, 2016) and on the characteristics and presentations of patients with chronic pain in the Emergency Departments [ED] (Poulin et al, 2016). In these particular studies, researchers have drawn on various numerical scales as well as on interviews to generate new awareness of the phenomenon in question and to obtain a richer, more comprehensive understanding of the participant's experiences.

Pain Profiles – Description and Relevance

Pain profiles are particularly relevant to providing good clinical care and to studying or evaluating care or health interventions, and they are a meaningful way of capturing women's pain experiences, especially among women experiencing violence, because pain profiles take into account the context of women's lives. While there are mixed methods studies that examine pain and trauma experiences in various populations (Gorecki et al., 2011; Poulin et al., 2016; Wideman et al., 2016), there are no studies that specifically look at the use of pain profiles to understand chronic pain in women who have experienced IPV.

So far the use of "pain profiles" described in the literature has been limited to individuals with particular health concerns such as arthritis and specific to particular anatomical areas such as the knees or back (Johnson et al., 2015; Matteliano et al., 2014; Rabey, Beales, Salter & O'Sullivan, 2015). For example, in a study on chronic low back pain [CLBP] researchers

obtained data from clients using a multidimensional framework and recommended that pain assessments for CLBP include various dimensions such as: peripheral nociception, movement, treatment, psychosocial, neurophysiological, comorbidities, and biopsychosocial classification systems to develop more individualized, flexible, and adaptive plans of care (Rabey et al., 2015).

In some studies, pain profiles have also tended to privilege quantitative data, such as in the building of biobehavioral profiles for individuals with chronic spine pain to guide cognitive behavioral therapy [CBT] (Matteliano et al., 2014) or in the comparison of pain magnitude with induced pain tolerance in people with knee pain (Johnson et al., 2015). In a study on knee pain, researchers constructed pain profiles based on data that they obtained during client visits, then physicians reviewed the data on a computer screen with clients (Johnson et al., 2015). The authors suggested that pain profile information could help guide therapeutic choices for clients and present them with available options for alleviating their pain (Johnson et al., 2015). While there is a recognition of the need for a more holistic understanding of pain that takes into account physical, cognitive, psychological, and cultural aspects (Johnson et al., 2015; Matteliano et al., 2014; Rabey et al., 2015), this approach is lacking in the care of women who have experienced violence.

Although pain profiles have not been applied in the context chronic pain and IPV, they have the potential to help account for the complexity of women's pain experiences in this particular context and inform recommendations on how to improving health care services, nursing education, and research practices.

To address this gap in knowledge, pain profiles compare:

- quantitative data from standard scales and instruments used to assess chronic pain and disability (often used in clinical practice and in research) and,
- themes from interview data collected asking women specifically about their pain, its effect on their lives, and their experiences in the health care system. This data could also be collected as part of clinical quality improvement initiatives designed to enhance patient care in health settings.

I propose that pain profiles be constructed to: 1) help facilitate an understanding of how Indigenous women who have experienced violence understand their pain, 2) how they cope with their pain, and 3) what they identify as being especially helpful or harmful while navigating the health care system. The pain profiles may facilitate the emergence of themes and any similarities and differences between what women describe qualitatively around pain and what they report quantitatively. For example, if women report higher or lower levels of pain on scales than they describe in the interviews, what might this tell us about strength and resilience, for example, and the influence of their support networks as well as the nature of their relationships and community? These comparisons are meaningful and contribute to a greater understanding of the women's lived experiences. Therefore these individualized pain profiles provide the foundation of a novel analysis that could include numerical data from various assessment scales, as well as the women's own words about their pain.

The specific construction of pain profiles will depend on: 1) the nature of their intended purpose, such as whether they are used in the clinical setting or in research to collect data to gather client information and be used the provision of care, 2) the population of women the pain profiles would be used for, for example, women belonging to a specific community may have shared experiences in their access to a particular type of health care service or clinic, and

questions could therefore be added to the pain profiles to capture and reflect this commonality, 3) the application of the information, whether in in patient care, or in nursing education.

The Circumstances of Indigenous Women as a Particular Case in Point

While chronic pain is a pervasive and urgent health problem around the world, Indigenous women in Canada face a uniquely challenging set of circumstances with regards to pain assessment and management which will be discussed in the following sections to illustrate the importance of developing a richer and more comprehensive understanding women's chronic pain experiences to improve care and the health outcomes of women who experience violence.

Indigenous Women Experience Higher Levels of Violence and Chronic Pain

In Canada, IPV is a pressing problem for Indigenous women who continue to experience much higher levels of violence than non-Indigenous women including assault and homicide (Brennan, 2011; Perreault, 2011). In a highly publicized report from 2012 called "Forsaken," 33% of the missing and murdered women from Vancouver's Downtown East Side were Indigenous despite comprising only 3% of the province's population (Oppal, 2012). The heightened risk of violence for Indigenous women across Canada occurs within a "broader pattern of marginalization and inequality" as well as social disadvantage and exclusion as well as policy responses that are often inadequate (Oppal, 2012, p.7), inequitable, and culturally unsafe. These issues have received heightened national attention in Canada through the current National Inquiry on Missing and Murdered Indigenous Women (2017).²

² The National Inquiry into Missing and Murdered Indigenous Women has sought to inquire into and report on the systemic causes of violence against Indigenous women and girls in Canada and the institutional policies and practices put in place in response to the violence, as well make recommendations on actions that help to remove these systemic causes of violence, increase safety, and honour and commemorate the missing and murdered Indigenous women and girls.

The increased risk of violence has been linked to the ongoing effects of Canada's colonial history which disconnected Indigenous people from their land, their rights, and their history. The "Indian Act" passed in 1876 legally sanctioned a myriad of injustices towards Indigenous people: the residential school system, the apprehension of Indigenous children from their families of origin and their placement into foster care, the higher rates of incarceration, and the segregation of Indigenous clients into "Indian Hospitals," were all done in an attempt to forcibly assimilate and systemically annihilate Indigenous identity and culture, leaving a widespread and terrible legacy of collective trauma, grief, and loss that have profoundly eroded the collective community, political and cultural foundations, and national consciousness of Indigenous people (Alfred, 2009; Battiste & Henderson, 2000; British Columbia Government & First Nations Health, 2017; Haskell & Randall, 2009; Lux, 2016). Also crucial are the effects of both historical and current trauma on the lives of Indigenous women – trauma that is ongoing, complex and continuous (Alfred, 2009; Bourque Bearskin et al., 2016; Ermine, 2007; Haskell & Randall, 2009).

In Canada, Indigenous women rate themselves as having poorer overall health and are more likely to report chronic conditions, including pain, than non-Indigenous women (Arriagada, 2016). The inadequate management of chronic pain in the aftermath of violence is worsened by health care that is often stigmatizing and discriminatory (Bourque Bearskin et al., 2016; British Columbia Government & First Nations Health, 2017; Pauly et al., 2015; Salmon et al., 2009; Varcoe et al., 2017). This is compounded by negative stereotypes and ineffective practices related to substance use and the multiple barriers faced by Indigenous people in accessing health care services (British Columbia Government & First Nations Health, 2017; Browne et al., 2011; Browne et al., 2016; Browne & Fiske, 2001; McCall & Pauly, 2012) and the lack of culturally

adapted tools available to health care providers (Fenwick, 2006; Julien et al., 2018; Strong, Nielsen, Williams, Huggins, & Sussex, 2015). Across Canada, there are few services that take into consideration the unique social and cultural contexts of Indigenous women (Cameron, Carmago Plazas, Salas, Bourque Bearskin & Hungler, 2014; Halseth, 2013; Varcoe et al., 2017).

Because of the often negative media portrayals of Indigenous peoples specifically related to pain medications, there has been increased media and scholarly attention paid to the systemic racism directed against Indigenous women embedded within governmental and public systems, including health care services (British Columbia Government & First Nations Health, 2017; Browne & Varcoe, 2009; Browne & Fiske, 2001; Nelson, Brown & Lavoie, 2016; Salmon et al., 2009; Varcoe et al., 2017). Despite historical and ongoing colonization and racism, however, Indigenous women continue to thrive and demonstrate great strength and resilience, often even in the most adverse circumstances, while drawing on their diverse traditional knowledge (Bourque Bearskin et al., 2016; Browne & Fiske, 2001; Haskell & Randall, 2009; Smith, 2012; Varcoe et al., 2017).

The multiple layers of pain experienced by Indigenous communities as a result of colonization and historical trauma has been examined more closely in the context of a well-publicized “opioid crisis” which has resulted in the unintentional and unprecedented deaths of individuals in British Columbia due to substances tainted with fentanyl and fentanyl analogues (British Columbia Government & First Nations Health, 2017). Between 2015 and 2016, Indigenous women experienced eight times more overdose events and five times more deaths from overdose than non-Indigenous women, with the highest risk of death occurring in women aged between 40-49 years (British Columbia Government & First Nations Health, 2017). The report by the BC Government and First Nations Health highlights the work of Dr. Gabor Mate

who asserts that substance use is “an understandable response to a set of unnatural circumstances, namely the historical trauma inflicted on First Nations throughout Canadian history, and up to the present” (British Columbia Government & First Nations Health, 2017, p. 1). The high rates of intergenerational trauma and the oppressive colonial policies and practices have been linked to high rates of mental health problems, as well as an increased risk of substance use to cope with the painful effects of trauma (British Columbia Government & First Nations Health, 2017; Hart-Wasekeesikaw & Aboriginal Nurses Association of Canada, 2009). The disproportionately high number of Indigenous people adversely affected by the opioid crisis highlights the ongoing disparities and inequities that they face in British Columbia.

The importance of effective pain assessment and management are of pressing concern in Indigenous communities, and there is an urgent need to provide care that is culturally safe, appropriate, and trauma-and-violence informed. Approaches to understanding chronic pain in Indigenous women should therefore take into account the potential effects of ongoing intergenerational trauma, systemic violence and racism, and increased incidence of chronic health concerns. Such approaches should also be strengths-based, and guided by how women understand their pain within the context of their health.

Indigenous Women Face Extensive Barriers to Health Care

In Canada, despite facing higher levels of health challenges including pain related to IPV and greater inequities in social determinants of health, Indigenous women experience multiple barriers to accessing health care that can be traced to social, political, and colonial historical

factors, the effects of which continue on in the present day in a classic example of inverse care³ (Cameron et al., 2014; Halseth, 2013). One systematic review examining the experiences of Indigenous peoples in Alberta identified some of these barriers as: the geographical locations of health facilities in proximity to rural Indigenous communities, long wait lists, costs of travel, lack of culturally competent or culturally safe care and services, lack of insurance or financial coverage for services and/or lack of familiarity in accessing funds (Nader, Kolahdooz, & Sharma, 2017). The authors of the study categorized unmet health needs of the Indigenous participants into three main groups: 1) availability of services, 2) accessibility and 3) acceptability, and made recommendations on the importance of strengthening these particular areas of unmet needs to help address health care access and usage gaps (Nader et al., 2017).

Indigenous peoples also identify that barriers to care also include how previously negative experiences in health care settings, and ongoing marginalization, on both macro and micro levels have created a sense of tension and distrust between Indigenous peoples and the health care system (Cameron et al., 2014). This can foster the reluctance of some Indigenous peoples to seek care or request health care services, including pain assessment and management, out of concern for being treated in ways that are culturally unsafe, racist, and discriminatory (Cameron et al., 2014; Fenwick, 2006; Lafontaine, 2016; Salmon et al., 2009; Strong et al., 2015). The delay in seeking care can have potentially severe health outcomes, and results in poorer health in Indigenous peoples. Therefore for Indigenous individuals, racism and discrimination should be considered as determinants of health, and strategies must be developed to help address the detrimental health effects of both (Browne et al., 2016). The barriers

³ Inverse care is the notion that the availability of adequate or good care tends to vary inversely with the need for it in a particular population, and was put forward as the “inverse care law” by physician Julian Tudor Hart in 1971 (Watt, 2002).

encountered by Indigenous women in accessing care, and the challenges they face in their interactions with health care providers, point to a need to identify and remove these barriers at the policy-level as well as to train and educate health care providers on how to unpack their assumptions with regards to pain and provide culturally safe, trauma-and-violence informed care.

Specific to Chronic Pain, Indigenous Women Experience Ongoing Key Dynamics that Result in Poor Care and Management

Indigenous women face two key dynamics in relation to chronic pain: 1) pernicious stereotypes related to their pain experiences such as stoicism (Doane & Varcoe, 2015; Fenwick, 2006) and substance use (Browne et al., 2016; Lafontaine, 2016; Salmon et al., 2009), as well as 2) the historical overprescribing of pain medication (Alberta Health, 2017; British Columbia Government & First Nations Health, 2017; Gupta, 2017). These intersecting issues create the conditions for poor care related to chronic pain for Indigenous women.

Previous studies on the pain experiences of Indigenous peoples in Australia found that there exists a poor understanding of the pain experiences of Indigenous people by health care providers, including a tendency to label Indigenous persons as “stoic” if they do not express their pain vocally; yet Indigenous people have described remaining quiet about their pain because of poor communication with a health care provider and wanting to avoid being stereotyped or stigmatized (Fenwick, 2006; Lin & Coffin, 2017; Strong et al., 2015). These factors can lead to substandard care including inadequate pain assessments and management.

There is a paucity of literature on the pain experiences of Canadian Indigenous peoples and the perceptions of health care providers on pain. One recent systematic review concluded that chronic pain related to arthritis affects a greater proportion of Indigenous than non-

Indigenous Canadians, and that more research around all dimensions of the pain experience including sensory, emotional, cultural, spiritual and behavioral domains, is needed (Julien et al., 2018).

Despite the lack of clinical care and research on the pain experiences of Indigenous peoples, the problematic portrayal of the pain experienced by Indigenous peoples by Canadian media outlets perpetuates inaccurate and harmful stereotypes (Nelson et al., 2016). Culhane (2003) asserts that the sensationalist media portrayals of the “dramatic and photogenic spectacle of social suffering” (p. 594) of Indigenous communities in Vancouver, B.C. actually perpetuates the continued invisibility of Indigenous women and erases them from public discourse. This erasure occurs because of a particular form of “race blindness” that stems from Canada’s uncomfortable and shameful history towards Indigenous peoples, a history that continues to unfold in the present day and that remains continuously traumatic (Culhane, 2003; Haskell & Randall, 2009).

A systematic analysis regarding media portrayals of Indigenous peoples and pain medications in Canada concluded: 1) there is a lack of analysis regarding experiences of pain and pain management in relation to Indigenous people and communities, 2) there is a tendency to make generalizations from one Indigenous individual to entire communities, and 3) there is language employed related to the inevitability addiction, despair, victimhood, and hopelessness in media news items (Nelson et al., 2016). The authors concluded that the silence regarding experiences of pain in Indigenous peoples is of particular concern, especially considering the high rates of chronic pain arising from various kinds of injuries, chronic illness, violence, and the ongoing effects of colonialism (Nelson et al., 2016).

The inaccurate representation of Indigenous peoples in the media can have a harmful effect on the perceptions of Canadians about Indigenous communities, and these communities may then be viewed as more likely to be “damaged” or susceptible to substance use without considering the wider social and historical contexts that influence the use of substances to cope with unmanaged pain (Nelson et al., 2016). This can increase the likelihood of the public to associate Indigenous peoples with problematic substance use, which can negatively influence the care Indigenous peoples receive in health care settings and result in stigmatization (McCall & Pauly, 2012; Nelson et al., 2016; Pauly et al., 2015). Negative labels ascribed to the requests for pain medication such as “drug-seeking” can mean health care providers overlook important history-taking or symptomatology and discount an Indigenous person’s self-report or the information provided by family and community members (Doane & Varcoe, 2015; Nelson et al., 2016). The ongoing impacts of colonialism, paternalism, and the assigning of Indigenous peoples to racialized categories can cause mistrust and suspicion among Indigenous individuals, who may delay seeking health care, especially around pain management, or who may have their access to health care restricted or withheld, which can have profoundly detrimental health consequences (Browne et al., 2009; Fenwick, 2006; Strong et al., 2015).

The over-prescription of pain medications for Indigenous peoples by health care providers in comparison to non-Indigenous people has caused a number of health care authorities, governmental organizations, and media outlets to raise the alarm (Alberta Health, 2017; British Columbia Government & First Nations Health, 2017; Gupta, 2017; Lafontaine, 2016; Webster, 2013). The overreliance on pain medications can be attributed in part to a lack of awareness of the socioeconomic and historical conditions that influence health and wellness, a lack of cultural awareness related to Indigenous health and wellness, as well as the possibility of

implicit bias in health care providers who may make snap judgements without doing the needed assessments, investigations, and tests (Lafontaine, 2016) in an already overextended health care system where many Indigenous communities deal with a lack of available health care providers who struggle to provide continuity of care (Webster, 2013).

Addressing the key dynamics that Indigenous women face in relation to chronic pain requires developing an approach to more comprehensively understand the chronic pain experiences of Indigenous women, and this will also create an approach that will improve understanding for all women. The rationale for this particular focus stems from the dearth of literature that aims to extend an understanding of Indigenous women's experiences, the author's research training experiences as a graduate student on studies involving Indigenous women, and the need for health interventions that take into account the unique context of Indigenous women's lives in Canada. These contextual factors include the harmful impacts of colonialism, the increased risk of interpersonal violence due to the high rates of ongoing systemic violence, the higher rates of health concerns including chronic pain, and the tremendous strength and resilience of communities, families, and individuals in the face of these many challenges.

Approaches to understanding and managing chronic pain experienced by Indigenous women must consider that Indigenous women will have a high likelihood of a) negative interactions with health care providers and systems, b) poor pain management, including under-treatment and overprescribing, and c) care with regards to pain they perceive as being dismissive, discriminatory or perfunctory. Such approaches must also anticipate that providers and system practices are steeped in multiple stereotypical assumptions ranging from assumptions that Indigenous women are stoic with high pain tolerance, to assumptions that they are likely to be "drug seeking."

Approaches to Expanding Understandings of Chronic Pain with Women Who Have Been Experiencing IPV

Given Canada's colonial and racist history, it is vital to understand Indigenous women's experiences in context (Bourque Bearskin et al., 2016; Varcoe et al., 2017). To gain a fuller appreciation of Indigenous women's chronic pain, it is crucial to include an approach to practice and research that respects the women's own words and includes an awareness of the Indigenous teachings, ideals, spiritualities and philosophies that are so fundamental to a holistic and more complete understanding of Indigenous people's health and wellness (Alfred, 2009; Bourque Bearskin et al., 2016). In the literature reviewed for this paper, there were no published studies specifically focused on the chronic pain experiences of Indigenous women who have experienced violence.

Multiple sources and types of knowledge are required for a more comprehensive and complete understanding of women's pain experiences. In developing the following tools and resources for this project, the specific circumstances of Indigenous women were taken into account. I have created an example of a clinical pain tool for use when talking to clients about pain in health care settings (Appendix 2), and this tool could be used by providers and students alike. Based on the literature and my experiences as a nurse, educator, and graduate student, I have also created a generic pain profile as a template for what I consider to be an essential starting point in talking about pain with women who have chronic pain (Appendix 3). I have included a blank pain profile based on a health promotion intervention (Appendix 4) to illustrate how a pain profile could look based on quantitative data from a selection of numerical standardized scales and outcome measures (Appendix 5), as well as qualitative data based on one-on-one interview questions that focus specifically on pain (Appendix 1).

Seeking to learn about and understand women's experiences of pain in the context of IPV requires more than simple rating scales and history taking. Rather, diverse approaches can be used to promote exploration of women's experiences in ways that are both safe and therapeutic. Indigenous approaches could assist in expanding and enriching our current understanding of pain. In developing trauma-and-violence informed and culturally safe approaches to understanding the pain experiences of women who have experienced violence, I have created Table 1 with content adapted from Smith (1999, pp. 142-16; 2012, pp.143-163) that could be useful in understanding women's pain experiences. These approaches combine a variety of existing methodological approaches drawing on Indigenous knowledge, traditions, and practices.

Table 1: Potential approaches to expanding understandings of pain using a decolonizing approach

<u>Approach</u>	<u>Brief description</u>	<u>How approach could be used to expand understandings of pain</u>
Testimonies	A formal, structured event in which an individual can share a deeply personal and painful truth with an audience.	Sharing testimonies on pain led by an experienced Elder and nurses in a culturally safe and trauma-and-violence informed environment.
Story-telling	Used to convey or pass down beliefs and values of a culture, and connects the past and the future. Stories can be as simple or as complex as the storyteller chooses and can use familiar themes, characters and motifs to convey meaning.	Sharing stories within a healing circle, led by an experienced Elder. Interviewing women one-on-one to ask them about their pain experiences and its meaning to their lives and providing women with the opportunity to share their experiences by using stories.
Celebrating survival	A focus on the positive and the celebrating of resistances. Can be affirming of Indigenous identity both at the individual and community level.	When sharing about pain, building on and celebrating a woman's journey, and her strength and resilience, both individually and as a group/community.
Remembering	Used in remembering a painful past and a person's response to that pain whether conscious or subconscious. Requires healing and transformation strategies.	Using Indigenous health practices or strategies led by an experienced Elders and counsellors with trauma-and-violence-informed training.
Indigenizing	An approach that borrows from feminist and critical approaches to research and	Exploring and honouring dimensions around language, stories, images, themes, metaphors,

	privileges Indigenous voices, identity, and cultural action.	and landscapes, pertaining to pain that are meaningful to participants.
Intervening	Designed around making structural and cultural changes. Directed at changing institutions to fit what Indigenous people need and not changing Indigenous people.	Advocating for changes at a policy and cultural level, for example, in health care around accessibility to pain assessments, medication and counselling, for example.
Revitalizing	Initiatives helping to preserve endangered Indigenous languages and ways of knowing.	Using Indigenous language to understand the pain experience. For example, using Cree concepts to understand health, wellness, illness and pain.
Connecting	Involves reconnecting people to one another, to the land, and to particular rituals or practices affected by colonization. Establishing good relations.	Honouring Indigenous rituals and ceremonies around pain, as determined by participants such as smudging, drumming, and healing circles.
Reading	Requires a critical rereading of Western history, and viewing history not as a single narrative story to help understand the effects of colonialism.	Reading about the experiences of Indigenous people in health care, and “Indian Hospitals” may help participants to understand the legacy of oppressive and colonial health care practices that continue in the present day.
Writing	Using various modalities such as story-telling, poetry, plays, song-writing to share and capture aspects of the Indigenous experience.	Asking participants to share their experiences of pain and its meaning to their lives through one of these modalities.
Reframing	Resistance to being labelled or placed into particular categories based on Indigenous identity. Challenges stereotypes and seeks to reclaim control of the discussion.	Inviting dialogue on how Indigenous people are portrayed around the issue of pain and pain medication in health care settings and in media, how to start to change that conversation more broadly.
Restoring	Based on a model of healing, and restorative justice.	Using Truth & Reconciliation strategies to address pain, led by an experienced Elder.
Naming	Uses Indigenous language to rename the world, people, realities, and experiences.	Exploring and understanding the pain experience and healing strategies by using Indigenous language and principles.
Creating	Highlights the ability to create or be creative and to use Indigenous elements in devising unique and innovative solutions to problems.	Devising or adapting programs on pain self-management based on Indigenous principles and ways of knowing.
Sharing	Emphasizes the sharing of knowledge as a collective benefit and a form of resistance.	Involving participants to speak about their pain experiences at a broader community level.

One final example of how multiple sources of information can provide a richer understanding of the unique context of women's lives is in a health intervention study known as "Reclaiming Our Spirits" [ROS], which used a variety of outcome measures and scales to assess pain intensity and interference to generate new insights on how chronic pain intersects with various other factors in shaping the lives of Indigenous women (Varcoe et al., 2017). In ROS, researchers developed and tested a health promotion intervention for Indigenous women who have experienced IPV through a collaborative process with Indigenous women leaders from academic, community, and health care with knowledge and expertise specific to IPV (Varcoe et al., 2017). Key information about pain, obtained through various outcome measures used in ROS, helped to inform researchers on the level of intensity, persistence and disability experienced by the women participants (Appendix 5) and guided recommendations to the subsequent full study on how to address pain in innovative, culturally safe, and trauma-and-violence informed ways.

With the pain profiles proposed in this project decisions on the specific outcomes measures and scales to use should be guided by the research team in consultation with Indigenous stakeholders. Due to the lack of currently available culturally appropriate pain tools, any existing scales or tools used may need to be locally adapted and revised to reflect the unique location, needs and priorities of the participants. Many of these data collection tools have relevance in clinical practice settings in the context of quality improvement initiatives or in evaluations of specific health interventions aimed at supporting women.

This section has offered a variety of options for developing a more diverse and nuanced understanding of pain by proposing tools that collect information across multiple dimensions and

suggesting approaches that build on the unique knowledge and diverse experiences of Indigenous women.

Considerations and Potential Limitations

There are several considerations and potential limitations to gathering information from women about their pain experiences. For example, when asking women to share about their experiences around pain, there is a risk of the women becoming more aware of their pain which may cause it to intensify (Varcoe et al., 2017). The nature of the questions in both quantitative and qualitative measures could also be potentially triggering, so a contingency plan should be in place and support offered to women should this occur (Varcoe et al., 2017). Interviewers should have the skills to interview women about pain in a sensitive way that is flexible to the women's needs (Testa et al., 2011) and allows the voices of the participants to reveal themselves whether one-on-one, in focus groups or in Sharing Circles, for example (Rothe, Ozegovic & Carroll, 2009). Another potential limitation is that the quantitative measures selected for the analysis are shaped by the information deemed as especially valuable or necessary, which is subject to the particular lens of the research and the researchers. Numerical scales for measuring or quantifying pain can also be problematic in quantifying pain, which is explored further in Section V of this paper.

When Indigenous women are involved, obtaining feedback from a committee and from Indigenous stakeholders on all aspects of an analysis would be especially helpful in reflecting on what type of data is collected, and why. Drawing on multiple types of knowledge and sources of information may also require additional resources, be more time-consuming, and incur greater financial costs (Polit & Beck, 2012). Finally, other potential limitations of current quantitative outcome measures include questions that make assumptions around a woman's home, car, or

employment, for example (Varcoe et al., 2017). It is therefore important that members of a research team adapt existing tools or measures to remove questions that may contain implicit biases around class and to ensure that they are culturally safe and appropriate as well as trauma-and-violence informed.

Section V: Clinical Care and Educational Implications

Education about Pain and Assessment of Pain

Nursing education related to pain is lacking and often fragmented. Studies have established that nurses overestimate their own knowledge on pain assessment and treatment, and underestimate pain in clients, particularly in women (Bailey et al., 2013; Chow & Chan, 2015; Duke et al., 2013; Pierik et al., 2017). Further, studies have underscored how cultural differences in pain expression, previously negative experiences in the health care settings, and the mistrust of care providers in Indigenous peoples can lead to further under-assessment and under-treatment (Fenwick, 2006; Strong et al., 2015).

The underassessment and under-treatment of pain continue to have deleterious consequence on the health and wellbeing of clients despite the advances in technology and knowledge (CIHR, 2016; Duke et al., 2013; Pierik et al., 2017) and despite access to pain treatment being acknowledged as a fundamental human right (Lohman, Schleifer, & Amon, 2010). There are few studies examining the knowledge and attitudes about pain in nursing faculty and among nursing students (Duke et al., 2013). While learning about pain as the “fifth vital sign” is a common experience within nursing undergraduate programs, what is missing is greater awareness around the multiple contexts shaping the lives of nurses and providers, including historical and social contexts (Doane & Varcoe, 2015). Although pain assessment is

generally taught in undergraduate programs, studies have shown that a health care provider's lack of knowledge about pain and negative attitudes about pain medications continue to contribute to ineffective pain management in clinical settings (Chow & Chan, 2015; Duke et al., 2013; Pierik et al., 2017).

Among nursing faculty, one study reported that less than half of the faculty felt adequately prepared to teach about pain despite receiving basic preparation during their training (Voshall, Dunn, & Shelestak, 2013). Yet nurses play an integral role in pain assessment and management so they need to be equipped with the skills and knowledge to meet the pain needs of clients. Yet as one study demonstrated, simply having pain management content in a nursing curriculum may not be sufficient for the efficient translation of this knowledge and its effective application to patient care (Duke et al., 2013). Studies have demonstrated that in some hospital nurses with additional education and training on pain called "pain resource nurses" [PRN] have been helpful in supporting staff to improve overall pain management by strengthening peer support around best practices, providing education, and helping to liaise between nurses, patients and families, and members of the health care team (Williams et al., 2012). Further strategies that may help students to reflect and apply learned content include: learning collaboratively with other programs and disciplines to consider other points of view on managing pain, encouraging the unpacking of assumptions around pain, receiving training on other worldviews and perspectives around the meaning and significance of pain including Indigenous ways of knowing, and having a relational inquiry approach role modeled to them by faculty when teaching about pain assessment and management (Browne et al., 2009; Chow & Chan, 2015; Dion Stout, 2012; Doane & Varcoe, 2015; Duke et al., 2013; Weiss, Tilin, & Morgan, 2018).

Currently most Canadian nursing students receive little training and education on responding to intimate partner violence and understanding its potential health effects of violence and trauma on chronic pain. Exposure to various realities, worldviews, and perspectives are also missing as illustrated by educational materials still lacking in diversity. For example, medical textbooks still display a preponderance of lighter skin tones which may contribute to racial bias among future health care providers and introduce the possibility of missing key information in individuals with darker skin tones (Johnson-Jennings, Tarraf & Gonzalez, 2015; Louie & Wilkes, 2018).

To help address a lack of inclusion on Indigenous perspectives in Canadian educational settings, the Truth and Reconciliation Calls to Action committee (Truth & Reconciliation Commission of Canada, 2015) has made a number of recommendations at the postsecondary level to integrate Indigenous knowledge and teaching into the classroom and to develop culturally appropriate curricula. Within nursing programs, there is a growing body of literature acknowledging the colonization of nursing knowledge and education, the White privilege and racism within the profession itself, and the need to work collaboratively toward decolonization (Browne et al., 2009; McGibbon et al., 2014; Moffitt, 2016). The process of decolonizing involves embedding postcolonial concepts and ideas into nursing to help address the presumption of superiority of Western ways of knowing over Indigenous epistemologies and increase the counter-narrative to this discourse (Browne et al., 2009; Hovey, Delormier, McComber, Levesque, & Martin, 2017; McGibbon et al., 2014). In education, nursing programs have privileged Western and Eurocentric knowledge (McGibbon et al., 2014; Moffitt, 2016) typically building on biomedical, reductionist models of understanding health and illness, including pain. The exclusion of Indigenous knowledge, teaching, and perspectives within education is now

being addressed by various educational institutions including in the postsecondary institution where I am currently working as nursing faculty.

The confusion around defining pain is further complicated by the inadequacy of quantifying pain by using reductionist means, for example, through numerical scales. This idea has been eloquently explored by health care providers and non-health care providers alike. In an essay using a Foucauldian analysis of the impact of health care on nursing knowledge and practice, Wheaton (in review) argues that while standardization has merit in improving patient safety, health outcomes, and nurses' accountability, the use of standardized tools and scales also tends to homogenize the lived experiences of patients, which is particularly problematic for the highly individualized and contextualized experience of pain. Currently in clinical settings pain is most often measured or quantified using pain scales such as the Numeric Rate Scale [NRS-11] which requires patients to rate their pain between zero and 10, with zero representing no pain and 10 representing the worst pain imaginable (Robinson-Papp et al., 2015). The inadequacy of numbers-only approach to measure pain is echoed in the work of Robinson-Papp et al (2015) in a qualitative study examining the patient-identified barriers to chronic pain measurement through the use of numerical scales to measure pain intensity in which they found that patients felt doubtful that pain could be accurately measured. In an essay called "The Pain Scale" which Biss (2005) wrote based on her own experiences with chronic pain, she argues that pain has no fixed point. She mentions the studies that suggest the conflation of emotional and physical pain in children using the Wong-Baker Faces Scale, a scale that provides six faces displaying a variety of facial expressions from happy to highly distressed, from which clients select to represent their own pain levels. This idea of "conflation" between physical and emotional pain risks creating a false dichotomy between the body and the mind, and promoting a Cartesian view of physical and

emotional domains rather than appreciating how these realms are inextricably intertwined and influenced by a myriad of contextual factors (Doane & Varcoe, 2015).

I have suggested tools in Appendices 2 and 3 that could potentially be used in clinical and educational settings to help promote conversations around pain between care providers and clients, and between members of the interprofessional health care team. The tool in Appendix 2 includes the numerical scale for pain, but only as a general guide. The tool builds on selected domains of the Clinical Alignment Pain Assessment [CAPA] tool described by Gordon (2015) and also includes questions on what the pain is like, the location of the pain whether specific or generalized, the meaning of the pain experience including the client's own words, aggravating and alleviating factors, how the pain is trending, the client's goals for pain management and strategies being used by the health care team and client to achieve these goals, and what the client states would be most helpful for health care providers to do with regards to their pain. The tool in Appendix 3 builds on questions adapted from the West Haven-Yale Multidimensional Pain Inventory (Kerns, Turk & Rudy, 1985), Comparative Numerical Pain Rating Scale (Robinson-Papp et al., 2015) and interview questions from the ROS study on pain (Varcoe et al., 2017) to generate a brief, basic pain profile that encompasses various aspects of the pain experience as a starting point for conversations with women experiencing pain. Tools that build on the idea on a relational approach of "not knowing" (Doane & Varcoe, 2015) or negative capability (Weiss et al., 2018) may help to direct the conversation of a care provider toward the client and their pain experience instead of the conversation centering on a nurse's assumptions about a client's pain based only on a numerical value and conclusions on how a client's pain should be managed.

There is new evidence coming to light of the potential benefits of routine measurement and monitoring in psychotherapy through the use of surveys, also called feedback-informed therapy, to address the tendency of psychologists to overestimate how well their clients are responding to therapy, mitigate their therapeutic blind spots, and elucidate the reasons why some clients drop out of therapy when they do not feel it is working (Anderssen, 2018). Using the tools and surveys suggested in this SPAR (Appendices 2 and 3) either in pen-and-pencil form, or by using technology such as tablets, could help to enhance client care with regards to pain by giving clients the opportunity to share how they are doing in real time and mitigate the potential for social desirability bias, or the pressure to respond positively to questions to be perceived as a more “acceptable” patient. This, in turn, could help clinicians individualize care, identify gaps, and help improve health services for pain. The use of a pain assessment tool that promotes a patient-centered approach may also help to mitigate the negative stigma around chronic pain and the imbalance of power in health care that silently sanction questionable practices such as a nurse’s judgement about whether a client’s pain is legitimate, and the intentional withholding of pain medication if a client is labelled as “drug-seeking,” for example (Doane & Varcoe, 2015; Poulin et al., 2016). An enhanced understanding of understanding of pain that moves beyond pathology and endeavours to include social, environmental, historical and cultural contexts would be helpful in bridging the chasms between how health care providers conceptualize pain and how clients represent their pain experiences (Mintz, 2011).

Women who experience the health effects of violence, including pain, are overrepresented in health care settings. Given the prevalence of IPV in Canada, and globally, it is critically important that nursing students become educated in responding and addressing the effects of violence before they become clinicians and to become part of a critical mass with

knowledge of global contexts helping to develop and test interventions and services for women experiencing IPV and its health effects, including chronic pain (McGibbon et al., 2014). Two strategies that may assist students and providers in developing a compassionate and non-judgmental approach include cultural safety and trauma-and-violence informed care.

Cultural Safety

The stigma around chronic pain conditions can cause people to feel unsafe while in health care settings and to delay seeking treatment which can worsen health outcomes and lead to a decreased quality of life. Cultural safety is a model and strategy that emerged from work established with Indigenous populations in New Zealand, and has been taken up in Canadian health care settings as a way to help mitigate some of the potential harms of deeply entrenched power differentials in health care settings (Browne & Varcoe, 2009; Browne et al., 2016; Fenwick, 2006; Hart-Wasekeesikaw et al., 2009; McCall & Pauly, 2012; Pauly et al., 2015; Stout & Downey, 2006). In the Canadian context, cultural safety has helped to promote an understanding of the impacts of historical trauma, and the racial discrimination that affect the health, and health care experiences, of Indigenous peoples (Pauly et al., 2015). It has also been helpful in other contexts, such as in guiding clinicians and educators on how to provide culturally safe nursing practice for individuals who encounter stigma and discrimination in health settings, such as with clients who use illicit drugs (Pauly et al., 2015).

There is variability in how people express pain depending on a myriad of internal and external factors that includes customs, language, socialization, historical contexts, among others that may include what is commonly referred to as “culture” (Fenwick, 2006). Yet culture is also a “dynamic relational process of selectively responding to and integrating particular historical, social, political, economic, physical, and linguistic structures and processes” (Doane & Varcoe,

2015, p.139) and it is seen as a living, dynamic, and creative force that can positively affect the health of entire populations and communities (Browne & Dion Stout, 2012) . Therefore cultural safety is not about bridging the perceived “cultural gap” between people in the a traditional, superficial, and narrowly defined sense nor about categorizing people in a way that perpetuates unconscious bias and erroneous stereotypes, it is rather about an approach that enhances a care provider’s ability to foster a sense of trust with clients as well as conduct assessments and manage care in a safe and respectful way (Doane & Varcoe, 2015). Key aspects of cultural safety include reflecting on one’s own power and privilege as a health care provider, as well as examining one’s biases and assumptions and how these might impact the ability to form therapeutic relationships (Pauly et al., 2015). Cultural safety also has an impact more broadly by helping to address unfair power differentials, systemic discrimination and racism, and the ongoing effects of colonial policies and practices (Browne et al., 2016; Doane & Varcoe, 2015). While the concept of cultural safety is meant to be inclusive, there is a risk that it could reinforce the idea of difference between a nurse and the cultural “Other” which therefore requires ongoing critical self-reflection (Browne et al., 2009).

Being able to establish rapport and communicate effectively with clients and other members of the interdisciplinary health care team around pain is facilitated through the use of culturally safe pain assessment practices (Doane & Varcoe, 2015). In a paper about pain assessment written with the assistance of Indigenous peoples in Central Australia, Fenwick (2006) describes several specific aspects of Aboriginal and Torres Strait Islander culture that may be helpful for health care providers to consider when doing pain assessments. This collaboration points to a need to involve Indigenous peoples in all levels of research and policy-making to help in the creation of culturally appropriate assessment tools, guide culturally safe

practices around pain, and to help identify which pain management outcomes are of greatest importance (CIHR, 2016; Fenwick, 2006; McGrath, Rawson, & Adidi, 2015) while also recognizing that Indigenous ways of knowing are influenced by local contexts, communities, histories, and protocols (Browne et al., 2016).

Trauma-and-Violence Informed Care

There has been recognition of the importance of addressing trauma and its impact in all individuals who have experienced violence. The principles of trauma-informed care [TIC] include: trauma awareness, emphasis on safety and trustworthiness, opportunity for choice, collaboration and connection, and is strengths based and skill based (BC Provincial Mental Health and Substance Use Planning Council, 2013).

Trauma-and-violence informed care [TVIC] builds on trauma-informed models but adds a decolonizing lens to trauma discourses in relation to Indigenous peoples (Browne et al., 2016). This helps to focus on the effects of violence as both historic and ongoing, and calls attention to the continuously traumatic effects of structural violence (Browne et al., 2016). A TVIC approach emphasizes respectful care, recognition of the intersections of individual and structural violence on health, and an understanding of the contextual nature of the health and social issues of individuals and communities, and efforts to try and mitigate the potential for re-traumatization (Browne et al., 2016).

With regards to chronic pain, using a trauma-and-violence approach includes: recognizing the negative effects of violence and trauma on the health of women, creating safe and supportive environments for women to talk about their pain experiences if they choose to without requiring a disclosure of violence or trauma, creating opportunities for choice,

collaboration and connection, and using a strengths and resilience-based approach to help women build on their existing capacities (Public Health Agency of Canada, 2018). This kind of holistic approach also recognizes the potential for secondary or vicarious-trauma on service providers who work with individuals experiencing violence, and will actively support the wellbeing of providers through education and wellness programs (Public Health Agency of Canada, 2018).

Recommendations Guided by the Project

The preparation of this project has guided the following recommendations based on the extant literature review and the author's experience as a graduate nursing student, Registered Nurse, clinical nurse educator, and nursing instructor in classroom, lab, and clinical settings:

Education:

- Advocate for more inclusive, broader, and more nuanced definitions of pain and pain treatment instead of relying on traditional, biomedical models and strictly numerical scales by drawing on multiple forms of information and seeking out various types of knowledge.
- Consider the use of clinical pain tools (such as the tool suggested in Appendix 2) to provide students and clinicians with a framework to guide client interactions on pain in the clinical setting, facilitate communication between members of the interprofessional team, and enhance patient-centered care. Clinical pain tools may also be used in fictional case studies for teaching purposes in the laboratory, in the classroom, in post-conference and in simulation.
- Use a relational inquiry approach (Doane & Varcoe, 2015) that includes the notion of “not knowing” to engage nursing students in unpacking their own assumptions about

pain, and consider how their perceptions around pain and pain management may affect their ability to assess and treat pain effectively.

- Encourage nursing students to reflect on non-pharmacological ways to manage pain and how to integrate these with pharmacological approaches.
- Provide opportunities for students to learn and socialize with students and health care providers from different allied health programs and disciplines around case studies that center on pain to foster collaboration and promote patient-centered care.
- Build cultural safety and trauma-and-violence informed care into the curriculum of nursing undergraduate programs.
- Include thoughtfully threaded Indigenous content in undergraduate nursing programs to promote reflection of the impacts of colonialism, and violence, on the health of Indigenous Canadians. Additional training and resources are available in free Massive Open Online Courses [MOOC] such as *Reconciliation through Indigenous Education* on the edX platform and through courses such as the *San'yas Cultural Safety Training* course by the Provincial Health Services Authority of B.C. which is funded for employees of various health authorities and for Indigenous peoples working in health and mental health care settings.

Health Care:

- Build routine pain assessment and documentation into nursing practice by providing nurses, and members of the interdisciplinary team, with education and training on pain. This may include a reflective exercise during which attendees can unpack their own

assumptions about pain for their own information, and/or as a starting point for a larger group discussion.

- Use, or adapt with permission and as appropriate, existing clinical best practice guidelines on the assessment and management of pain, such as those by the Registered Nurses Association of Ontario (2013).
- Provide cultural safety and trauma-and-violence informed training to health care providers with a focus on developing a broader, more nuanced understanding of pain as a complex, subjective phenomenon.
- Promote the use of pain specialists in nursing through programs such as the Pain Resource Nurse [PRN] training program (Williams et al., 2012). Within the BC Lower Mainland, pain resource nurses could receive additional training, potentially through a local agency such as PAINBC for example, on assessing, responding to, and managing pain. Specially trained nurses could help to promote high quality care around pain as well as mentor and guide colleagues, new staff including recent graduates, and nursing students. This in turn would assist in advancing a critical mass with knowledge and skills in pain assessment and management.
- Consider the use of clinical pain tools (such as the tool suggested in Appendix 2) or the CAPA tool (Gordon, 2015) to provide students and clinicians with a framework to guide client interactions on pain in the clinical setting, facilitate communication between member of the interprofessional team, and enhance patient-centered care.
- When Indigenous people are involved, develop and pilot culturally safe and appropriate pain assessment tools through consultation with local Indigenous stakeholders including Elders, clinicians, researchers, leaders, and members of the local community.

Research:

- Consider how to create and pilot pain profiles that could help to guide locally-determined strategies, policies, and practices. Appendix 3 provides a general pain profile which could be used as a starting point in collecting information from women on chronic pain, and adapted as needed with input from key stakeholders.
- Create pain profiles by: collecting and analyzing data from standard scales and instruments used to assess chronic pain and disability (such as those in Appendices 4 and 5), AND collecting and analyzing data that seeks to capture women's experiences of chronic pain in the context of IPV in their own words (Appendix 1) while using culturally safe, and trauma-and-violence informed approaches and providing support for women should they feel triggered or should their pain increase.
- If Indigenous peoples are involved, ensure that Indigenous Elders, knowledge-keepers, scholars, health providers and stakeholders are involved in the research process whenever feasible, and in doing so, this will help to ensure that the research questions, priorities, and problems reflect the unique needs, concerns and aspirations of the local community (Smith, 2012).
- In a cross-cultural research context, Smith (2012) states that some of the following questions should be asked of any study and that researchers must go further than simply recognizing their own personal assumptions and beliefs, and this includes: who defined the research problem, what knowledge the researcher and the community will gain from the study, the potential positive and negative outcomes from the study, whether the negative outcomes can be eliminated, the accountability of the researcher, and what supports are in place for the research, the researched, and the researcher?

- When doing research in partnership with Indigenous peoples, Smith (2012) advises that researchers take being Indigenous “as a given, to think critically and address structural relations of power, to build upon cultural values and systems and contribute research back to communities that are transformative” (p. 214). In the case of pain, the use of pain profiles would be developed with the purpose of improving the health care experiences of women and developing interventions that could help to manage pain and improve quality of life, and with the goal of inviting women to participate in knowledge translation and the dissemination of information as appropriate.

Section VI: Conclusion

A more in-depth understanding of women's experiences of chronic pain in the aftermath of IPV is needed as a foundation for more effective clinical practice and interventions, with Indigenous women, and for women more generally. Given the urgent health care needs of Indigenous women living with chronic pain in the context of IPV, and the current lack of research, a richer appreciation of the unique experiences of Indigenous women in the health care system may help to improve the effectiveness of health care approaches, interventions, and access in primary and tertiary care settings, as well as to guide educational initiatives for nursing curriculum which in turn will benefit all women. Such approaches, interventions, and initiatives may include culturally-based harm reduction, holistic pain assessments such as pain profiles, traditional healing practices, cultural safety, trauma-and-violence informed care, technological modalities that increase service access, as well as the recognition and inclusion of Indigenous methodologies and ways of knowing (British Columbia Government & First Nations Health, 2017; Browne et al., 2016; Browne et al., 2009; Ford-Gilboe et al., 2017).

An unsettling awareness of knowledge gaps on the pain experiences of women, of the barriers they report in accessing and receiving care, and of the often stigmatizing discourse and problematic representation of Indigenous peoples around pain will assist current and future health care providers to “tug at the blindfold” (Geddes, 2017) around the systems and policies that silently perpetuate the colonial beliefs and practices that result in health inequities and poorer health outcomes for Indigenous peoples.

Nursing as a profession prides itself on its lifelong learning, and this spirit of inquiry, respect, openness, curiosity and negative capability should be cultivated both in nursing educational programs and across health care settings helping nurses to deeply listen, unpack their

own assumptions, disrupt the status quo, and collaborate with clients as partners in their own health. This, in turn, may lead to improved health outcomes as well as greater satisfaction with health care experiences for all women who have experienced violence.

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Appendices

Appendix 1

Qualitative Questions on Pain

Preamble: Part of what I am interested in learning more about with this study is around women's experiences with pain, both within the study and in the health care system itself. So I would like to ask you a couple of questions around that if I can.

a) Is pain an issue for you? When I am asking this question, I am thinking of pain as however you define it (physical, emotional, psychological, spiritual...)

Probes: Can you tell me if you are experiencing pain or have experienced it previously? What your pain is like? How long have you had it? How intense is the pain? How does it affect your life/what has this experience been like for you?

b) What do you do for your pain?

c) Can you describe whether you have received any support from the health care system in addressing your pain? If so, can you describe this further?

d) Have you encountered any barriers in the health care system around having your pain assessed and treated?

e) Do you have any suggestions for health care providers on what would be helpful in addressing pain in general?

Appendix 2

Pain Tool Draft – Clinical Practice and Education

<p>What is the pain like?</p> <p><i>Explore what pain is like to the client.</i></p> <p>What words does the client use to describe their pain?</p>		
<p>Where is the pain?</p> <p><i>Is the pain is localized to a particular area or region of the body? If so, where? Is the pain more generalized?</i></p>		
<p>Meaning of pain experience:</p> <p><i>Ask about what the pain means to the client</i></p> <p><i>This does not mean asking about the origin of pain, or eliciting a trauma history, but rather inquiring about the effect of the pain on the client's life at present such as on their comfort, their sleep, or how much it interferes with what they want to accomplish and letting them lead the conversation.</i></p>		
	Start of Shift	End of Shift
<p>Pain scale (rate pain from 1-10):</p> <p><i>This should only be used as a very general guide and may not be helpful with clients for whom assigning a numerical value to pain may not be appropriate.</i></p>		
<p>How is the pain trending?</p> <p><i>Is the client's pain improving, staying the same, worsening?</i></p>		

Aggravating factors: <i>What makes the pain worse?</i>		
Alleviating factors: <i>What makes the pain better?</i>		
Goals for pain management: <i>As determined by the client</i>		
How the client and team are working towards the above pain management goals: <i>Client</i> <i>Health care team</i>		
What would be most helpful for HCPs to do: <i>As determined by the client</i>		
Additional notes:		

Generic Pain Profile Sample - Research

0	1	2	3	4	5	6
No suffering						Extreme suffering

0	1	2	3	4	5	6
No change			Extreme change			

0	1	2	3	4	5	6
Not at all						Extremely well

0	1	2	3	4	5	6
Not at all irritable						Extremely irritable

0	1	2	3	4	5	6
No change			Extreme change			

0 1 2 3 4 5 6
Not at all tense or anxious Extremely tense or anxious

0	1	2	3	4	5	6	7	8	9	10
It's a really good day				It's an average day				It's a really bad day		

1. What is living with pain like for you?

⁵ Question adapted from the Comparative Numeric Pain Rating Scale

2. How does pain affect your life?
3. What do you do for your pain?
4. Do you have any suggestions for health care providers on what would be most helpful in addressing your pain?
5. Based on your previous health care experiences, is there anything you can think of that would be especially unhelpful for a health care provider to do for your pain?
6. Is there anything else that you would like us to know? ⁶

⁶ Questions adapted from Reclaiming Our Spirits (Varcoe et al., 2017)

Appendix 4

Blank Pain Profile

Social history (any pertinent info from bio/summaries and field notes):

Quantitative Data

Medical diagnoses

Woman (#)	Diagnoses – Pilot and post pilot

Health

Question	Pilot	Post Pilot
	Rating (1-5)	
5. Emotional problems interfered with work/daily activities – past 4 weeks		
a) Accomplished less		
b) Did routine more carefully		
6. Pain interfere with normal work		
7. c) Felt downhearted and depressed		
8. Physical and emotional health interfered		

Symptoms, pain and trauma

Symptoms	Pilot			Post Pilot		
	Y/N	Frequency (0-5)	Interference (1-10)	Y/N	Frequency (0-5)	Interference (1-10)
ii) Back pain						
iii) Headaches						

xiii) Upset stomach/heartburn						
xv) Bowel problems, diarrhea, cramping, gas, constipation						
xvi) Chest pain						
xx) Vaginal/pelvic pain						
xiv) Painful intercourse (sex)						
xxvi) Sexually transmitted infections (e.g. Herpes, AIDS, Syphilis, etc.)						
xxviii) Bladder infection (“burning” on urination)						
xxxiii) Swollen/painful joints						
xxxiii) General aches and pains/muscle soreness						
xxxv) Dental problems (pain, decay, loose teeth, etc.)						
xxxvi) Cutting, burning or hurting yourself (self-mutilation)						
xxxviii) Suicidal thoughts						
xxxviii) Attempting to kill yourself						
xxxix) Feeling worried or uptight						
xl) Panic attacks						
xli) Feeling sad or depressed						

11. Physical pain:	Pilot	Post Pilot
	Rating (0-10)	
i) Pain at present time		
ii) Worst pain in past 6 months		

iii) Average pain in past 6 months		
	Days	
iv) Kept from usual activities due to pain in last 6 months		
	Interference (0-10)	
v) Pain interfered with daily activities in past 6 months		
	Change (0-10)	
vi) Pain changed social and family activities in past 6 months		
vii) Pain changed ability to work in past 6 months		

Center for Epidemiologic Studies Depression Scale – Revised (CESD-R)

12. In the past week or so:	Pilot	Post Pilot
	Rating (0-4)	
Poor appetite		
Couldn't shake off blues		
Trouble keeping mind		
Depressed		
Sleep restlessly		
Sad		
Could not get going		
Nothing made me happy		
Felt like bad person		
Lost interest in usual activities		
Slept much more than usual		
Felt moving too slowly		
Felt fidgety		

Wished I were dead		
Wanted to hurt myself		
Tired all the time		
Did not like myself		
Lost a lot of weight without trying		
Lots of trouble getting to sleep		
Could not focus on important things		
CESD total score		
Positive screen for CESD at 16? (Y/N)		
Positive screen for CESD at 21? (Y/N)		

PTSD Checklist – Civilian Version (PCL-C)

13. Response (In the last month):	Pilot	Post Pilot
	Rating (1-5)	
i) Memories, thoughts, or images		
ii) Dreams of a stressful experience		
iii) Stressful experience happening again		
iv) Upset when reminded of a stressful experience		
v) Physical reactions when reminded of a stressful experience		
vi) Avoid thinking/having feelings about stressful experience		
vii) Avoid activities/situations remind you of a stressful experience		
viii) Trouble remembering parts of a stressful experience		
ix) Loss of interest in things used to enjoy		
x) Feeling distant or cut off from others		
xi) Feeling emotionally numb/unable to have loving feelings		

xii) Feeling as if your future will somehow be cut short		
xiii) Trouble falling/staying asleep		
xiv) Feeling irritable/ having angry outbursts		
xv) Having difficulty concentrating		
xvi) Being “super alert”/watchful on guard		
xvii) Feeling jumpy/easily startled		
PTSD total score		
Positive screen for PTSD? (Y/N)		

Experiences of abuse

1. In the past 6 months, any partner(s) ever:	Pilot		Post Pilot	
	Y/N	Frequency or # of times	Y/N	Frequency or # of times
a) Hit, kick or hurt you physically				
b) Force to have sexual activities against will				
c) Do things to make you feel afraid of him				
d) Do things to try to intimidate you or control your thoughts, feelings, actions				

2. Experiences of harassment:	Pilot (12 months prior)	Post Pilot (6 months prior)
	Y/N	
1) Have you been harassed?		
2) By whom?		
3) Experienced harassment from (other than index partner)		

4) How distressing has the harassment been?		

Qualitative Data

(Would be extracted and analyzed from an interview transcript on questions pertaining to pain such as those suggested in Appendix 1)

Appendix 5: Sample of Measures for Proposed Quantitative Analysis Questionnaire in ROS – Used and adapted with permission from Colleen Varcoe, 2018

HEALTH AND HEALTH HISTORY	Purpose	Items	Description
YOUR HEALTH	To record women's perceived health in the past 4 weeks. Measure: Short-form General Health Survey	14 items	Each item has response options on a 5-point or 3-point Likert-type scale and the respondent's answers are based on perceived health over the past four weeks. Raw scores are transformed to 0-100 scale score, higher scores reflect greater health functioning.
MEDICAL DIAGNOSES	To record women's diagnosed health problems she has had in the past 12 months. In post-intervention surveys, women are asked about any health conditions they have had diagnosed since the previous survey	12 Items	
SYMPTOMS, PAIN, AND TRAUMA	To record the occurrence, frequency and severity of symptoms women have experienced in the past month, whether or not these symptoms are related to abuse. Measure: Partner Abuse Symptom Scale	45 Items	Measures a) whether participants have experienced symptoms in the last 12 months as well as b) frequency in the last 12 months (on a 5-point Likert scale) and c) interference of the symptom in everyday activities (on a scale from 0-10).
PHYSICAL PAIN	To record the severity and disability of chronic pain in women's lives. Measure: Chronic Pain Grade Scale	7 Items	Scored to generate: Pain Intensity Score, Disability Score, and Pain Grade Classification (Grades 0-4): <ul style="list-style-type: none"> • 0: Pain free • I: Low disability low intensity • II: Low disability high intensity • III: High disability moderately limiting • IV: High disability severely limiting
DEPRESSIVE SYMPTOMS	To record women's depressive symptoms in the past week or so. Measure: Center for Epidemiological Studies Depression Scale-Revised	20 Items	Each item has response options along a 5-point Likert Scale. The items are summed with a possible range of 0-60). Scored using cut-off score of 16 as an indicator of possible clinical depressive symptoms. Also scored using an algorithm to classify participants

			as: <ul style="list-style-type: none"> • Subthreshold depression symptoms; • Possible Major Depressive Episode; • Meets criteria for Major Depressive Episode; or • No clinical significance
TRAUMA SYMPTOMS	To record women's trauma symptoms in the past month. Measure: PTSD Checklist-Civilian Version (PCL-C)	17 Items	Based on DSM-IV criteria. Each item has a response option on a 5-point Likert scale. Items are summed with a possible range of 17-85. Participants are categorized according to: <ul style="list-style-type: none"> • Meeting DSM-IV criteria for PTSD, and • Score above or below pre-determined cut-off of 44 as an indicator of clinical trauma symptoms.
USE OF SUBSTANCES-CIGARETTE SMOKING	To record women's lifetime and recent use of cigarettes	3 Items	
USE OF SUBSTANCES-AUDIT	To record problematic alcohol use patterns. Measure: Alcohol Use Disorders Identification Test (AUDIT)	10 Items	10-item questionnaire developed to screen for hazardous (or risky) drinking, harmful drinking, or alcohol dependence. Items' response options are on a 5-point or 3-point Likert scale. Scores range from 0-40 and we use a cut-off score of 6 to identify probable problematic drinking
USE OF SUBSTANCES-DRUG USE	To record women's use and frequency of use of drugs, including marijuana. Source: Questions modified from Canadian Alcohol and Drug Use Monitoring Survey	17 Items	
USE OF SUBSTANCES-	To record women's use of alcohol detox and treatment services as well as women's		

DETOX, TREATMENT AND HARM	perception of whether their drug or alcohol use has been harmful in the past year.		
HEALTH & SOCIAL SERVICE USE	Purpose	Items	Description
CONFIDENCE ACCESSING SERVICES	To record women's rating of their confidence accessing services and difficulty accessing services	3 Items	
DOCTORS	To record whether women have seen doctors and number of times in the past month, how women rate these experience with their doctor(s), and whether women needed to access doctor(s) in the past month and were unable to do so.	9 Items	
OTHER HEALTH AND SOCIAL SERVICES	To record whether women have accessed different social and health services and the number of times in the past month, how women rate these experiences and whether women needed to access services in the past month and were unable to do so.	24 Items	
YOU, YOUR FAMILY, AND YOUR RELATIONSHIPS	Purpose	Items	Description
QUALITY OF LIFE	To record how satisfied women are with particular areas of their life Measure: Sullivan	11 items	Each response option is on a 7-point scale measuring how satisfied women are with particular areas in their lives. Total possible scores range from 9 to 63 with 1=

	Quality of Life Scale		extremely pleased to 7 which = terrible. The items are reverse-scored and summed with higher scores indicative of higher quality of life.
EMPLOYMENT AND FINANCES	Purpose	Items	Description
EMPLOYMENT AND WORK	To record women's employment status and whether and how much women have worked in the past year	4 Items	
SOCIAL ASSISTANCE AND DISABILITY ASSISTANCE	To record whether women are receive Social Assistance or Disability Assistance and for how long	5 Items	
FINANCIAL STRAIN INDEX	To record the difficulty participants are having meeting their financial obligations Measure: Financial Strain Index	15 items	Summated scale measuring extent of difficulty meeting current financial obligations in 14 different areas such as housing, transportation, and dental expenses, on a 4-point scale ranging from 1 (very difficult) to 4 (Not at all difficult). Total scores range 0-56.
MEETING YOU AND YOUR FAMILY'S NEEDS	To record how difficult it is for women to live on their total household income and how certain women are that they can get what they and their family needs	2 Items	
EXPERIENCES OF ABUSE	Purpose	Items	Description
ABUSIVE PARTNERS AND CONTACT WITH ABUSIVE PARTNERS	To record how many abusive partners women have had, the gender of these abusive partners, and women's contact patterns with their abusive partners.	5 Items	

ABUSE EXPERIENCES	To record women's experiences of intimate partner, including emotional and physical abuse, harassment, sexual violence, and severe combined abuse. Measure: Modified Composite Abuse Scale (CAS)	31 Items	Four dimensions of abuse: Severe Combined Abuse, Emotional Abuse, Physical Abuse, and Harassment and includes acts of sexual abuse. Each item has response options on 6-point Likert scale. We slightly modified three sexual abuse items. This is a summated-category scale with total scale scores of 0-150, several studies have used cut-off scores of 3 for low levels of abuse and a cut-off of 7 for high levels of abuse. There are four other options for scoring.
HARASSMENT EXPERIENCES	To record women's experiences of harassment	4 items	Two questions from Violence Against Women Survey and sexual assault questions in the CAS.
CHILDHOOD ABUSE EXPERIENCES	To record women's histories of childhood maltreatment (abuse and neglect) Measure: 4 questions adapted from the Childhood Trauma Questionnaire (CTQ)	4 Items	28 items-summated rating scale developed to document histories of childhood maltreatment. Each item's response choices are on a 5-point Likert scale ranging from Never true to Very true. Scored to produce five clinical subscales: emotional abuse, physical abuse, sexual abuse, physical neglect, and emotional neglect. Each sub-scale score ranges from 5 to 25.
SEXUAL ASSAULT SINCE AGE OF 16	To record whether women have experienced sexual assault since the age of 16 according to Criminal Code definitions. Source: Violence against Women Survey	2 Items	Two questions from Violence Against Women Survey and sexual assault questions in the CAS.
DEMOGRAPHIC QUESTIONS	Purpose	Items	Description
DEMOGRAPHIC INFORMATION	To record women's demographic information: age, what culture(s) women identify with, what Nation women identify with, whether women have status under the <i>Indian Act</i> , whether women were born in Canada, as well as what languages women first learned to speak and speak now.	7 Items	