

PAIN ASSESSMENT AND TREATMENT IN BLEEDING DISORDERS:  
THE NEED FOR SOCIAL WORK SPECIFIC EDUCATION

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By

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## **ABSTRACT**

The aim of this research was to examine what social workers currently understand and practice in pain management, specifically in bleeding disorder care. First, a scoping review was conducted to examine the breadth of research relevant to social work in pain management and bleeding disorders. Second, qualitative interviews were conducted with members of the Canadian Social Workers in Hemophilia Care (CSWHC) to identify the current state of understanding of the social work role in pain management and to explore the requirements for future pain education.

The research question for the scoping review was: What do social workers currently contribute to pain management in patients at risk of pain with chronic disease? In total, there were 13 articles included. These articles discussed three core social work interventions utilized in pain management practice: instrumental services, counselling services, and assessments. Advocacy and policy development were noted in a small number of these studies and require further development and research.

To address the overall aim of this project, qualitative interviews were conducted with 12 members of the CSWHC and examined using thematic analysis. The two research questions guiding the inquiry were: 1) What do social workers in the CSWHC currently understand about pain and bleeding disorder care and their practice, and 2) What specific pain knowledge and training is prioritized by social workers in the CSWHC. Four themes were developed: 1) Limited comprehension of key issues related to pain; 2) Conditioned to push through pain; 3) Expanding pain knowledge to enhance practice; 4) How we practice social work and choose to step in.

The findings from each study were synthesized and indicated there are common elements of the social work role in pain management and bleeding disorder care. While assessments were identified in both studies, the types of assessments explicitly used in pain management require further study. This study identified that future education and research is required in knowledge of pain mechanisms, assessments specific to pain, and the awareness of non-pharmacological pain interventions. Advocacy and policy development require further development in the understanding and function of daily practice.

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## **DEDICATION**

For my husband, Devin, who encouraged me in every single step of this journey. He provided all the emotional support I needed to persevere.

For my daughters Persephone and Rowynn who remind me daily of the pure joy of learning. They make it look so easy. Their love and joy keep me moving throughout the day.

Hast thou not known? hast thou not heard, that the everlasting God, the LORD, the Creator of the ends of the earth, fainteth not, neither is weary? there is no searching of his understanding. He giveth power to the faint; and to them that have no might he increaseth strength. Isaiah 40:28-29 KJV

## TABLE OF CONTENTS

<b>PERMISSION TO USE AND DISCLAIMER STATEMENT</b>	<b>i</b>
<b>ABSTRACT</b>	<b>ii</b>
<b>ACKNOWLEDGEMENTS</b>	<b>iii</b>
<b>DEDICATION</b>	<b>iv</b>
<b>TABLE OF CONTENTS</b>	<b>v</b>
<b>LIST OF TABLES</b>	<b>x</b>
<b>LIST OF FIGURES</b>	<b>xi</b>
<b>LIST OF ABBREVIATIONS</b>	<b>xii</b>
<b>CHAPTER 1.0 INTRODUCTION</b>	<b>1</b>
1.1 The Purpose of Research on Bleeding Disorders Care and Pain Management	1
1.2 Bleeding Disorders and Underlying Pain Mechanisms	2
1.2.1 Consideration of Endogenous Pain Modulation for Bleeding Disorders	3
1.2.2 Management of Pain and Bleeding Disorders Throughout the Life Span	4
1.2.3 Studies Examining Pain Experiences in Bleeding Disorder Populations	4
1.2.3.1 The HERO Study	5
1.2.3.2 The National Pain Study	5
1.2.3.3 A Survey of Self-Management Needs	6
1.2.3.4 Patient, Caregiver, and Provider Perceptions of Pain and Pain Management	6
1.2.4 Best Practices for the Treatment of Bleeding Disorders	7
1.3 An Overview of Pain Management	8
1.3.1 Best Practices in Pain Management	9
1.3.2 Exploring the Social Work Role in Pain Management	10
1.4 Multidisciplinary Teams and the Role of Social Work	11
1.4.1 Multidisciplinary and Interdisciplinary Teams and Function Defined	11
1.4.2 The Social Work Contribution Within Teams	12
1.5 Advocacy and Policy Development in the Role of Social Work	13
1.6 Conclusion	15

1.7 References	16
<b>Chapter 2.0 RESEARCH OBJECTIVES AND METHODS</b>	<b>22</b>
2.1 Research Objectives	22
2.2 The Researcher	23
2.2.1 The Research Committee	23
2.3 Project Summary	24
2.4 Method: Scoping Review	25
2.4.1 The Case for Utilizing a Scoping Review	25
2.4.2 Introduction to Manuscript A	26
2.5 Method: Thematic Analysis	28
2.5.1 An Overview of Thematic Analysis	28
2.5.2 Trustworthiness Through Detailed Framework	29
2.5.2.1 Phase 1	29
2.5.2.2 Phase 2	29
2.5.2.3 Phase 3	29
2.5.2.4 Phase 4	30
2.5.2.5 Phase 5	30
2.5.2.6 Phase 6	30
2.6 Relevance and Implications	30
2.7 References	32
<b>CHAPTER 3.0 SCOPING REVIEW - MANUSCRIPT A: THE CURRENT PRACTICE OF SOCIAL WORK IN PAIN MANAGEMENT: A SCOPING REVIEW ON CHRONIC DISEASE</b>	<b>34</b>
3.1 Preamble	34
3.1.1 Abstract	34
3.1.2 Funding	34
3.1.3 Keywords	34
3.2 Introduction	34
3.3 Methods	36

3.3.1 Identifying the Research Question	36
3.3.2 Identify Relevant Studies	37
3.3.3 Study Selection	37
3.3.4 Quality Assessment	39
3.4 Results	39
3.5 Discussion	46
3.6 Limitations	47
3.7 Conclusion	48
3.8 Acknowledgements	48
3.9 References	49
<b>CHAPTER 4.0 LINKING CHAPTER</b>	<b>53</b>
4.1 References	56
<b>CHAPTER 5.0 THEMATIC ANALYSIS - MANUSCRIPT B: PAIN MANAGEMENT IN BLEEDING DISORDERS CARE: PERSPECTIVES OF CANADIAN SOCIAL WORKERS IN HEMOPHILIA CARE</b>	<b>57</b>
5.1 Preamble	57
5.1.1 Abstract	57
5.1.1.2 Background	57
5.1.1.3 Aims	57
5.1.1.4 Method	57
5.1.1.5 Results	57
5.1.1.6 Conclusion	57
5.1.1.7 Keywords	58
5.2 Introduction	58
5.2.1 Pain in Bleeding Disorders	58
5.2.2 Social Work Practice in Haemophilia Care and Pain Management	59
5.2.3 Aims	59
5.3 Method	60
5.3.1 Ethics	60



5.3.2 Data Analysis	61
5.4 Results	61
5.4.1 Limited Comprehension of Key Issues Related to Pain	64
5.4.2 Conditioned to Push Through Pain	65
5.4.3 Expanding Pain Knowledge to Enhance Practice	65
5.4.4 How We Practice Social Work and Choose to Step In	67
5.5 Discussion	68
5.5.1 Future Research	70
5.5.2 Strengths and Limitations	70
5.6 Conclusion	70
5.7 Acknowledgements	71
5.8 References	72
<b>CHAPTER 6.0 DISCUSSION AND CONCLUSION</b>	<b>76</b>
6.1 Social Work Research	76
6.1.1 Synopsis of Scoping Review and Further Discussion	78
6.1.2 Advocacy and Policy Development	78
6.2 Synopsis of Thematic Analysis and Further Discussion	80
6.3 Contribution to Research	83
6.3.1 Social Work Practice in Non-Pharmacological Approaches to Pain Management	86
6.4 General Limitations	87
6.5 Clinical and Policy Implication	88
6.6 Future Research Recommendations	89
6.7 Conclusion	90
6.8 References	91
<b>APPENDICES</b>	<b>96</b>
A. Preferred Reporting Items for Systematic reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) Checklist	96
B. COnsolidated criteria for REporting Qualitative research Checklist (COREQ)	98
C. Ethics Approval	100

D. Recruitment Poster	101
E. Consent Form	102
F. Interview Guide	105

## LIST OF TABLES

Table 2.1 Search Terms: Searched 1980 – November, 2020	27
Table 2.2 Screening Criteria	28
Table 3.1 Summary of Papers Meeting Inclusion Criteria	40
Table 3.2 Summary of Findings	44
Table 4.1 Initial Codes and Theme Development	54
Table 5.1 Participant Demographics	62
Table 6.1 Pain Education Outline for CSWHC Members	85

## LIST OF FIGURES

Figure 3.1 PRISMA Statement	38
Figure 5.1 Theme Development	63

## LIST OF ABBREVIATIONS

ACT	Acceptance and Commitment Therapy
CASW	Canadian Association of Social Workers
CBT	Cognitive Behavioural Therapy
CHS	Canadian Hemophilia Society
CIHR	Canadian Institutes of Health Research
COREQ	Consolidated criteria for Reporting Qualitative research checklist
CSEPM	The Coalition for Safe and Effective Pain Management
CSWHC	Canadian Social Workers in Hemophilia Care
FTE	Full Time Equivalency
HERO	Haemophilia, Experiences, Results and Opportunities
HFA	Hemophilia Federation of America
HTC	Hemophilia Treatment Centre
IASP	International Association for the Study of Pain
IMPACT QOL	Interrelationship Between Management of Pain, Adherence to Clotting Factor Treatment and Quality of Life
MDT	Multidisciplinary Team
NASW	National Association of Social Workers
POMS	Profile of Mood States
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PRISMA-SCR	Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews
PTPQ	Pain Treatment Planning Questionnaire
PwBD	People with Bleeding Disorders – Describes patient or patient group with a diagnosis of Hemophilia A or B, vWD, or platelet function disorders
PwH	People with Hemophilia – Specifically used to refer to patient or patient group with a diagnosis of Hemophilia
QoL	Quality of Life
SASW	Saskatchewan Association of Social Workers
SBDP	Saskatchewan Bleeding Disorders Program

SIP	Sickness Impact Profile
SSRL	Social Science Research Laboratories
U of S	University of Saskatchewan
U of R	University of Regina
VAS	Visual Analogue Scale
vWD	von Willebrand Disease

## **CHAPTER 1.0 INTRODUCTION**

### **1.1 The Purpose of Research on Bleeding Disorders Care and Pain Management**

Royalty and anguish are components of the history of bleeding disorders which have brought it to public attention. Hemophilia is a rare genetic X-chromosome linked bleeding disorder that was evident in the royal bloodline of Queen Victoria with the birth of her son Leopold in 1853 and his death in 1884 after falling on a set of stairs (English Monarchs, 2018). The second historical event was the tainted blood tragedy that spanned the 1980s and 1990's resulting in the infection or coinfection of AIDS and Hepatitis to patients who received blood transfusions (Canadian Hemophilia Society [CHS], 2018a; World Federation of Hemophilia [WFH], 2020). With this public awareness and tragedy, the Canadian Hemophilia Society (CHS) was developed. The CHS advocated for Hemophilia Treatment Centres (HTCs) with a comprehensive care team including the professional roles of hematologist, nurse, physiotherapist, and social worker.

The physical and emotional toll of this rare disease on patients has required support from the HTCs, while treatment, outcomes, and professional knowledge continue to evolve (Konkle, 2012; Witkop et al., 2012; WFH, 2020). Patients have identified pain management within bleeding disorders as a concern requiring further support (Barlow et al., 2007; Forsyth et al., 2013; Lambing et al., 2017; Witkop et al., 2012). The study and research of pain management itself is rapidly developing and professionals have a responsibility to provide up-to-date pain management with their patients. Pain management in bleeding disorder care requires further development and recognition among HTCs including the of social work role.

The purpose of this research was to examine current understanding of pain management for patients among Canadian Social Workers in Hemophilia Care (CSWHC). Two studies were developed to explore this area of practice and are described in this thesis. The first study is a scoping review of the current literature. The research question is: What do social workers currently contribute to pain management in patients at risk of pain with chronic disease? The second study details the interviews of 12 social workers in Canada who work within bleeding disorders care. The research questions for the second study were: 1) What do social workers in

the CSWHC currently understand about pain and bleeding disorder care and their practice? 2) What specific pain knowledge and training is prioritized by social workers in the CSWHC? These interviews were analyzed using thematic analysis (Braun & Clarke, 2006; Nowell et al., 2017) and four themes were identified. In the final discussion of this thesis, a link between the two studies is made with further elaboration on the role of social work including research, advocacy, and policy development.

## **1.2 Bleeding Disorders and Underlying Pain Mechanisms**

Bleeding disorders are rare genetic conditions with Hemophilia A affecting approximately 2500 people and Hemophilia B affecting approximately 600 people in Canada (CHS, 2018b). Hemophilia is an X-chromosome linked disorder impacting males as well as female carriers (Bolton-Maggs & Pasi, 2003; James, 2010; Peyvandi et al., 2016). Female carriers may have bleeding symptoms although they often do not receive a specific diagnosis of hemophilia (Bolton-Maggs & Pasi, 2003; James, 2010). Severity in hemophilia is typically classified by factor levels: mild (6-40%), moderate (2-5%) and severe (<1%) (Bolton-Maggs & Pasi, 2003; Mannucci & Tuddenham, 2001). In the past hemophilia A and B have made up the majority of the population receiving care in the HTC. Recently other bleeding disorders have been recognized and are increasing in the HTC in diagnosed numbers (WFH, 2020).

von Willebrand Disease (vWD), platelet function disorders, and factor deficiencies are also classified as bleeding disorders, which are typically treated within Canadian HTCs. Not specifically tied to the X-chromosome (Mannucci & Tuddenham, 2001) these types of bleeding disorders will affect both men and women in similar severity. Women will experience more symptoms based on menorrhagia, pregnancy, and childbirth (James, 2010), while men and women may require treatment for dental procedures or surgery based on the severity of the diagnosis (Rodeghiero, 2002). Bleeding disorders result in decreased activity of clotting factor or platelets leading to ineffective blood clots and increased bleeding tendency factor (Peyvandi et al., 2012; CHS, 2018b).

Severe hemophilia often results in hemarthrosis or bleeding episodes within joints, muscles, internal bleeds or head bleeds causing concern for severe and permanent injury or death when factor replacement therapy is not utilized to control the bleed (Bolton-Maggs & Pasi, 2003; CHS, 2012; Rambod et al., 2016; Young et al., 2014; Peyvandi et al., 2012). These types of bleeds frequently cause increased swelling and pressure at the site resulting in acute pain



(Bolton-Maggs & Pasi, 2003; Hemophilia Federation of America [HFA], 2020; CHS, 2012). A significant bleed or several bleeding episodes in the same joint can lead to synovitis where blood damages the cartilage lining in the joint causing the bones to sit against each other (Bolton-Maggs & Pasi, 2003; CHS, 2010; HFA, 2019; Peyvandi et al., 2012). Damage to the synovial tissue may also occur at the same time as arthritis; chronic pain may develop with inflammation or damage to the cartilage and bones within a joint (Bolton-Maggs & Pasi, 2003; CHS, 2010; Peyvandi et al., 2012; CHS, 2012; Young et al., 2014). Joint disease is one of the most common complications of hemophilia often resulting in surgery at a young age (CHS, 2018c; Rambod et al., 2016; Young et al., 2014).

The impact of bleeding episodes on the physical and emotional health of patients requires acknowledgement, even more so with emerging evidence of decreased pain modulation within this population.

**1.2.1 Consideration of endogenous pain modulation for bleeding disorders.** Beyond the discussion of acute and chronic physical pain resulting from bleeding episodes, the impact of endogenous pain modulation requires awareness and consideration. The endogenous pain system is a component of the central nervous system (CNS), which allows the individual to adapt to their environment by applying inhibitory or excitatory modulation that may increase or decrease pain experiences (Roussel, 2018); modulation of inputs through the CNS is, in part, influenced by the attention and expectations of the person experiencing pain (Roussel, 2018). Recent findings by Kruger & Hilberg (2020) provide evidence that people with hemophilia (PwH) exhibit decreased functioning in descending pain inhibition modulation. PwH may experience higher subjective levels of pain accordingly, and the authors suggest that psychological pain intervention is beneficial in the overall management of pain (Kruger & Hilberg, 2020; Roussel, 2018; Young et al., 2014). In recent reports approximately 40-60% of patients described their pain as not well-controlled or well treated (Rambod et al., 2016; Witkop et al., 2012; Young et al., 2014) and reported areas in which they would benefit from further pain management including increased non-pharmacological methods (Buckner et al., 2016). The impact of bleeding episodes and the response of the endogenous pain modulation is not limited to one specific time during a lifespan. Rather, pain episodes occur throughout the lifespan of a PwH and requires different care at different stages.

**1.2.2 Management of pain and bleeding disorders throughout the life span.** People with bleeding disorders (PwBD), young and old, experience both acute and chronic pain despite the current prophylaxis treatment available (CHS, 2018a; Penica & Williams, 2008; Rambod et al., 2016; Young et al., 2014). Pain is associated with intravenous interventions of factor replacement therapy for pediatric patients (Penica & Williams, 2008). It is necessary for pediatric teams and parents to help children with bleeding disorders manage acute pain resulting from bleeding episodes and needle pokes as these can significantly impact the subjective experience of pain in the future (Cassis et al., 2012; Young et al., 2014). Due to the genetic component of the disease most patients are aware of the diagnosis at birth; however, approximately one-third of patients have no previous history (Bolton-Maggs & Pasi, 2003; Lillicrap, 2010). Either way, children are at risk of experiencing untreated bleeding episodes during developmental phases of crawling, walking, and running with unintended falls (Bolton-Maggs & Pasi, 2003; Rivard et al., 2010). Untreated bleeds increase the risk of developing chronic pain as previously described and requires assistance from the HTC in the identification of a diagnosis and regular treatment.

As treatment has become broadly accessible over the past fifty years in Canada, the lifespan for people with severe bleeding disorders has also increased. Early death was common before prophylaxis and on-demand treatment being available (Konkle, 2012; Witkop et al., 2012; WFH, 2020). The increased availability of factor replacement therapy has modified the prognosis for PwH who now reach normal life expectancies requiring new considerations in health management (Cassis et al., 2012; Konkle, 2012; Smith et al., 2014; Witkop et al., 2012; WFH, 2020). Therapeutic uncertainties for older PwBD now include the management of age-related comorbidities such as cardiovascular disease, osteoarthritis, chronic pain, and cancer along with the treatment and management of the bleeding disorder (Konkle, 2012; Witkop et al., 2012).

Professionals in the HTC require pain education tailored to respective life stages in order to provide essential care requirements (Krueger & Hilberg, 2020; Rambod et al., 2016; Witkop et al., 2012; Young et al., 2014). To meet this challenge, education on pain and bleeding disorders requires attention from members of the HTC.

**1.2.3 Studies examining pain experiences in bleeding disorder populations.** There are four seminal studies that contribute to the current discussion of pain management among the bleeding disorder population and supports the further exploration of the roles for pain

management within HTC's. These include one international study, a study from the United Kingdom, and two studies from the United States of America. They report the patient experiences of pain and pain management.

**1.2.3.1 The HERO Study.** Patients with bleeding disorders described the ways in which pain affected their quality of life (QoL) in the Haemophilia Experiences, Results, and Opportunities (HERO) study (Forsyth et al., 2013). This study specifically explored the psychosocial impact of bleeding disorders on the QoL of 561 pediatric and 675 adult respondents in two online surveys across ten countries (including Canada). The questionnaires included over 100 questions from validated questionnaires, multiple choice, and rating scales. Pediatric (< 18 years of age) patient surveys were completed by parents of children with hemophilia. The QoL indicators included "relationships, sexual intimacy, quality of life, barriers to treatment and sources of information" (Forsyth et al., 2013, p 44). Descriptive statistics were used to analyze the questionnaires and focused on identifying trends throughout the data.

Of the adult population 38% of PwH A, 42% of PwH B reported chronic pain as a direct result of hemophilia (Forsyth et al., 2012). This group also reported comorbidities of arthritis (PwH A 48%; PwH B 55%), and psychological conditions of depression, anxiety, stress, or fatigue related to hemophilia (PwH A 28%; PwH B 33%) (Forsyth et al., 2012). It is important to note that there was no discussion concerning pain in the pediatric population although inhibitors and bleeding episodes (52%) were noted as significantly impacting parental time off work (Forsyth et al., 2013). The lack of data on pain in the pediatric population does not allow us to understand the impact of pain on QoL.

**1.2.3.2 The National Pain Study.** The National Pain Study, conducted in the United States, aimed to investigate the use of pain language, pain management strategies, and QoL for PwBD. Respondents included 764 persons with hemophilia A or B (Witkop et al., 2012). The study used prospective descriptive data, which participants provided by website or phone call.

Poorly controlled pain was reported by 39% of participants with an average acute care pain score associated with a bleed of 5.97/10 and an average persistent pain score of 4.22/10 (Witkop et al., 2012). The participants used pain descriptors such as throbbing, aching, sharp, tender, and miserable (Witkop et al., 2012). Acute pain (due to a specific bleed) and chronic pain (lasting more than six months) presented in 39% of participants who reported that "their pain was not well treated" (Witkop et al., 2012, p e115). The authors report that 59% of HTCs are

providing primary pain management for patients and indicate a call to action for further professional development in pain management (Witkop et al., 2012). The type of pain management provided for patients is not described and it is noted that HTC's did not see pain management as part of their role (Witkop et al., 2012). There is a discrepancy between providers and patients on pain management within the HTC, however, the authors note that providers ought to move in this direction.

**1.2.3.3 A survey of self-management needs.** The third study reviewed was a survey of 307 members of the UK Hemophilia Society with the aim to understand self-management among PwH (Barlow et al., 2007). Paper questionnaires were sent to members and returned to the society or the research team. The majority of participants indicated a diagnosis of hemophilia A (66%) (Barlow et al., 2007). Descriptive statistics were used to analyze the data.

Worry, depression, and stigma were reported as psychological concerns (32%) and participants reported the need for education and training in these areas (Barlow et al., 2007). Participants indicated a desire for information about joint damage (48%), getting the most from health care visits, managing fatigue, drug treatments, and bleeding disorder (33-36%) (Barlow et al., 2007). At the same time, 35% of respondents wanted more information about managing pain (Barlow et al., 2007), noting they would prefer medical information face-to-face with their health care provider.

**1.2.3.4 Patient, caregiver, and provider perceptions of pain and pain management.** The final study being examined is focused on teens and young adults age 13-25 with data obtained from the *Interrelationship Between Management of Pain, Adherence to Clotting Factor Treatment and Quality of Life* (IMPACT QoL) study (Lambing et al., 2017). There were 89 participants who had a diagnosis of Hemophilia A or B or vWD. This study aimed to examine the similarities and differences between patients, caregivers, and health care providers on the perception of pain and pain management. Measurements for acute and chronic pain, medicinal, and non-pharmaceutical interventions were statistically analyzed for distribution and between-group correlations (Lambing et al., 2017).

The results from this study indicated disagreement between patients, caregivers, and health professionals of pain levels and perception of pain as well as effective pain management (Lambing et al., 2017). Patients also indicated that regardless of prophylaxis treatment beginning at a young age they continue to experience chronic pain (Lambing et al., 2017). Lambing et al.,

(2017) recommend that health care providers need to initiate discussion about pain with their patients. As discussed in the next section prophylaxis treatment is highly recommended, however, it does not preclude chronic pain from developing and being managed by the patient and health care professionals.

These four studies indicate that pain management has been a concern of PwH and the necessity of bleeding disorder care providers to address these concerns. Subsequent is a discussion of best practices for the management and treatment of bleeding disorders.

**1.2.4 Best Practices for the Treatment of Bleeding Disorders.** Conventional treatment for bleeding disorders initially involved substitution therapy (whole blood or fresh frozen plasma) and specific factor concentrate (CHS, 2010; Peyvandi et al., 2016; Sankar et al., 2019). The development of third-generation products no longer required additional animal or human proteins, having alleviated the risk of infections similar to the Tainted Blood Tragedy (Sankar et al., 2019). This treatment is available for patients in Canada as a home-treatment therapy where patients self-infuse. Treatment schedules for patients can be as frequent as daily infusions for patients with severe hemophilia A or several times a week for severe hemophilia B patients (Sankar et al., 2019). For pediatric patients treatment is often administered through a surgically placed implantable venous access device (Bollard et al., 2000). Prophylaxis treatment refers to regular factor replacement therapy regardless of physical injury in attempt to prevent bleeds from occurring (Sankar et al., 2019). While individualized prophylaxis treatment has been available, real-life events will, at times, prevent prophylaxis treatment from taking place (CHS, 2018a; Lambing et al., 2017; McLaughlin et al., 2014). Events that may prevent prophylaxis from taking place include early morning rush, needle fatigue, difficulty accessing the port or vein, not having enough factor replacement at home, and other life stresses (Hacker et al., 2001). When prophylaxis or treatment of bleeding episodes is delayed the risk for tissue damage from excessive bleeding increases. Current treatment protocols have decreased the prevalence of severe joint damage, yet even with regular prophylaxis treatment Sankar et al. (2019) report that complete prevention of pain and joint damage is not a feasible expectation. This can be attributed to unknown factors including breakthrough bleeds, inhibitors, or inconsistent prophylaxis treatment (Sankar et al., 2019).

The application of prophylaxis treatment in the prevention of bleeds is a high priority for providers, however, pain knowledge and management are equally necessary for optimal

management of bleeding disorders (Krueger & Hilberg, 2020; Roussel, 2018). Further to the pharmaceutical treatment of bleeding episodes and the dedication to the prevention of bleeds, comprehensive care teams play a significant role in best practice when working with PwBD. The CHS has encouraged HTC across Canada to develop and maintain a comprehensive care team, which includes at minimum, a hematologist, nurse coordinator, physiotherapist, and social worker. Within the Standards of Care "[c]omprehensive care is the recommended method of care delivery, enable people with inherited bleeding disorders to have access to effective and expert health care." (Canadian Hemophilia Standards Group, 2007, p. 6). This same document encourages practitioners to manage "all aspects of bleeding episodes" (Canadian Hemophilia Standards Group, 2007, p. 7) as well as to advocate and support self-determination in patients' health care decisions. Bleeding episodes must receive appropriate management at the time of the injury from the comprehensive care team. An essential role of the HTC and comprehensive care team in this discussion includes the multidimensional nature of pain as well as appropriate pain management strategies (CHS, 2012).

### **1.3 An Overview of Pain Management**

It is imperative to have a working definition and understanding of pain when considering pain in bleeding disorder care. The definition of pain by the International Association for the Study of Pain (IASP) is applied and used for the duration of this thesis as provided in Manuscript B. The definition of pain based on the IASP definition does not require actual tissue damage to occur for a person to experience pain. Peripheral needle pokes, procedures, hemarthrosis, and synovitis have the potential to contribute to the pain experienced by the patient; however, the anticipation of these incidents can also have a significant impact on pain encounters. Anticipating injuries and treatments may increase stress, which in turn may increase the unpleasant perception of the pain experience (van Hecke et al., 2013; Hruschak & Cochran, 2017; Therivel, 2017). These events are subjective and require an individualized approach in pain management from a multidisciplinary team (The Canadian Pain Task Force, 2019). Further to this, the role of social work in psychosocial intervention for assessment and treatment of chronic pain requires consultation with patients of their current situation and interventions with the appropriate professional skill (Cassis et al., 2012; IASP, 2017; Young et al., 2014).

The type of pain experienced by PwBD requires specialized management by the HTC. The prevention of pain or the use of adequate management of acute pain has the potential to alter

future chronic pain (Borsook et al., 2018). Chronic pain may alternatively influence genetics/epigenetics, mental health, QoL, demographics, and neural connections, which requires professionals to develop tools to support patient self-management (Borsook et al., 2018; van Hecke et al., 2013). To determine the impact of chronic pain on a patient, a detailed chronic pain assessment including “domains, such as psychological and physical functioning and quality of life” is required (Fillingim et al., 2016, p. T11). The impact of pain on the physical body, emotional and mental capacities, families and productivity, have a bearing on QoL for patients (Cassis et al., 2012; Forsyth et al., 2013; Penica & Williams, 2008; Smith et al., 2014; Young et al., 2014). The development of professional skills in the best practices of pain management have an impact on patient QoL.

**1.3.1 Best practices in pain management.** Recommendations for general interdisciplinary pain management teams follow a similar requirement of HTC teams. DeBar et al. (2012) state at minimum a team consists of "physicians, behavioural specialists, nurse case managers, and physical therapists to help patients develop the skills to actively self-manage their conditions" (p. 523). Scascighini et al. (2008) also describes the minimum treatment standard for pain as:

individual exercising, regular training in relaxation techniques, group therapy led by a clinical psychologist (1.5 h) per week, patient education sessions once a week, two physiotherapy treatments per week (CBT) for pacing strategies, medical training therapy and neurophysiology information given by a trained physician. (p. 676)

These types of interventions describe medical/pharmacological and non-pharmacological treatments. Jensen (2011) further describes non-pharmacological treatments to include hypnosis, relaxation training, mindfulness, operant treatment, exposure, motivational interviewing, cognitive behavioural therapy (CBT), and acceptance and commitment therapy (ACT).

Current documentation in Canada shows that professionals are not receiving pain education and that the minimum standards for patients to access appropriate pain services are not met (The Canadian Pain Task Force, 2019).

Although the CHS and research identify the significant impact of pain on patients, pain assessment and knowledge are limited in other countries with limited understanding in Canada (Buckner et al., 2016; Lambing et al., 2017; Rambod et al., 2016). Pain education for HTC professionals would assist in pain assessment and management by the comprehensive care team

and would likely increase appropriate referrals of patients with complex pain management needs to pain clinics. A referral to an interdisciplinary pain clinic is ideal for those with complex pain that does not respond to approaches delivered through primary care and the HTC; however, not all HTCs have access to pain clinics or the waitlist is lengthy (The Canadian Pain Task Force, 2019). Patients are provided regular appointments in the HTC and the team has the potential to bridge this gap as pain resources are being developed. Within the HTC, social workers have a role to play in advocating for the appropriate pain services to meet best practices.

**1.3.2 Exploring the social work role in pain management.** Social workers have a critical role in pain management, specifically in non-pharmacological approaches due to the nature of pain and the impacts it has on QoL and domains of living. The IASP (2017) recognizes that "[b]ecause pain is the most common reason a person seeks clinical care, and social workers are present in a variety of clinical settings, social workers are well-positioned to identify patients' unique needs when versed in pain's presentation and impact" (IASP, 2017). Further to this, the National Association of Social Workers (NASW, United States of America) indicates the social work role can include "multidimensional approaches to prevent and alleviate pain, helping individuals to advocate for effective pain care, and helping other disciplines to understand ...unique biopsychosocial environment" (NASW, 2017, p.1). This policy indicates there are roles in every area of practice and not specifically in specialized pain clinics. Social workers with training in pain assessment and management are positioned to support, refer, and advocate for patients. As examined in the literature and the thematic analysis of social work interviews conducted for this thesis, social workers offer three interventions in practice for pain management: instrumental services, counselling services, assessment. Further to this, Hruschak & Cochran (2017) affirm that the services social work provides "ought to address psychological and sociocultural factors in addition to biomedical or physiological aspects of chronic pain" (p. 582).

The Canadian Association of Social Workers (CASW) asserts the "profession has a particular interest in the needs and empowerment of people who are vulnerable, oppressed, and/or living in poverty" (CASW, 2005, p. 3). The Canadian Pain Task Force (2017) affirms that pain typically occurs among those who are more vulnerable including those who are ageing, children, women, and some ethnic groups. Pain has the potential to affect QoL in multiple areas and to be diagnosed as comorbidity; knowledge and competence in pain management require



further development within the profession. Considering that pain and stressors create a multidimensional effect (Duenas et al., 2016; Reddan & Wager, 2019; van Hecke et al., 2013), social workers are uniquely positioned to assist in the alleviation of stressors, which have a direct impact on the pain experience (Hruschak & Cochran, 2017).

The fundamental principles for social work in this discussion of pain management must be included; advocacy and policy development are core issues in social work and understated in the literature. Browne et al. (2017) express the requisite for social workers to assume these roles asserting that health inequities remain in place and require attention. Advancement in advocacy and policy development has the potential to shift the current state of pain management. Specific to pain management, the IASP (2017) curriculum outline includes four ethical principles, two of which are access to care (political, policy, public health, and regulatory factors) and advocacy. Social work has a unique role to play recognizing macro, mezzo, and micro systems of care (Social Work License Map, 2020). Macro social work encompasses research, community initiatives, policy and advocacy (Social Work License Map, 2020). Social work that focuses on mezzo systems include neighbourhoods, schools, hospitals and prisons while the focus of micro social work is on individual care and support including families (Social Work License Map, 2020). While pain management at first glance appears to be an individual micro concern the far-reaching impacts include family systems, work and community resources as well as the cost to society and the health care system indicating pain truly is a macro, mezzo, and micro. These issues require advocacy for social change and assisting individuals to self-advocate within the system.

#### **1.4 Multidisciplinary Teams and the Role of Social Work**

Best practice frameworks for pain management and bleeding disorder care both recommend a multidisciplinary team. According to Craig et al. (2016) patients report they require “practical guidance and emotional support” (p. 52) and that the social work role is able to provide this support. For the purpose of this discussion it is necessary to understand the differences between multidisciplinary and interdisciplinary teams and to examine the social work role among these teams.

**1.4.1 Multidisciplinary and interdisciplinary teams and function defined.** The application of terminology for multidisciplinary and interdisciplinary teams are at times unclear and are often used interchangeably. Choi & Pak (2006) suggest these terms are on the same

continuum and include a third term; transdisciplinary. These terms describe the involvement of professionals working together at differing levels of contribution in decision making for health care services (Choi & Pak, 2006). On the continuum of teamwork, at minimum a multidisciplinary team works side-by-side while maintaining professional boundaries (Choi & Pak, 2006). Multidisciplinary practice typically means that different professions work with the client simultaneously, yet independently, with little communication, coordination of care, or shared care planning taking place between different providers. The interdisciplinary team narrows the focus and the team works to harmonize and coordinate services as a group (Choi & Pak, 2006). Moving beyond these two commonly used terms, transdisciplinary teams remove boundaries between roles and promotes and supports the full integration of team members where members can step in for each other when required (Choi & Pak, 2006).

The function of these teams has been explored by Best and Williams (2019) who indicate several areas of awareness required for team development. The recommendations from Best and Williams (2019) were based on a scoping review examining “the area of research connecting professional identity and interprofessional teams” (p. 171). The scoping review examined teamwork between doctors, nurses, social workers, and many other health care professionals (Best & Williams, 2019); the professions included in the scoping review are similar to the recommendation for both pain and bleeding disorder multidisciplinary professionals. Well-functioning multidisciplinary teams encourage members to engage with open-mindedness, build trust, and develop active engagement in the process (Best & Williams, 2019). Leadership in both planning and reporting benefits is recommended as well as persistence during the pains of growing a team (Best & Williams, 2019).

**1.4.2 The social work contribution within teams.** An excellent example of interdisciplinary teamwork and the role of social work is described by Maramaldi et al. (2014). In this framework, the individual role of social work practices “360 screening” by taking in multiple sources of information to create a full biopsychosocial assessment to determine if intervention is required (Maramaldi et al., 2014). The social work role included crisis intervention, education, psychosocial interventions, assisting with reactions and decision making, completing referrals for outside resources, and cultural awareness (Maramaldi et al., 2014). The authors promote the interdisciplinary work by stating the necessity for social workers to communicate assessment, interventions, and medical knowledge with the family and the team, to

state outcomes and goals, and to assert the role social work can provide within the team (Maramaldi et al., 2014). The authors note there is flexibility for nurses to provide psychosocial interventions if a social worker is not available (Maramaldi et al., 2014).

Craig et al. (2016) reviewed patient experience through self-reported psychosocial assessment and examined the role of social work in the interdisciplinary team. The interdisciplinary team for this study consisted of a physician and two social workers. The role of social work is described as providing practical and emotional supports, providing education for self-management, strategies, support services, and supporting informed decision making (Craig et al., 2016). Counselling services as well as referrals to community programs, assisting with communication, family interventions, and stress reduction is also noted (Craig et al., 2016). Further to the individual roles identified above, Craig et al. (2016) note the importance of coordinating supports, collaborating as a team to determine treatment goals, monitoring the current situation, and communicating to support the function of an interdisciplinary team.

It may be tempting to look at interdisciplinary teams as the gold standard of treatment and to implement them in every area of health care; however, there are several considerations to make when implementing teams. Choi and Pak (2007) discuss the use of multiple discipline teams (multidisciplinary, interdisciplinary, transdisciplinary) within health research, services, education, and policy. The areas to consider when developing a strong team can include selection of team members, maturity and flexibility of team members, personal commitment, support from institutional structure, clarity of roles, shared goals and vision, as well as communication (Choi & Pak, 2007). Poor management of any one of these areas can lead to difficulty and ineffective care.

Recommendations for pain management include the use of interdisciplinary teams and bleeding disorder care uses the term comprehensive care teams. It is difficult to assess the full expectation of how these teams should function on the continuum discussed above. For the purpose of this paper the term multidisciplinary team will be used as a minimum standard of care for each group.

### **1.5 Advocacy and Policy Development in the Role of Social Work**

Social work has an historical and present call to both advocacy and policy development; advocacy and policy development often work synergistically. Advocacy encourages change within systems and society. Advocacy appears in the form of case (individual) or cause

(community) and can be conducted with a wide variety of techniques (McNutt, 2011). In the past, advocacy focused on change outcomes for vulnerable and oppressed groups. To determine the current themes of advocacy, Brown et al. (2015) examined themes of advocacy within the NASW. The authors found that current advocacy is strongest for professional self-interest and the advancement of social work (Brown et al., 2015). Other areas of advocacy include health care, child welfare, mental and behavioural health, poverty and employment, domestic violence, homelessness and housing, elder and civil rights (Brown et al., 2015). Active advocacy is evident in contemporary practice, however, McNutt (2011) cautions against the use of interventions if they do not provide the change they are intended for based on the economic cost. The economic cost includes cost-benefit analysis, return on investment, as well as the direct and indirect consequences that may or may not be intended (McNutt, 2011). These considerations are encouraged in order to use the limited resources of social work as wisely as possible. McNutt (2011) further discusses the history of social work and economists working together in order to give greater insight into the issues and costs of advocacy.

The role of social work in policy development can work together with advocacy (Browne et al., 2017), however, these are separate processes. Policy development must include a focus on solutions that come from the population being served, efforts in prevention, and promotion of health (Browne et al., 2017). Health inequalities continue to persist and require attention by social workers in both advocacy and policy change.

The CASW body offers direction of advocacy and policy development providing a website containing a section with positional statements and letters. They also provide a list of resources for advocacy and policy development including the Canadian Public Health Association indicating the necessity of application in practice. The website does not include a clear description of advocacy or policy development or the contexts of the application of the practices.

Advocacy and policy development have a strong place in social work; however, the extent of the application in practice varies. Consideration of advocacy for appropriate pain support and policy development at a clinical level plays a role in establishing evidence-based treatment for pain care in bleeding disorder populations. Determining the current function of advocacy and policy development in the arena of pain management and bleeding disorder care is required.

## **1.6 Conclusion**

PwH have reported the impact of pain and the importance of comprehensive care teams being involved with pain management. Recommendations for bleeding disorders and pain management practice indicates at minimum a multidisciplinary team. Social work is identified in these teams and the literature suggests a role for social work in pain management with the bleeding disorders population. The social work role has a history of advocacy and policy development which requires further consideration in the scope of pain management in bleeding disorders. It is necessary to determine the current role of social work in pain management as well as what social workers in HTC's currently know and contribute to pain management in the HTC. A two-part research project was developed to explore the current literature and social work position. This research entailed a scoping review of literature addressing the role of social work in chronic pain management followed by a thematic analysis of qualitative interviews of CSWHC members.

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## **CHAPTER 2.0 RESEARCH OBJECTIVES AND METHODS**

### **2.1 Research Objectives**

The research objective was to determine the current scope of social work understanding of pain management in bleeding disorder care and future learning requirements. This research project was developed in response to patient needs identified in the HERO study (Forsyth et al., 2013) and from clinical experience within the Saskatchewan Bleeding Disorders Program (SBDP) in the development of the Pain Treatment Planning Questionnaire (PTPQ). The SBDP in collaboration with the Strategy Consultant for Pain Quality Improvement and Research developed the PTPQ (Tupper et al., 2020) to assess pain during clinical appointments. This tool aimed to improve clinical communication by reducing the number of times a patient would be required to tell their pain history to each member of the comprehensive care team (Tupper et al., 2020). Pain intensity, suffering, and management strategies are reported on the questionnaire at every patient visit and reviewed by each member of the HTC (Tupper et al., 2020). Non-pharmacological aspects of pain management are assessed on this questionnaire (Tupper et al., 2020) and are followed up by the social worker. The social worker typically responded to the PTPQ non-pharmacological interventions, however with limited training in pain management, assessing the current pain status of the patient was difficult. Based on conversations with CSWHC members, it was determined that further evaluation of the HTCs social work role in pain management was required.

These grassroots discussions led the researcher to distribute an initial survey to the CSWHC members in 2016-2017 to develop an overview of the current state of knowledge and practice of pain management. This survey consisted of a revised version of the Rehabilitation Professionals' Knowledge and Attitudes Survey Regarding Pain with follow up questions asking about current practice. The results indicated that social workers had adequate pain knowledge when answering the questionnaire; however, they were not confident in their ability to address pain within patient care and indicated further support was required. Due to the discrepancy between the questionnaire answers and the low confidence of practice in pain management, it was determined that qualitative interviews would allow the social workers to further examine

their current knowledge and practice and requirements for education; they reported interest in further development and knowledge in this area.

The researcher developed the proposal for this thesis to further explore the need for education in pain assessment and management for social workers in bleeding disorder care. To ascertain the full extent of the social work experience of knowledge in pain management, it was concluded that a scoping review of the literature and qualitative interviews with members of the CSWHC would answer the research questions. The researcher along with committee member, Dr. S. Tupper, received funding from the Canadian Hemophilia Society and Novo Nordisk Psychosocial Research grant. An ethics exemption for this project was granted by the University of Saskatchewan (U of S) Behavioural Research Ethics Board.

## **2.2 The Researcher**

The researcher is a practicing registered social worker with the SASW. The majority of her practice focused on health care, primarily in mental health followed by acute care and then chronic disease management, specifically in the Saskatchewan Bleeding Disorders Program (SBDP). Part of her role at the SBDP included membership on the CSWHC committee with a chair/co-chair role for three years. During this time working relationships were developed with other members of the CSWHC in way of joint projects and research. In 2016-2018 she was a member of a research team with two other CSWHC members conducting surveys and analysis on vocations and PwH. These pre-existing relationships were acknowledged during the recruitment stage as well as in the verbal informed consent at the beginning of the interview. Given the small community of social workers within bleeding disorder care, pre-existing relationships were unavoidable, and no participants indicated they would decline participating based on this information.

**2.2.1 The research committee.** It was imperative that the committee supporting this research and thesis was comprehensive and reflected each area being examined. This project encompassed the social work role in pain management within bleeding disorders; however, it was comprised of four elements that would all require attention: bleeding disorders, pain, social work, and research. The Health Sciences Graduate Program provided the flexibility to develop a committee that would support specialties from each of these four areas to inform the development and outcomes. Each committee member had a Ph.D. or medical degree and an appointment with a university; three members were from the U of S and one member from the

University of Regina (U of R). The committee was involved by providing direction, reviewing the research, and submitting recommendations.

Teater (2017) advocates for social work researchers to practice implementation science in which research is easily transferred to practice; this approach requires clear research definitions and aims, integration into education, accessibility of tangible research results and discussions with practitioners, and a practice-based focus in academics. In this research two of these approaches to practice implementation were clearly taken. First, the research project focused on practice and clearly identifying the objectives of the study; second the results are being shared in public journals and directly provided to the members of the CSWHC. While this research has a strong commitment to constructing an accurate representation of the social work position and presenting this to practitioners, we are unable to ascertain whether this research will impact the academic and education processes. The committee members of this research, however, are all immersed with both practice and academics suggesting there is a strong desire to apply implementation science. Supporting this, Browne et al. (2017) affirms the value of doctoral students to “work across disciplines, to integrate public health content” (p. S230) with their research. From the initiation of this project the researcher sought to integrate the knowledge of multidisciplinary professionals to reflect the nature of social work practice in HTCs.

### **2.3 Project Summary**

To identify the gaps in social work pain knowledge among CSWHC members this researcher conducted a scoping review of current literature followed by a thematic analysis of in-depth interviews with the CSWHC members. A scoping review provided the means to determine the current state of the literature and contributions of social workers in pain management in a timely and effective way while the qualitative interviews allowed the members to provide insight on their own experiences and pain knowledge and required education.

The research question identified for the scoping review was: What do social workers currently contribute to pain management in patients at risk of pain with chronic disease? Initially, this question was specific to bleeding disorders; due to the dearth of research in this specific area of practice the question was expanded to include chronic disease.

The qualitative interviews for thematic analysis were guided by the following research questions: 1) What do social workers in CSWHC currently understand about pain and bleeding disorder care and their practice? 2) What specific pain knowledge and training are prioritized by

social workers in the CSWHC? The questions sought to capture the thoughts and feelings of social workers about the current state of pain knowledge and management for the bleeding disorder patients they support. Further to this, it was essential to assess any requirement of pain education among this group.

## **2.4 Method: Scoping Review**

**2.4.1 The case for utilizing a scoping review.** The research community has scrutinized scoping reviews in their utility and function. Arksey and O'Malley (2005) outline four reasons to undertake a scoping review and for our study, we focus on the fourth reason to "identify research gaps in the existing literature" (p. 21). The authors do warn that completing a scoping review will not expose the quality of the research due to the exclusion of quality analysis of the papers (Arksey & O'Malley, 2005). This process only describes the scope of the available research (Arksey & O'Malley, 2005). A scoping review is fluid allowing researchers to revise, examine, and exchange steps as needed to generate a comprehensive review (Arksey & O'Malley, 2005). There are five complete stages required for the scoping review; however, a sixth step is optional. These five steps are: 1) Identifying the research question, 2) Identifying relevant studies, 3) Study selection, 4) Charting the data, and 5) Collating, summarizing, and reporting the results (Arksey & O'Malley, 2005). When following these steps and providing evidence for them, the scoping review "can provide a rigorous and transparent method for mapping areas of research" (Arksey & O'Malley, 2005, p. 30). The sixth step of consultation is recommended for assisting with insight and discussions that may not have arisen from the first five steps and some authors view this as an optional step (Arksey & O'Malley, 2005). Colquhoun et al. (2014) state the necessity of the sixth step to complete a scoping review. For our review due to financial and time restraints this step was not included.

In follow up to Arksey and O'Malley's (2005) method, Colquhoun et al. (2014) provided a detailed account of the process with insight to complete a scoping review with rigour. One of the recommendations is to examine the "implications of findings within the broader context...for research, policy, and practice" (Levac et al., 2010, p. 7). The research questions have a focus on breadth, not depth, which clearly defines what is being studied by the researchers. Examining potential outcomes assist in defining the question at the beginning of the project; however, due to the iterative processes, this question can be refined as needed. Levac et al. (2010) support the functional role of scoping reviews in funding, time, and resources without compromising

outcomes. The ability to provide a comprehensive review of the breadth of research requires consideration in the planning stages.

The outcomes of a scoping review are expected to produce a report of data analysis, results and implication for policy, practice, and future research (Arksey & O'Malley, 2005; Levac et al., 2010). To produce a rigorous report, Colquhoun et al. (2014) suggest using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). The PRISMA allows methodological rigour and quality to be assessed in the scoping review itself. The PRISMA-ScR (extension for Scoping Reviews) (Tricco et al., 2018) was completed for Manuscript A (Appendix A).

The Canadian Institutes of Health Research (CIHR) supports the use of scoping reviews stating, "[r]eviews have always played an important role in health research and knowledge translation," (Grimshaw, 2010). The use of a scoping review to map literature, "key concepts, theories, sources of evidence and gaps in the research" (Grimshaw, 2010) is critical to acquire complete examination of the breadth of literature. Anderson et al. (2008) states a description of the development of the work overtime includes the critical theories and components involved rather than just a summary. Rumrill et al. (2010) supports the use of a scoping review to map the literature. These authors utilize a scoping review to examine the breadth of research and to examine gaps that may exist in the literature (Rumrill et al., 2010).

Scoping reviews have been prescribed rigour for the examination of literature in order to further policy development and research. The researcher and committee decided a scoping review method would provide the information required to determine the literature and existing gaps in research on the role of social work in pain management within chronic disease management.

**2.4.2 Introduction to Manuscript A.** Manuscript A details the process of the scoping review including the search terms and an expanded discussion. The search began with a narrow question of what social workers contribute to pain management within bleeding disorders. The initial search terms were explored with the assistance of the U of S Library. The first search of SocIndex included "social work" "pain/or acute pain/ or chronic pain/ or musculoskeletal pain/ or nociceptive pain" "adjustment disorders/ or Middle-Aged/ or 'Quality of Life'/or Health Status/or Stress, Psychological/or Evoked Potentials/or 'Surveys and Questionnaires'/or Adult/or social work" "Adult/or von Willebrand Diseases/ or Hemophilia A".



Initial search terms explored in MedLine search engine included "social work," describing the role in terms of community resources, individual casework, or group work to promote the adaptive capacities of individuals concerning their social and economic environments (Table 2.1). This search included social service agencies, "social work," "pain management or Pain Management," "Pain or Pain Measurement" "Pain Management/or Pain," "Hemophilia A/or Blood Platelet Disorders,/or von Willebrand Diseases", and a combination of these terms.

Search terms were examined and due to the limited results the research question was expanded from bleeding disorders to chronic disease management. Table 2.2 details the final search strategy that was used. Further details for the screening process, results, and discussion are outlined in Manuscript A.

Table 2.1 *Search Terms: Searched 1980 – November, 2020*

Data	Medline
Source/Search Strategy	Social Work/ Pain Management/ hemophilia a/ or von Willebrand diseases/ or blood platelet disorders 1 and 2 1 and 3
	SocIndex Social work practice or social work Pain management or pain relief or pain control or pain reduction 1 and 2

Table 2.2 *Screening Criteria\**

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
English language	Foreign language
Social work practice	Cancer and/or palliative services
Qualitative or quantitative studies	Opinion pieces
Published peer review articles	Massage
Community or outpatient care	Pharmacological
Impact for social workers <b>or</b> patient/client care is described	Dissertation
Psychosocial management of pain	
Acute <b>or</b> chronic pain	
<b>Minimum Criteria for Quality Assessment</b>	
Does the research explore the social work role in pain management?	
Does the research describe the methods used to examine the role?	
Does the article describe the impact for social workers? AND/OR Does the article describe the impact on patient/client care?	
Include if Yes for each question	

\*Adapted from Best and Williams (2018)

## 2.5 Method: Thematic Analysis

**2.5.1 An overview of thematic analysis.** The scoping review produced limited results with thirteen finalized papers which supporting pursuing the second stage of research for this thesis. The researcher and committee developed this research study in the form of qualitative research by semi-structured interviews of the CSWHC members. The researcher employed thematic analysis as the research method to examine the data from the qualitative interviews. Choosing a methodology to analyze the data from the interviews was motivated by the research and potential outcomes. The researcher was interested in listening to the voices of participants and drawing out their experiences. Results indicated future education development in pain assessment and management was required. Applying thematic analysis and documenting the process allowed this to progress. Braun and Clarke (2006) as well as Nowell et al. (2017) support the use of thematic analysis in its own right as an analytical method. Following the steps outlined by Braun and Clarke (2006) produced a final research project that is credible and trustworthy. Flexibility and reflexivity are the strength of this method through the documentation of the

process (Braun & Clarke, 2006). A documented thematic analysis creates the trustworthiness required to produce research that is acceptable and useful. Trustworthiness can be developed through the use of credibility, dependability, and confirmability (Nowell et al., 2017). The purpose of this section is to explore trustworthiness by detailing the framework used to guide this project.

**2.5.2 Trustworthiness through detailed framework.** The contribution to the trustworthiness of this study was the examination and detail of the research framework outlined by Braun and Clarke (2006). This framework as discussed in further detail below, includes five phases (Braun & Clarke, 2006): 1) Familiarizing yourself with your data, 2) Generating initial codes, 3) Searching for themes, 4) Reviewing themes, 5) Defining and naming themes, 6) Producing the report.

**2.5.2.1 Phase 1.** Familiarizing yourself with your data: The researcher who conducted the interviews (JK) also took brief notes of the interviews. The U of S, Social Sciences Research Laboratories (SSRL) transcribed the interviews. JK listened through the interviews and reviewed the transcriptions to meet the trustworthiness criteria (Nowell et al., 2017). The researcher (JK) then emailed each participant the original transcript for review with specific clarifying questions for each interview. Each participant responded to confirm the accuracy of the transcript and responded to any clarifying questions from the researcher. These responses were brief and considered in the full analysis; however, this information did not contribute to the thematic quotes. The second reviewer, DG, examined the transcripts at this time.

**2.5.2.2 Phase 2.** Generating initial codes: Once the researcher received consent for the transcripts, each transcript was read through a second time by JK while making notes about the data. The first reviewer made initial notes on a paper copy and proceeded to enter the data into NVivo. The first round of notes from DG was recorded in NVivo, and JK began to place the initial codes into similar groupings. The initial codes were brief descriptors of what was said by the participant and compared across all twelve of the interviews.

**2.5.2.3 Phase 3.** Searching for themes: Once the codes had been reviewed and entered into NVivo, JK, considered core concepts and tested these against the research questions.

Fourteen initial codes which were refined to seven codes during the second coding review. Reviewers excluded several possible themes as they did not contribute to the

understanding of the research questions. In line with our theoretical approach, the focus remained on how the participants answered the initial research questions.

**2.5.2.4 Phase 4.** Reviewing themes: The final development of four themes was reviewed and examined through the entire data set. Both reviewers explored the initial names for the four themes as they related to the research questions. A map outlining the interconnectedness of the themes relating to each other and the research questions evolved during the writing process following the iterative process of thematic analysis and is provided in Chapter 5.

**2.5.2.5 Phase 5.** Defining and naming themes: Reviewers developed each theme based on the research questions. The name of the themes were developed through the writing process based on the language of participants. The full research committee deliberated and made suggestions based on specific language around pain avoidance and pain ignoring, and the committee finalized the themes.

**2.5.2.6 Phase 6.** Producing the report: During the production of the report, further refinement of the themes as the cohesive meaning of the research questions emerged. The notes made during data analysis supported the writing phase. Telling a cohesive story was formed by considering the information from the data set based on the research question, which allowed the themes to reflect on the experiences of the participants. The research committee reviewed the final project for confirmation of definitive themes and articulation.

Thematic analysis was applied to the analysis of our qualitative interviews to develop themes that would speak to the research questions. To strengthen the analysis the six steps described by Braun and Clarke (2006; Braun et al., 2019) were considered. The flexibility and reflexivity in the process, as described above, provided credibility in the final report. The interviews and analysis brought some unexpected results; providing a respectful way to share the information was of utmost importance as further explained in the manuscript.

Sub-themes that did not relate to the research questions but were important as considerations were discovered in the process. A COnsolidated criteria for Reporting Qualitative research checklist (COREQ) (Appendix C) (Tong et al., 2007) was completed for Manuscript B to consider reflexivity in this qualitative research.

## **2.6 Relevance and Implications**

The subjective nature of pain requires professional expertise for effective management. Bleeding disorders are genetic and lifelong conditions with increased risk pain; this should

compel professionals in HTC's to develop knowledge and skills to assist in the pain management of this chronic condition. The multidimensional implications of pain with QoL indicate social workers have a role in assisting in pain management, yet there is a dearth of research to support the requirement. Teater (2017) describes how research must look to develop relevance for those who continue to practice the profession. The aim of this research is that it will shape the future practice of social work in HTC's assessment and management of pain.

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## **CHAPTER 3.0 MANUSCRIPT A - THE CURRENT PRACTICE OF SOCIAL WORK IN PAIN MANAGEMENT: A SCOPING REVIEW ON CHRONIC DISEASE**

### **3.1 Preamble**

King, J., Fletcher, K., Tupper, S., Brose, K., & Goodridge, D. (2021). The current practice of social work in pain management: A scoping review on chronic disease. *Social Work in Health Care*. doi: 10.1080/00981389.2021.1878318

**3.1.1 Abstract.** While social workers have the capacity and scope of practice to make a significant contribution to pain management, little is understood about how they enact these roles. The initial goal of this scoping review was to examine the role of social work in pain management specifically in bleeding disorder care. Due to lack of published data on this topic, the review goal was broadened to examine the role of social work in patients with chronic disease who are at risk for pain. Two electronic databases were searched providing a total of 13 published articles meeting the inclusion and exclusion criteria. Instrumental services, clinical services and assessments were identified as primary roles of social workers, while advocacy, policy development, education, and skills development require further exploration in the literature.

**3.1.2 Funding.** This work was supported by the Canadian Hemophilia Society CHS-Novo Nordisk Psychosocial Research Grant

**3.1.3 Keywords.** social work; pain management; psychosocial pain management; bleeding disorders; chronic illness; health care

### **3.2 Introduction**

The pain experience and psychosocial well-being of individuals living with a chronic disease can be influenced by stress, depression, or anxiety, for which trained social workers are uniquely positioned to conduct assessments and provide interventions (Hruschak & Cochran, 2017; IASP, 2017a; NASW, 2017; Therivel, 2017). The Canadian Pain Task Force (2019) has called for increased pain awareness, effective, and timely practice by way of interdisciplinary teams. To date, there has been limited investigation into how the social work role in pain management has been described in the published literature. A clear and defined role of social



work practice in pain management will support future actions in policy development, social work training curricula, and the implementation of evidence-based practice guidelines for interdisciplinary pain practice (IASP, 2017a; NASW, 2017).

Close to half of Canadian adults (44%) live with at least one chronic disease, defined as “conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both” (Centers for Disease Control and Prevention, 2019). Pain is the most common challenge that interferes with quality of life for individuals living with chronic diseases, affecting over half of people with one chronic disease and over 70% of those with two or more chronic diseases (Agborsangaya, 2013). Pain associated with chronic diseases can be episodic or persistent. Pain is defined by the IASP (IASP, 2017b) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or the description in terms of such damage”. Due to the biopsychosocial and subjective nature of pain, the emotional experience of pain must be taken into account by health care providers (Hruschak & Cochran, 2017; Pavlek, 2008).

Successful pain management for individuals living with chronic diseases usually incorporates pharmacological, psychological, physical, and self-management techniques offered within a multi-disciplinary or interdisciplinary team context (IASP, 2017a; van Hecke et al., 2013). In order for health care providers to offer effective management, each member of the interdisciplinary team must have specialized knowledge of pain mechanisms, treatment options and appropriate management. The IASP Curriculum (2017a) in Pain management outlines four key areas of knowledge development, which include: the multidimensional nature of pain; pain assessment and measurement; management of pain; and clinical conditions. While the IASP (2017a) has developed a specific educational curriculum outline for social workers, a developed curriculum is not yet available, and pain assessment and management skills have not been integrated into most traditional training curricula or post-graduate courses.

Social workers have an established role in psychosocial assessment and intervention to address stress, depression, anxiety, living conditions, work status, and social supports (CASW, 2005; Colon & Otis-Green, 2008; Mendenhall, 2003). Further to this, social workers are called to advocate and bring concerns to social action “for those who are marginalized, disadvantaged, vulnerable, and/or have exceptional needs” (CASW, 2005, p. 5). Chronic pain has the potential to place people in disadvantaged situations increasing the need for specialized intervention. As

The Canadian Pain Task Force (2019) describes, chronic pain significantly impacts not only individuals in their relationships, career and mental health, but also the broader context of community and society. For example, the National Association of Social Workers (NASW) (NASW, 2017) state that the social work role needs to use “multidimensional approaches to prevent and alleviate pain, helping individuals to advocate for effective pain care, and helping other disciplines to understand the wide-reaching effects of pain within the context of each person’s unique biopsychosocial environment” (p. 1). This indicates an opportunity to develop an effective social work role within pain management of chronic disease.

The goal of this scoping review was to examine the role of social work in pain management of bleeding disorders as described in the published literature. To provide a complete overview of the role of social work in this capacity, the search allowed a broad range of chronic disease pain management to be included. Scoping reviews provide researchers the opportunity to examine the breadth of research on a particular topic and examine gaps that may exist (Arksey & O’Malley, 2005). The utility of a scoping review according to Colquhoun et al. (2014), allows “mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge” (p. 1294). Examination of this literature will support ascertainment of gaps in practice, education, and research related to the role of social work in chronic disease pain management.

### **3.3 Methods**

The methodology for conducting this scoping review was guided by the work of Arksey and O’Malley (2005), as well as Colquhoun et al. (2014) through a framework of five steps including “identifying the research question, identifying relevant studies, study selection, charting the data, collating, summarizing and reporting the results” (Arksy and O’Malley, 2005, p 22). There is a sixth step, “consultation”, in the framework which is viewed as optional by Arksey and O’Malley (2005), but as necessary by Levac et al. (2010). The final step was not conducted due to feasibility concerns.

**3.3.1 Identifying the research question.** In order to explore the full scope of the literature the research question for the scoping review asked: What is the current role of social work in pain management of patients with chronic disease who are at risk of pain? For the purpose of this study, a social worker was defined as an individual with a bachelor’s degree or graduate degree in a program of social work and registration with a local regulatory body. Pain

management was defined as the use of treatments that work toward improving pain or quality of life (QoL) or management of pain through pharmacological, physical, psychological, and/or preventative factors (Canadian Pain Task Force, 2019; The Coalition for Safe and Effective Pain Management [CSEPM], 2019).

**3.3.2 Identifying relevant studies.** The initial exploration of the literature was conducted with an experienced university librarian, to determine the databases and search terms that would form the basis of the review. Based on this inquiry, it was determined that Medline and SocIndex were the primary databases encompassing social work and health care research relevant to this review. Search terms were agreed to by three independent reviewers (JK, DG, KF) (Table 2.2), including variations of “social work” AND “pain management” or “social work” AND “haemophilia/or blood platelet disorders/or von Willebrand diseases”. Search dates encompassed 1980 to November, 2020 for both databases.

**3.3.3 Study selection.** Screening criteria (Table 2.2) included: peer reviewed articles involving primary data collection that described social work role in pain management; conducted in outpatient or community care settings; and described impact on social workers or patient/clients. Studies were excluded (Table 2.2) if the social work role in was in cancer or palliative care, as treatment goals and outcomes in these specialized areas may differ from other chronic disease management. Opinion pieces, papers and dissertations were excluded.

The results of the search (n = 69) (Figure 3.1) were entered into an Excel document, hand screened for duplicates, and divided into two sections for abstract review. The first reviewer (JK) screened each article while the second reviewers (DG, KF) each reviewed half of the article list. Each article was reviewed in this way by two independent reviewers. Following the abstract review, the articles were exchanged between the second reviewers for the full article review. Once the review process was complete, consensus was reached through discussion based on the criteria for inclusion/exclusion/minimum criterion (Table 2.2) for the articles that were unclear. Beyond the inclusion and exclusion criteria, an assessment checklist for minimum criterion was created by the reviewers. Reliability in the review and acceptance of articles between the three reviewers was established with the development of three minimum criteria questions answered with a YES, NO, Undetermined (Table 2.2). In the title and abstract review if the article was Undetermined it moved to the full article review. For the full article review all three questions required a YES to be included in the final selection.

Once the articles were selected the first reviewer (JK) and second reviewer (DG) completed a hand search of articles listed within the references of the included articles. This produced an additional two articles that were included in the final number (See Figure 3.1).

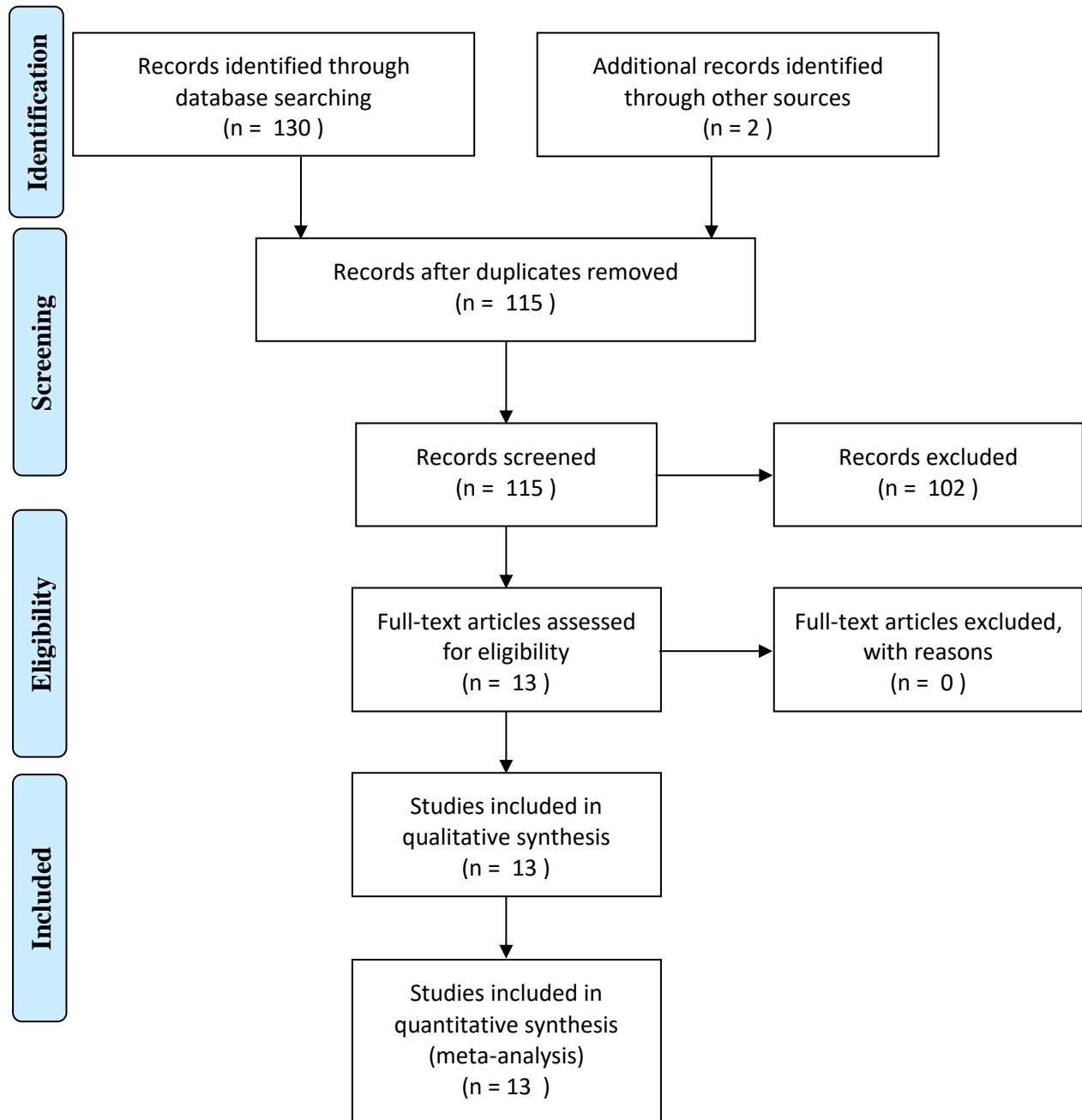


Figure 3.1 Prisma Statement \*

\* Adapted from Moher et al., 2009

**3.3.4 Quality assessment.** Quality appraisal was not undertaken as our main objective was to map the entire scope of the literature. Arksey and O'Malley (2005) state the quality of included articles is not considered in a scoping review; Daudt et al. (2013) strongly recommend assessment for quality based on their experience if the study will “provide research that in itself can be disseminated to others in a way that is useful to practice or policymaking and for future researchers” (p. 5-6). For the purpose of this study, all articles that met the eligibility criteria were included.

### **3.4 Results**

The initial search process yielded 69 articles from SocIndex, 25 articles from Medline (social work and pain) and 11 articles from Medline (social work and bleeding disorders) (Figure 3.1). Two review papers were hand searched and included following discussion between the reviewers, one based on a retrospective chart review and the second a review of randomized control studies. The full text review produced thirteen final articles (Table 3.1) represented in qualitative (n = 4), quantitative (n = 4), mixed methods (n = 3), and review (n = 2) (Table 3.2).

Table 3.1 *Summary of papers meeting inclusion criteria*

Paper Title	Year	Author(s)	Study populations	Aim of the paper	Methodology	Key Findings	Country
“It has changed my whole life”: The systemic implications of chronic low back pain among older adults	2018	Stensland, M.L., Sanders, S.	Over 65 years of age (n=21) participants recruited from five pain clinics	Study seeks to contribute to improved insight into chronic lower back pain and its multi-dimensional consequences among older adults	Qualitative	Social workers can better understand the impact of CLBP in older adults - in essence, it changes their whole lives	USA
A psychoeducational relaxation group for pain and stress management in the nursing home	2004	McBee L., Westreich L., Likourezos A.	Nursing home residents with chronic pain and stress n=14 Median age 85 years	Identify the social work role for assisting frail elderly residents focus on strengths	Mixed methods	Residents reported decreased pain and stress. Techniques were used in day to day situations to help reduce stress	USA
Acceptance and commitment therapy for psychological and physiological illnesses: a systematic review for social workers	2011	Montgomery, K.L., Kim, J.S., Franklin, C.	Systematic review of outcome studies (RCTS) on acceptance and commitment therapy	Identify basic premise of ACT approach with social workers and to identify the extent of ACT utilized in psychological health concerns	Systematic review	ACT has been the subject of several promising research studies, the subject of several promising research studies	USA
Anti-oppressive practices with chronic pain sufferers	2008	MacDonald J.E.	Six women from helping professions who had worked with chronic pain and also had experienced chronic pain for at least two years	The stories of women in the helping profession informing ant-oppressive approach to social work	Qualitative	Emotional supportive approaches were required for treatment and care. Education is vital to treatment. Policy must be addressed	Canada

Attitudes toward and knowledge of chronic pain: a survey of medical social workers	1996	Sieppert, J.D.	Sample taken from the Canadian Association of Social Work Administrators in Health Facilities CASWAHF - list of 293 departments were identified	Medical social worker attitudes in the management of chronic pain	Quantitative	Social workers state they need more information on social work role in chronic pain and they want more non medical information on the management of chronic pain for their own practice Current training is lacking and required for required to treat issues associated with chronic pain	Canada
Long-term follow-up of a structured group treatment for the management of chronic pain	1994	Subramanian, K.	Original Study: 39 participants randomly assigned to treatment or wait list control groups (n=19; n=20)	To contribute to long-term follow up data on cognitive-behavioural management of pain	Quantitative	SIP showed long term results continued to move toward baseline but with a nonsignificant result.  POMS depression scale was most significant	USA
Nonpharmacological pain management by ethnically diverse older adults with chronic pain: barriers and facilitators	2013	Park, J., Hirz, C.E., Manotas, K., Hooyman, N.	Older adults registered in the Healthy Aging Research Initiative (HARI) who met criteria for chronic pain (44 interviews)	To explore participant's (individuals living with chronic pain (non-cancer)) experiences with barriers to/facilitators for non-pharmacological treatment of chronic pain	Qualitative	Social workers have an important role in reducing barriers and facilitating appropriate interventions for this population	USA

Pain management treatment: a 2-year follow-up study	1988b	By: Subramanian, K., Rose, S.D.	39 patients with chronic pain - age? 18, pain 6 months+, no serious medical or psychological problems, no immediate plans for surgery	Hypothesis: clients in treatment would improve more on dependent measures than wait-list; clients would improve more pre-test to post-test; clients in treatment would maintain post-test improvements at the 6 month follow-up	Quantitative	Significant improvement in physical and psychosocial dysfunction and negative mood states; severity of pain reduced; treatment gains maintained at 6 months. Older people did as well as younger	USA
Patients referred from a multidisciplinary pain clinic to the social worker, their general health, pain condition, treatment and outcome	2010	Aho H., Kauppila T., Haanpaa M.	55 patients referred to the social worker in pain the pain clinic (during this time a total of 556 patients were referred to the clinic)	Identify the type of chronic pain conditions of patients referred to social workers	Quantitative	Musculoskeletal conditions; neurological diseases, mental disorders, miscellaneous conditions	Finland
Social work and the treatment of chronic pain	1988a	Subramanian, K., Rose, S.D.	21 people with chronic pain (>6 months) with either a self-referral or physician referral	To develop and evaluate explicit social work interventions for chronic pain	Mixed Methods	CBT group reduced physical and psychosocial dysfunction significantly more  Pain on three scales was decreased significantly by the CBT group	USA
Social work perceptions and observations regarding men's management of hemophilia and use of community based support	2015	Rolstad, E.B.	Social workers (n=16)	Explore challenges, adaptations and needs of men with hemophilia from SW perspectives	Qualitative	Men have conflicting feelings about available medical and social services	USA



Structured group work for the management of chronic pain: an experimental investigation	1991	Subramanian, K.	39 outpatients with chronic pain wither self-referred or referred by a physician  over 18 years of age  pain for more than 6 months	To provide a methodologically sound treatment outcome study and to develop a model of research	Mixed methods	SIP pre and post-test for those who received treatment 60% improved, 20% did not change 20% got worse  POMS pre and post indication 73% improved 27% got worse	USA
Traumatic exposure history as a risk factor for chronic pain in adult patients with sickle cell disease	2016	Works, T., Jones, S., Grady, J., Andemariam, B.	Patients with sickle cell disease who presented for medical evaluation	To review charts after the integration of an LCSW to better understand risk factors for chronic pain in adults with SCD	Retrospective chart review	Connection of trauma and chronic pain	Review USA

Table 3.2 *Summary of Findings*

	Methodology				Interventions		
	Qualitative	Quantitative	Mixed Methods	Review	Instrumental	Clinical	Assessment
Aho et al. (2010)		•			•	•	•
MacDonald (2008)	•				•		•
McBee et al. (2004)			•		•	•	•
Montgomery et al. (2011)				•		•	
Park et al (2013)	•				•	•	•
Rolstad (2015)	•				•		•
Sieppert (1996)			•		•		•
Stensland & Sanders (2018)	•				•	•	•
Subramanian & Rose (1988a)		•				•	•
Subramanian & Rose (1988b)		•				•	•
Subramanian (1991)		•					•
Subramanian (1994)			•			•	•
Works et al. (2014)				•	•	•	

The methodologies identified in the qualitative studies were grounded theory (n = 2), phenomenology (n = 1), and narrative (n = 1). Five studies were published prior to 2000, two studies published between 2000-2009 and six studies published in or after 2010. The studies took place in USA (n = 10), Canada (n = 2), and Finland (n = 1). The total number of patient participants were n = 271 and social work participants were n = 228. The two studies that conducted follow up to the Subramanian & Rose study (1988b) and Subramanian (1991) study, were not added to the final number of participants as these included the same participants as reported by Subramanian & Rose (1988a). Due to the nature of the scoping review by

Montgomery et al., (2011), the total number of participants were not included. In this review four studies were directly related to chronic pain with n = 230 patients (Montgomery et al. 2011).

Three areas of practice in which social workers contribute to pain management intervention were noted in the results. The three areas of practice included instrumental services, clinical services, and assessment of pain outcomes as described below. Social workers provided instrumental services to patients experiencing pain through provision of health management/referrals (Aho et al., 2010; Park et al., 2013; Rolstad, 2015; Sieppert, 1996; Stensland & Sanders, 2018; Works et al., 2014), transportation (Park et al., 2013; Works et al., 2014), education (MacDonald, 2008; McBee et al., 2004; Park et al., 2013; Rolstad, 2015; Stensland & Sanders, 2018; Subramanian, 1994), housing (Park et al., 2013), career/work(Stensland & Sanders, 2018). While clinical services provided to patients in pain management included one-on-one counseling (Aho et al., 2010; Park et al., 2013; Stensland & Sanders, 2018; Works et al., 2014), group work with a focus on relaxation, cognitive restructuring, assertiveness training (McBee et al., 2004; Subramanian, 1988a; Subramanian & Rose, 1988b), and Cognitive Behavioural Therapy (CBT) (Subramanian & Rose, 1988a) or Acceptance and Commitment Therapy (ACT) (Montgomery et al., 2011). Assessment tools used by social workers to examine outcomes in these studies included Sickness Impact Profile (SIP), Profile of Mood States (POMS), the Visual Analogue Scale (VAS) (Subramanian, 1988a; Subramanian & Rose, 1988b; Subramanian, 1991; Subramanian, 1994), the Coop Inventory (McBee et al., 2004), as well as self-reports of pain treatment, interviews and questionnaires (MacDonald, 2008; Park et al., 2013; Rolstad, 2015; Sieppert, 1996; Stensland & Sanders, 2018). All three interventions identified (instrumental, counseling, assessment), were utilized in four of the studies (McBee et al., 2004; Park et al., 2013; Stensland & Sanders, 2018; Subramanian, 1994). Two of the interventions were applied in eight of the studies (Aho et al., 2010; MacDonald, 2008; Rolstad, 2015; Sieppert, 1996; Subramanian, 1991; Subramanian & Rose, 1988a; Subramanian & Rose, 1988b; Works et al., 2014) while one study reported the use of one intervention (Montgomery et al, 2011).

Twelve of the thirteen studies argued for the importance of strengthening the social work role in pain management. Social work skill and development in pain management was discussed in seven of the studies. This included the need for further pain education (MacDonald, 2008; Sieppert, 1996), identifying the role and the types of barriers to interventions (MacDonald, 2008;

Park et al., 2013; Rolstad, 2015; Sieppert, 1996), examining emotional supportive approaches and policy changes for improved patient outcomes (Stensland & Sanders, 2018), the use of ACT for pain management (Montgomery et al., 2011), and increased knowledge of the impact of pain on patients (Stensland & Sanders, 2018; Works et al., 2014). Advocacy was mentioned as part of the role in three of the studies (MacDonald, 2008; Rolstad, 2015; Stensland & Sanders, 2018) and one stated the need for policy change in order to accommodate patients experiencing pain (MacDonald, 2008).

Eight of the studies discussed patient outcomes related to social work intervention. The outcomes of the studies were not taken into account as a quality assessment of the research is not included in this scoping review. The interventions included relaxation groups (McBee et al., 2004), cognitive behavioural group work (Subramanian & Rose, 1988a; Subramanian & Rose, 1988b; Subramanian, 1991; Subramanian, 1994), individual social work intervention (Aho et al., 2010), as well as social work reflection on hemophilia and sickle cell patient groups (Rolstad, 2015; Works et al., 2014).

### **3.5 Discussion**

The current practice of social work in pain management associated with chronic disease as explored in this scoping review offers confirmation of practice in three focused areas: instrumental services, counseling services and assessment. It was evident that many social workers apply two or more of these practices concurrently in their role. What was not documented in the studies was the use of validated pain assessments including pictorial scales and body charts, McGill Pain Questionnaire (1987), Brief Pain inventory (1994), daily function and activity inference scales and psychological scales, which include Pain Catastrophizing Scale (1995), all of which are listed in the IASP curriculum guideline (IASP, 2017a). Integrating these pain assessment tools into current biopsychosocial assessments would likely have an impact on the proficiency in conducting appropriate pain referrals, intervention planning and outcome measures. The services described in all three of these practice areas fit well with the CASW Ethical Guideline, which include 1) Respect for the Inherent Dignity and Worth of Persons 2) Pursuit of Social Justice 3) Service to Humanity 4) Integrity in Professional Practice 5) Confidentiality in Professional Practice 6) Competence in Professional Practice (CASW, 2005).

The foundation of social work is one of advocacy and policy change for those in vulnerable and oppressed situations as supported by the IASP (2017a) and the CASW (2005). In

this review, only one study considered policy change and only three studies mentioned advocacy as a role of social work. The IASP Social Work Curriculum Guideline (2017a) includes the requirement of advocacy education in Multidimensional Nature of Pain: Advocacy – global and national initiatives and Clinical Conditions: Role of the social worker as advocate, to help patients meet individualized treatment goals. Browne et al. (2017) discuss the social work role of advocacy and policy change extensively within health care with the recommendation to “encourage and equip students to pursue policy careers by establishing policy practice concentrations, in which policy analysis, advocacy, and implementation skills are taught” (p. 233). The scarcity of discussion regarding the practice of advocacy and policy change within the scoping review indicates a potential direction for future research to investigate and provide recommendations for this aspect of practice. Social work has the responsibility to move beyond the individual impacts of pain and into societal impacts. It is also important to note that while documents and organizations (IASP, 2017a; NASW, 2017) support the need for social work to be involved in pain management, the preferred overall language in documents is psychological or behavioural specialists within interdisciplinary teams (DeBar et al., 2012, 2018; IASP, 2017b; CSEPM, 2019). This language does little to support the specialized role of social work role in this area or the promotion of advocacy and policy change that social workers can uniquely contribute. Further advocacy for the profession of social work not only for the individual and societal impact, but also for policy development is required.

This study revealed gaps in available research on the role of social work in pain management in chronic disease. These gaps include: the limited number and quality of articles on this topic, the narrow application of validated assessment tools, as well as the lack of discussion on policy and advocacy. The lack of research in these areas may be explained by the work of LeCroy (2010) who states social work has lacked critical analysis as well as support from educational institutions to broaden practice-based research. Further to this Teater (2017), states that “social work continues to lack a clear definition and aims of social work research” (p. 564). Developing further research in pain management for social work would assist in the development of a solid social work position within pain management.

### **3.6 Limitations**

We acknowledge several limitations to this scoping review. First, the exclusion of articles from cancer and palliative care significantly decreased the articles discussing the social work

role in pain management. A comparison between the two areas of practice could be explored in the future. Second, two databases were used for the search, and while it was determined these would be inclusive of most social work journals, additional databases could have contained some papers that were not captured in our search. The third limitation is the exclusion of the sixth step in the framework; consultation. Developing a consultation question for social work researchers and practitioners will be a necessary next step in this research. Finally, perspective from the patient experience was lacking in this study and in the future an examination of patient-oriented research to further understand the lived experience of those who are served by social workers would be important.

### **3.7 Conclusion**

This scoping review indicates the need for additional research to support policy development, education, and implementation of best-practice guidelines for social workers in the management of pain within chronic disease. There is a call by the NASW and IASP for social work engagement in pain management, however, evidence-based research lacks in supporting a clearly defined role. Further research addressing assessments, advocacy and policy change within this role is needed to guide the evolving practice of the social worker in pain management.

### **3.8 Acknowledgements**

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#### Declaration of interest statement

In accordance with Taylor & Francis policy and my ethical obligation as a researcher, I am reporting that I receive funding from CHS Novo Nordisk Psychosocial Research Grant a company that may be affected by the research reported in the enclosed paper. I have disclosed those interests fully to Taylor & Francis, and I have in place an approved plan for managing any potential conflicts arising from the funding.

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## **CHAPTER 4.0 LINKING CHAPTER**

The results of the scoping review indicated limited research on the role of social work in pain management within chronic disease management. Thirteen articles met the inclusion criteria for this scoping review. Three specific areas of practice were identified, including instrumental services, counselling and assessments. These three roles fit well with the CASW practice of social workers, while advocacy and policy development require further attention in research and practice. Our scoping review warrants the exploration of these roles within social work practice and for our study specifically with the bleeding disorder population.

The exploration of the role of social work in pain management in response to patient studies among bleeding disorder populations was vital to determine future pain education and practice. The scoping review revealed no studies having been conducted specifically among bleeding disorder social workers; it is necessary to conduct research to explore social workers current practice, understanding and development of pain resources. A qualitative research project allowed the topic to be explored and to outline recommendations for social work education in pain management for bleeding disorder care.

The examination of social work practice in bleeding disorder care through semi-structured qualitative interviews provided evidence related to the understanding of pain management and educational preferences. Nationally, the Canadian Hemophilia Society (CHS) supports comprehensive care teams in each HTC to meet the standards of practice outlined for patient-centred care. Currently there are 26 HTCs across Canada; sixteen of these centers have at minimum a 0.1 full-time equivalency (FTE) social worker who are members of the CSWHC. The second manuscript explores practice through a thematic analysis of qualitative interviews with 12 social work members of the CSWHC. Social work participants provided insight into the dedication of the care they provide as well as current pain knowledge and further need for skills development.

The process of identifying the themes for the second manuscript as outlined in Chapter 2 included refining the themes. For phase three the initial codes identified by JK and DG included:

acute pain, barriers, chronic pain, the impact of pain, multidisciplinary team, pain beliefs, skills development, and social work role (Table 4.1).

Table 4.1 *Initial Codes and Theme Development*

<b>JK Initial Codes</b>	<b>DG Initial Codes</b>	<b>Second Round of Codes</b>
acute pain	interesting quotes	exploring pain within social work
barriers	anticipated outcomes	and hemophilia care
chronic pain	asking for validation	anticipated skills development
the impact of pain	autonomy of role	how do we currently define pain
multidisciplinary team	composition of interdisciplinary	social work thoughts about pain
pain beliefs	teams	assumptions and beliefs
skills development	constraints of system	social work operational work
social work role	definition of acute pain	the practicality of social work role
	development of resources	working in multidisciplinary
	education as a motivation	teams
	falling through the cracks	
	focus on social impact	
	functional effects of pain	
	invisibility of hemophilia	
	minimal barriers	
<b>Sub-Themes Identified</b>		
barriers to providing care including the distance of patients from the clinic		
physical limitations of patients to attend appointments		
limited time available during clinic visits		
system constraints		
the stigma of social work in general		
wait times for pain clinic referrals		
underlying grief and blame		
the invisibility of those with hemophilia		
self-medication		

The second round of codes were: exploring pain within social work and hemophilia care, anticipated skills development, how do we currently define pain, social work thoughts about pain assumptions and beliefs, social work operational work, the practicality of social work role, and working in multidisciplinary teams. The excluded themes revolved around barriers and financial constraints for patients and social workers, the functional effects of pain, and falling through the cracks.

The analysis identified themes that were not included in the final results but were important to note. These sub-themes included barriers to providing care such as the distance of patients from the clinic, physical limitations of patients to attend appointments, limited time available during clinic visits, system constraints, the stigma of social work in general, wait times for pain clinic referrals, underlying grief and blame, the invisibility of those with hemophilia, and self-medication. These areas require acknowledgement; however, they did not contribute to answering the research questions (Treloar et al., 2000) and, therefore, were not included in the final results.

Outlining the process and results through the framework of Braun & Clarke (2006) establishes the basis for the following discussion of final results. The following manuscript describes the interview process and data analysis which identified four themes in response to the research questions.

#### **4.1 References**

Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101. doi: 10.1191/1478088706pq063oa

Treloar, C., Champness, S., Simpson, P.L., Higginbotham, N. (2000). Critical appraisal checklist for qualitative research studies. *Indian Journal of Pediatrics*, 67(5), 347-351. doi: 10.1007/BF02820685

**CHAPTER 5.0 THEMATIC ANALYSIS - MANUSCRIPT B:  
PAIN MANAGEMENT IN BLEEDING DISORDERS CARE: PERSPECTIVES OF  
CANADIAN SOCIAL WORKERS IN HEMOPHILIA CARE**

**5.1 Preamble**

King, J., Fletcher, K., Tupper, S., Brose, K., & Goodridge, D. (2020). Pain management in bleeding disorders care: perspectives of Canadian social workers in haemophilia care. *Journal of Haemophilia Practice*, 7(1), 110-120. doi: 10.17225/jhp00163

**5.1.1 Abstract**

**5.1.1.2 Background.** Pain associated with bleeding disorders has been demonstrated to have an impact on patients' and families' quality of life. Both acute and chronic pain are common experiences and require attention by professionals working in haemophilia treatment centres (HTCs). The benefits of psychological pain management strategies, such as cognitive behaviour therapy, and self-management skills training are well documented; however, it is not well understood how Canadian social workers involved in haemophilia care perceive and provide pain management support to patients.

**5.1.1.3 Aims.** To explore the current understanding of pain management and practice as well as the education needs of members of Canadian Social Workers in Hemophilia Care (CSWHC).

**5.1.1.4 Method.** Twelve semi-structured qualitative interviews were conducted with members of the CSWHC. Transcribed interviews were coded with NVivo software and thematically analysed.

**5.1.1.5 Results.** The four key themes reflecting the experiences of social workers are: 1) Limited comprehension of key issues related to pain; 2) Conditioning to push through pain; 3) Expanding pain knowledge to enhance practice; 4) How we practice social work and choose to step in.

**5.1.1.6 Conclusion.** The current practice of CSWHC members aligns with literature in three main areas including assessment, instrumental services, and counselling. Social workers support the development of pain education and practical resources for patients with

haemophilia who experience pain. While formal education, advocacy, and policy development of pain assessment and management are recognised, these areas require further research and development.

**5.1.1.7 Keywords.** Psychosocial pain management, social workers, bleeding disorders, Canada

## **5.2 Introduction**

Advances in recombinant factor replacement therapy in haemophilia care have increased life expectancy as well as quality of life (QoL); however, bleeds and missed treatments continue to influence acute and chronic pain among people with haemophilia (PwH) (Lambing et al., 2017; McLaughlin et al., 2014; Young et al., 2014). Due to the nature of chronic pain and the impact it has on QoL, social workers are uniquely situated to take an active role in pain assessment, treatment, and management (IASP, 2017; NASW, 2017). Current literature exposes gaps in the use of validated pain and mental health assessment tools, advocacy, and policy development in social work practice (King et al., 2020).

**5.2.1 Pain in bleeding disorders.** Bleeding disorders are inherited and genetic conditions, including haemophilia A, haemophilia B, von Willebrand disease (vWD), and platelet function disorders. Patients with these diagnoses are at increased risk for bleeding into joints, muscles and internal organs, increasing the probability of long-term tissue damage and chronic pain (CASW, 2018; HFA, 2019; Young et al., 2014). Acute pain can result from bleeds, typically associated with swelling, heat and restricted movement, as well as pain from medical procedures including factor infusions (CHS, 2018a; HFA, 2019; Young et al., 2014). Chronic pain experienced from permanent joint impairment may arise from damage to the synovial lining or surgical interventions such as joint replacements or fusions (CHS, 2018b; HFA, 2019; Young et al., 2014). Endogenous pain modulation regulated by the central nervous system influences the pain experience (Ossipov et al., 2010; Staud, 2013). The experience of pain in bleeding disorder patients may be amplified by impaired endogenous pain modulation (Kruger & Hilberg, 2020). Pain is a subjective experience including physical and psychological factors, yet there is support to define pain in purely psychological terms. Biro (2010), for example, moves beyond the strict biological view of pain and acknowledges that pain may exist in psychological form without physical tissue damage present (Biro, 2010). The biopsychosocial impacts of pain on QoL include relationships (MacDonald, 2000; Stensland & Sanders, 2018), work/school,



housing, health management (Aho et al., 2010; McBee et al., 2004; Stensland & Sanders, 2018), psychological concerns including depression/anxiety, fatigue or stress (Aho et al., 2010; Park et al., 2013; MacDonald, 2000; Stensland & Sanders, 2018; Works et al., 2014) , and finances (transportation/social services) (MacDonald, 2000; Park et al., 2013; Stensland & Sanders, 2018).

The Haemophilia Experiences, Results and Opportunities (HERO) study included 675 adult people with haemophilia (PwH) from ten countries who reported a high prevalence of comorbidities, including arthritis (49%), and psychological concerns such as stress, fatigue, depression/anxiety (47%), as well as chronic pain (43%) either related or unrelated to haemophilia (Forsyth et al., 2013). A national study in the US of 764 PwH found that 59% of participants rely on the haemophilia treatment centres (HTCs) for pain management, while 39% of participants indicated their pain was not well managed, suggesting that pain is a pervasive issue in this population (Witkop et al., 2012). These studies demonstrate the need for HTC care providers to be skilled in pain assessment and management to ensure appropriate treatment and referrals. Many PwH can find it challenging to distinguish between chronic pain and what could plausibly be an acute bleed (Witkop et al., 2012), suggesting a need for the professionals who work with them to assist PwH in developing knowledge of pain experiences and the language to describe them. Pain in PwH is widely recognised, and HTC social workers have the potential to provide support and skills to address these concerns.

**5.2.2 Social work practice in haemophilia care and pain management.** The predominant effort of the CHS has been to improve patient-centred care and QoL while supporting the search for a cure (CHS, 2018c). The standard of practice for the CSWHC includes psychosocial assessment, counselling/psychotherapy, advocacy, education and resources (patient, family and community), support and discharge planning (CHS Standards Group, 2018).

Current literature on the role of social work in the management of chronic pain demonstrates its impact on QoL and the needs for appropriate intervention (Duenas et al., 2016; Hruschak & Cochran, 2017; Turk et al., 2010). Social workers routinely conduct psychosocial assessments in these areas and are well situated to assess the impact of pain on QoL and provide intervention services.

**5.2.3 Aims.** As there is a need for PwH to receive adequate pain management from the HTC, it was important to explore the current understanding and practice of social work in pain

management. The aim of this study was to determine the scope of pain knowledge and current practice in pain management among social workers in the CSWHC, guided by two research questions:

- 1) What do social workers in CSWHC currently understand about pain and bleeding disorder care and their practice?
- 2) What specific pain knowledge and training is prioritised by social workers in the CSWHC?

### **5.3 Method**

The study was designed by a member of the CSWHC and supported by the interest of its membership. A purposive sample was drawn from the CSWHC membership (15–20 active members), who have specialised expertise in bleeding disorder care. Participants were recruited during the CSWHC's 2018 annual general meeting, where an invitation poster (Appendix C) and consent form (Appendix D) were distributed, and via email. Twelve social workers agreed to participate in the study.

Semi-structured interviews were conducted with study participants to allow them to reflect on and share their professional experience. An interview guide (Appendix E) was developed through discussion of the research questions among the research team. The questions aimed to obtain an understanding of social workers' current knowledge and experience around pain management. No pilot interviews were undertaken due to time restraints.

Participants were invited to interview via email. Interviews were conducted between September 2018 and February 2019 by a single interviewer (JK) in a private home office via Zoom.us and recorded, with participants' consent, to a password-protected computer. Field notes were kept during and after each interview. The interviews were subsequently transcribed by a research service at the University of Saskatchewan and reviewed for accuracy.

Interview transcripts were emailed individually to each participant for review and asked to confirm consent for the transcript and to provide any further comments to clarify their interview.

**5.3.1 Ethics.** The University of Saskatchewan Behavioural Ethics Board granted an exemption for this study.

As members of the CSWHC, participants were involved in initial discussions about the research; however, they were not involved in finalising the research or in developing the

interview questions. Participants signed and submitted informed consent to the interview (JK) in person at the 2018 CSWHC annual general meeting, or via fax or email. The consent form included the granting of permission to use quotes in publications. Participants received gift cards an honorarium for their time. This was approved through ethics and described in the consent form.

**5.3.2 Data analysis.** Funding to complete a scoping review and thematic analysis of the interviews was secured through the CHS and Novo Nordisk Psychosocial Research Grant in 2018.

NVivo was used to manage and analyse data, including the organisation and arrangement of codes and themes. Field notes recorded during the interviews were read prior to the analysis. Clarifying comments received from participants following the receipt of interview transcripts were not included in the analysis.

Data analysis was conducted using a thematic approach. Four considerations were applied to the analysis: 1) inclusion of the entire data set in the analysis using a rich thematic description; 2) inductive approach in building themes from this data set (Braun & Clarke, 2006); 3) utilising a shared meaning in the identification of themes; 4) using an essentialist approach to allow inference of theories or ideas from within the data set (Braun & Clarke, 2006).

This paper explores the understanding and application of the role of members of the CSWHC in pain management and the direction of future discipline-specific pain education.

## **5.4 Results**

Interviews were conducted with 12 registered social workers, representing five provinces across Canada, with a range of age, education, and experience. The demographic characteristics of the sample appear in Table 5.1. All participants worked in an HTC at the time of the interviews. Two indicated that they worked in a combined adult and paediatric clinic, while five indicated working in paediatric clinics. The other five participants did not explicitly indicate the nature of the clinic in which they worked; however, based on the interviews, the research team inferred that they worked within the adult population.

Table 5.1 *Participant Demographics (N = 12)*

<b>Characteristic</b>	<b>n</b>
<b>Gender</b>	
Male	2
Female	5
No response	5
<b>Age range</b>	
20-29	1
30-39	2
40-49	1
50-59	5
60-69	1
No response	2
<b>Educational preparation</b>	
BSW	2
MSW	7
Additional degrees	4
No response	2
<b>Years of practice</b>	
0-10	2
11-20	2
21-30	3
31-40	3
No response	2
<b>Additional pain education</b>	
Yes	1
No	9
No response	2

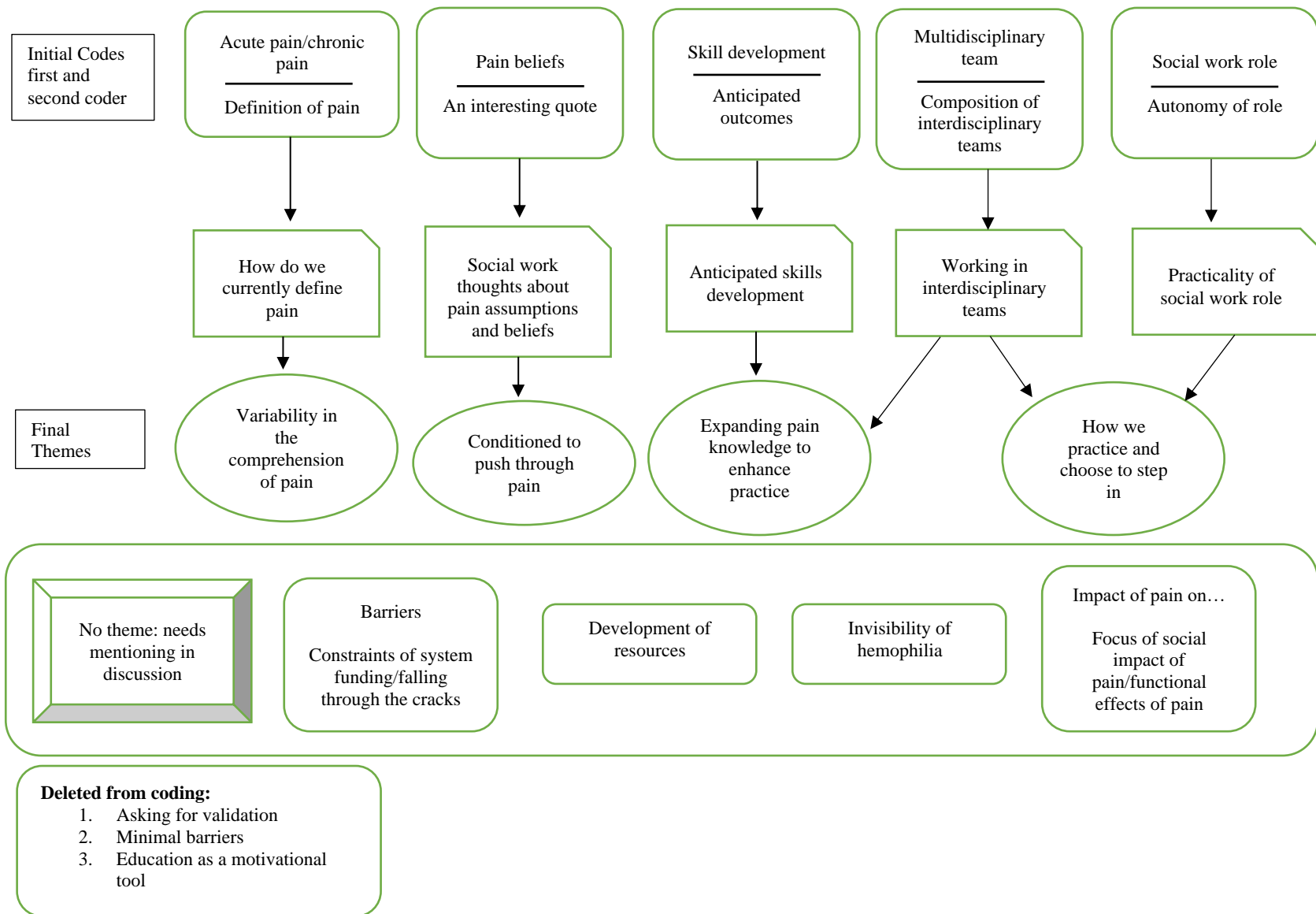


Figure 5.1 Theme development.

Four themes were identified in the analysis (Figure 5.1): 1) Limited comprehension of key issues related to pain; 2) Conditioned to push through pain; 3) Expanding pain knowledge to enhance practice; 4) How we practice social work and choose to step in.

**5.4.1. Limited comprehension of key issues related to pain.** This first theme emerged through the language social workers used to describe and differentiate between what they described as physical pain or emotional pain. The way in which participants articulated acute and chronic pain within bleeding disorders focused on tissue damage associated with physical injury. They established the connection of emotional pain with physical pain yet did not discuss the bidirectional effects or the influence of emotions on the pain experience. The development of this theme explored how social workers comprehend pain management, contributing to the analysis of both research questions. Examination of language used by participants provided the opportunity to explore gaps in their pain knowledge. When considered with the third theme, this helps to provide an understanding of the education required.

While four participants identified bleeds as a cause of pain, only one identified needles and procedures as a source of pain. One participant showed some uncertainty about how pain occurs from a bleed: “A joint bleed as an example of that which can result from trauma. Essentially blood, I believe, being released into the joints causing much pain” (P001).

Also noted was the application of a pain intensity scale to differentiate between acute or chronic pain:

Chronic pain, in my opinion, is probably something that’s above a six or seven on a one to ten rating of scale, but it can be higher... I see acute pain being the spike, so it goes from let’s say a two to an eight back down to a two, right? (P002)

Few participants identified joint damage due to recurrent bleeds, and there was no discussion of the specifics of how this occurs. The language participants used to describe chronic pain indicated a limited comprehension of pain language, for example: “Just the lack of relief from the pain. It’s always there” (P011).

Five participants went beyond physical pain and discussed the emotional response and impact of pain. Emotional pain was identified as a concern for participants: “Sometimes physical pain can also contribute to an emotional, psychosocial pain that, you know, once the physical pain has healed, there could be that psychological pain” (P010). “The pain isn’t always physical; sometimes there’s some emotional pain associated with this as well” (P011). Strong emotional

words were used to describe chronic pain in bleeding disorder patients: “[...] persistent, always there. Constant reminder that I have an issue. Depressing, disappointing” (P004).

Another participant articulated their lack of pain understanding: “I don’t know that I’ve ever heard us define it, so, therefore, I’m having trouble actually knowing if that is the correct definition of it” (P008). The social workers in our study also reported that their time dedicated to bleeding disorders care is limited, and that they cover other areas of the hospital away from their specific disease expertise.

**5.4.2 Conditioned to push through pain.** One of the interview questions asked about what messages participants hear about pain from society, patients, health care providers or their own families. Many participants spoke to their own experience growing up. One participant used the example of sports activity: “I was an athlete, so pain was always something that you – you suck it up” (P002). Specifically, the need to push through pain was discussed by two participants: “I think the other messaging within our family was, you sort of need to push through it” (P005). The perceived thoughts and attitudes of broader social and health care professionals were addressed: “I think for the hospital’s perspective we really don’t like to see people in pain, so we treat their pain. I think that’s a North American, or Western approach to pain, is that we want it to go away” (P007). “As a North American society, we’re kind of dismissive of the impact of chronic pain and how that impacts a person’s sense of self and just quality of life really” (P012).

Participants used self-reflection during the interviews and identified the need to challenge this thinking when it comes to the messages they give to patients experiencing pain. They considered how these messages could impact how they relate to patients in pain through empathy and through providing patients with new messages on pain identification and management. This change and its impact on patients was explored by P005, who described the approach to pain in their upbringing: “You don’t surrender to pain, you push through, you keep going, you be tougher than it is. So, you know, I’ve had to re-learn what I would say to patients” (P005).

**5.4.3. Expanding pain knowledge to enhance practice.** Participants noted how learning opportunities in pain management could benefit their patients, impact their practice, and strengthen their role in the multidisciplinary team (MDT). Learning about the specifics of bleeding disorders and pain management, and the development of resources for patient services, was of utmost interest. However, participants wanted to know whether this pain knowledge

would transfer into other areas of hospital work, indicating the shared role they have among other specialities and a desire to make the most of educational opportunities. A need for more specific information on diagnosis was identified: “to understand individually how the different severities in haemophilia A, haemophilia B, how that impacts each patient... really understanding that myself so that that education can be supported or provided in the patient” (P001).

Knowledge of specific pain types within bleeding disorders was deemed necessary to assist in discerning potential outcomes and communicating these to patients. One participant suggested “some sort of in-service [training] or maybe some recommended readings, or that sort of thing, on what is pain in terms of haemophilia in patients... what are the solutions or things that will make it easier” (P009). The impact pain education might have on the role of social work within the multidisciplinary team was similarly reported: “If I had more knowledge around the whole pain assessment piece, I would be able to maybe assess or have input earlier on with the diagnosis” (P006). “Right now, I usually leave it [pain] up to those areas, those disciplines, but I think if I had more knowledge, I would be more vocal and more active in reinforcing, I guess, maybe the treatment plans” (P006). Consideration was given to the type of pain education that would be helpful:

I think probably something that would give me an overall guide about pain, what is it, how medically it can be treated, what can we do to assist or lessen pain, how we can teach our patients to deal better with pain and our staff actually as well.  
(P004)

Participants indicated they would like to have strategies and resources for their interactions with patients, which would benefit both social workers and patients: “More written resource information to perhaps give them, to expand their knowledge, and some additional tools that they can use themselves to help support themselves through that aspect of their haemophilia” (P005).

Participants were asked to identify the area of pain knowledge that would be most helpful based on the International Association for the Study of Pain (IASP) Social Work Curriculum Outline (IASP, 2017). Of the four learning categories suggested, the multidimensional nature of pain was the most requested (8 participants), followed by pain assessment and measurement (5 participants), and management of pain (2 participants). The fourth category, clinical conditions, was not identified as a useful learning area by any participants.



Participants believed they would benefit from specific pain education, but appeared to have difficulty in saying that it was necessary or crucial, instead stating it would “enhance” (P004), be “important” (P001, P003, P005, P007), they “would be interested” (P006), or it would be “beneficial” (P008; P012). One participant stated specifically that social work requires involvement with patient care “so that we can address that more psychological [aspects], underlying pain” (P010); no participants stated that this would not or should not be part of their role.

Participants reflected on the positive impact that pain education would have not only on patient care but also on their own role within the MDT. They anticipated how pain education could strengthen their role in patient care, specifically knowing how to talk about pain with patients and how to use the language of pain to advocate for them. This would also impact on their role in pain management in the comprehensive care team.

**5.4.4 How we practice social work and choose to step in.** Consistencies in social work roles across Canada were evident in the interviews. Participants did not hesitate when describing the role of social work and most agreed on the core aspects. Three capacities were identified in their scope of practice: assessor, facilitator of instrumental work, and counsellor/therapist. As discussed in the introduction, these roles align closely with those identified in a scoping review (King et al., 2020).

Participants were unfamiliar with available assessments for pain but maintain the routine use of psychosocial assessment. They explained their roles in terms of “completing a psychosocial assessment”, “ensuring they have connections to appropriate community resources”, and “counselling around any issues that might arise” (P005). The instrumental role also includes “medication coverage, sometimes accommodation, transportation needs”, “systems navigation, advocacy”, and “illness adjustment strategies for coping, difficulties that someone might have in the workplace, something that they might have at home, in their relationship” (P007).

Participants identified that social workers could be more active in pain management. The instrumental role was described as being “a good advocate for the family to make sure that they’re understanding and making sure our team’s doing appropriate education” (P008), but this advocacy requires looking into the areas that pain impacts.

It's not just pain, it's the effect on their [patients'] mental health that it has, it's the effect on their activities of daily living, it's the effect on their ability to hold and maintain employment or education... social work should play a larger role in that. (P009)

Multidisciplinary or interdisciplinary teamwork were referred to. Understanding the role of each member in order to provide best practice in the team was the central interest: "I do have a different perspective and appreciate the perspective of the many other team members, so I think we end up complimenting each other in terms of our practice with our clients" (P011).

Social workers anticipated future education to have a positive impact on their practice within the MDT, including their capacity for patient advocacy.

## **5.5 Discussion**

Social workers in the CSWHC were interested in and open to discussing the current position of pain knowledge and considerations in prioritising education. Reflecting on the research questions, we found in our thematic analysis that the participants interviewed have a limited comprehension of key issues related to pain. Participants' partial discussion of bleeds and causes of muscle or joint pain, and their lack of identifying needles or procedures as pain-producing also evidenced their limited comprehension of pain in bleeding disorder care and came as a surprise to the researchers. The language used to describe acute or chronic pain and the use of pain rating scales indicated a requirement for further education, including the relationship of physical and emotional properties of pain.

Pain rating scales determine the subjective nature of pain in the moment and provide assessment for pain intensity and effect (Haefeli & Elfering, 2006), but cannot determine whether pain is chronic or acute. Pain scales and assessment of psychosocial functioning are suggested for the assessment of pain by professionals (Hruschak & Cochran, 2017; Fillingim et al., 2016; Turk et al., 2010). Understanding the assessment of pain in acute and chronic conditions is required for comprehensive care. The disclosure by P008 showing lack of knowledge around pain definitions exposes a need to develop education and pain literacy for social workers working in bleeding disorders care. The literature supports this call for further education in pain knowledge for social workers (MacDonald, 2008; Sieppert, 1996). Also required is general knowledge of health reform and community health (Browne et al., 2017).

Social workers must go beyond patient advocacy and make a call to universities and workplace management in order to fill this gap and provide superior care.

The second finding of this research is that the practice of social work in the CSWHC aligns with the literature noted in the introduction of pain-specific interventions; these include assessment, instrumental services, and counselling. Participants were unaware of pain assessment tools and enquired about what was available, although they conducted psychosocial assessments and were clear on the necessity to apply them in practice. They spoke to the instrumental services and counselling services they can provide and expressed a desire to engage in best practices for their clients, also indicating a desire to learn. Participants also used self-reflection and past educational experiences to create changes in their pain beliefs to offer professional care. Allowing time for self-reflection on the messages we receive about pain and how these impact the care of patients is an important exercise in professionalism.

Our third theme, expanding pain knowledge to enhance practice, supported the need for further education for social workers on validated pain assessment tools and outcome measures. Participants recognised this and were clear on the potential benefits to their practice and their patients of education specific to pain, although social workers may find it challenging to advocate for their own educational needs, in part because of limited time, resources, and education funds. The IASP Curriculum Guideline for Social Workers (IASP, 2017) outlines several tools to support pain intervention. Alongside this, further educational outcomes could be identified through the findings of Theme 1, in which gaps in knowledge were determined based on descriptions of pain and management of pain management of pain in general and with bleeding disorders care in particular.

While the results of this study were encouraging, in that participants were knowledgeable about their role, interested in further education, and open to self-reflection, an unexpected finding arose: there was a lack of use of specific pain terms for bleeding disorders around joint or muscle bleeds, needle or procedural pain, and surgery for joint fusion or replacements. Two possible reasons for this are that social workers are not involved in these types of concerns by team referrals, or they have insufficient time to respond to these types of issues due to shared time with other specialties. Buckner et al. (2016) recognised that patients identified a need for further pain education among care providers; in particular, education of non-pharmacologic

treatments among bleeding disorder providers is required in order to meet the needs of persons with bleeding disorders.

**5.5.1 Future research.** Participants acknowledged that an insufficient amount of education limited their understanding of pain in their social work practice; however, they are keen for this gap to be filled. This deficit of knowledge fundamentally begins within educational curricula, requiring further research on how targeted pain education would directly impact social work practice with individuals, families and societies, and the forward development of advocacy and policy change. Research and development of training programmes in universities are necessary as the impact of pain is far-reaching in QoL and seen in every area of health and social welfare.

The development of a specific pain course for CSWHC members, with research examining the full impact of such training on their professional work within HTC for patient and comprehensive care teams, would be a next step for this particular project. This would support further advocacy and development of policy for social workers in pain management.

**5.5.2 Strengths and limitations.** The CSWHC is a small group of social workers dedicated to serving patients in many areas including bleeding disorders. Using a qualitative study design enabled the contribution of valuable information to further the practice of social work. The small group allowed the researchers to interview all those interested in participating in the study, providing an opportunity to reflect on their beliefs and assess the research questions.

The sample for this study was drawn from a specialised group of social workers who work a modest full-time equivalency in their bleeding disorder role, potentially impacting on how they responded to questions specific to bleeding disorders. Due to the specific nature of the study and the limited number of participants, findings cannot be generalised to other areas of social work practice.

## **5.6 Conclusion**

The focus of this qualitative study using thematic analysis was to understand the current understanding of pain in bleeding disorder care among social workers in the CSWHC, and to explore the type of pain education social workers would prioritise. Participants used the interviews as a time for self-reflection, allowing thoughtfulness towards how new pain education might change their beliefs and impact on their day-to-day practice. Social workers are looking for practical resources, including assessment tools, to support their instrumental work and elevate

their contribution in pain management. To this end, we encourage further research and development of tools and knowledge to assist social workers working within comprehensive care teams.

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Jennifer King is a member of the Canadian Social Workers in Hemophilia Care (CSWHC); Dr Kelsey Brose is a member of The Association of Hemophilia Clinic Directors of Canada (AHCDC).

Informed consent has been obtained from the participants in the study reported in this paper.

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## **CHAPTER 6.0 DISCUSSION AND CONCLUSION**

The research and analysis conducted in the studies of this thesis were established by responding to patient needs and to the social worker members of the CSWHC. Patients with bleeding disorders have reported the requisite for support and care of pain management. The HERO (Forsyth et al., 2013), The National Pain (Witkop et al., 2012), A Survey of Self-Management Needs (Barlow et al., 2007) and The Patient, Caregiver and Provider Perceptions of Pain and Pain Management (Lambing et al., 2017) studies indicate the call for increased pain management by patients. These studies indicated that non-pharmaceutical care of pain and the management of pain was essential. The SBDP developed the PTPQ (Tupper et al., 2020) in order to assess and treat pain within the HTC. In follow up to this questionnaire it was imperative to ascertain the current position of social work in pain management, the current practice of CSWHC social workers, and further educational requirements.

The first paper examined the scope of literature available for chronic disease and social work practice in pain while the second paper focused on the practice and knowledge of social workers and future educational opportunities of the CSWHC members. The following discussion provides a deeper analysis and critique of the studies and merges the two papers together to identify further opportunities for development and research.

### **6.1 Social Work Research**

Social work research has been critiqued as lacking “some of the most common elements of good science” (Lecroy, 2010, p. 321), specifically the element of criticism in the process of hypothesis development and observations. Lecroy (2010) has suggested that researchers must spend more time thinking about the data and its meaning rather than simply processing data. Developing critical analysis of research by the research team and within the community of social work occurs through a dialogue of questions to establish clarity and challenge assumptions (Lecroy, 2010). Processing the data through the scoping review and thematic analysis in both projects provided the necessary time to process the data and consider the implications of not only the research but also on direct practice.

Perhaps more important would be a critique of the scoping review conducted for this thesis. The research question was broad and well-defined fitting the purpose of a scoping review (Arksey & O'Malley, 2005; Grimshaw, 2010; Levac et al., 2010) concerned with the current understanding of the social work role in a small subset of the population. Quality assessment for the scoping review was essential and achieved with the utilization of the PRISMA-ScR (Appendix A) (Cloquhoun, et al., 2014; Tricco, et al., 2018). The search parameters for inclusion and exclusion criteria were limited to chronic disease, excluding cancer and palliative care. Considering this, Otis-Green et al. (2002) outline the cancer and palliative care psycho-spiritual role, which includes emotional, cognitive, behavioural, social, and spiritual aspects offered in a multidisciplinary team similar to the elements found in our scoping review. Beyond these similar elements of cancer and palliative care social workers should also be educated in end of life care and psycho-oncology (Otis-Green et al., 2002) indicating that the care treatment for cancer and palliative care differs from chronic pain management. The role of social work in cancer and palliative care includes assessing for financial concerns, supports, religion, and impact of pain on QoL (Otis-Green et al., 2002). With the exception of religion these assessment areas align with the results found in this thesis. A strong focus on reviewing life and meaning in a patients' experience is also included in the role of social work in end of life care (Otis-Green et al., 2002), which was not identified from the results of this thesis. Bleeding disorders present serious outcomes when treatment is not available, however, end of life care has not been included in the outline of professional care for these patients (CHS, 2018). From the clinical perspective of this author, many parents with young children discuss their fear of a child dying from an untreated bleed; adult patients acknowledge concern of dying from an untreated bleed although there seems to be a lack of consideration of this topic in practice. It is also reported by Parker Oliver et al. (2009) that social workers in hospice care spend a great deal of time working with caregivers and providing support in their care. The two differences we gather from these studies are the use of specific end of life support and caregiver support. The exclusion of cancer pain and palliative care from our results can be critiqued and supported as there are significant differences in the specialization of care.

The further development of evidence-based social work research is similarly illustrated by Brekke (2012) who states, "we have had an ambivalent relationship with science in that we have piggybacked on science from other disciplines and have not taken seriously the definition

of a science of social work” (p. 457). Brekke (2012), notes that the social work practice of change strategies has “a growing body of research and experimental evidence in many of these areas, and this knowledge is central to a science of social work” (p. 461) indicating a shift toward stronger science in social work is occurring. Our scoping review indicates that gaps exist in the current literature regarding the social work role in pain management of chronic disease. Research providing specific knowledge of pain and impact of the social work role on patient experiences of pain is required. The call for social workers to be involved in pain management remains strong among national and international associations (IASP, 2017; NASW, 2017), however, available research to support this stance is insufficient. It may be that the calls to action are based on the literature in other practice areas of general non-pharmacological or psychosocial pain management and not specifically in social work research. Social work requires further study of the role of social work in pain management for chronic disease to support the current calls to action.

**6.1.1 Synopsis of scoping review and further discussion.** The purpose of the scoping review was to examine the breadth of research speaking to the social work role of pain management in chronic diseases. The scoping review based on Arksey and O’Malley (2005) and Colquhoun et al., (2014) provided the landscape for this process, and we concluded with 13 articles in our subject area. The scoping review did not require a quality assessment since we were investigating for the breadth of the literature, the current available research, and gaps in the research. The included articles for the scoping review answered our research question and revealed three areas of practice used in pain management while briefly mentioning advocacy and policy development as additional areas of practice. This scoping review exposed the limited amount of research in this area of study. It is critical to evaluate the current capacity of social work research in the broader context to ascertain if this outcome is specific to our topic.

**6.1.2 Advocacy and policy development.** Advocacy and policy development are core foundations in social work practice. The scoping review identified advocacy and policy development related to pain management in only three articles, indicating a substandard exploration of these practices. McLaughlin (2009) reports the overall discussion of advocacy in social work texts and curricula is deficient, which supports the findings from this scoping review. Advocacy is a process employed by professionals to assist vulnerable and oppressed populations (CASW, 2005). In this discussion, advocacy includes the individual client, community, goal-

oriented, micro, mezzo and macro levels of practice, and it can be instrumental, educational or practical (McLaughlin, 2009). The IASP Curriculum Outline (2017) states the micro, mezzo and macro levels of advocacy requires attention in pain management. Furthermore, this statement by the IASP (2017) not only encourages the practice of advocacy but also petitions advocacy to be a part of the ethical responsibility of social workers.

It is imperative to consider advocacy from several points of view. The benefits of advocacy can vary and what advances one group may not advance the second group, the collective group, or individuals (MacDonald, 2000; McLaughlin, 2009; McNutt, 2011). The cost benefit ratio of advocacy requires a partnership between social work and economics (McNutt, 2011), which has been largely ignored in the dialogue. Taking up the role of advocate for a vulnerable or oppressed group is obliged with the utmost attentiveness of the situation. The day-to-day practice of advocacy may be taking place; however, a dearth of literature exists to guide social workers in the application of advocacy concerning pain management and support (McLaughlin, 2009). The role of social work in the advocacy for appropriate, timely, and affordable pain management requires further research to determine the implications, cost benefit ratio and best practices.

Advocacy and policy development are often played out in a partnership. Policy development related to pain management was discussed in one of the papers in the scoping review. MacDonald (2008) emphasized that beliefs about chronic pain can contribute to a true condition of disability; participants indicated that changing pain beliefs would help to validate policy change in the cost of insurance, accommodation, and treatments. As far as policy development is concerned, Berkman (1990), considers it important for social workers to acquire general policy knowledge and skills in policy analysis; Browne et al. (2017) agrees that the comprehension of basic health care policy is a requisite for social workers. Berkman (1990) also acknowledges the contribution social workers can make based on their expertise of social systems and individualized care. The insufficient contribution of social workers to policy development is evident in our scoping review. Outlining practical strategies and developing research that supports social work practice in advocacy and policy development is essential. Point-of-care social workers who conduct biopsychosocial assessments of patients are in a compelling position to advocate and scrutinize policy development in pain management; however, these roles may not be supported or outlined in the workplace.

## 6.2 Synopsis of Thematic Analysis and Further Discussion

Following the scoping review a qualitative study was developed to determine the knowledge of pain assessment and management and the requisite for further education among members of the CSWHC. Thematic analysis was used to examine these interviews based on the methods of Braun and Clarke (2006) and Nowell et al. (2017). The analysis focused on answering the specific research questions in which four themes were determined. The following discussion will examine barriers between practice and research, the importance of self-reflection, supporting patients in disease management, and the requirement for multidisciplinary teams.

The first theme indicated a limited comprehension by members of the CSWHC in key issues related to pain. This was observed with acute, chronic, and specific bleeding disorder causes of pain. Social workers indicated their full-time positions are dedicated to several areas of hospital practice, which could have a bearing on developing disease specific knowledge. However, social workers require general skills in pain knowledge in order to provide appropriate assessments and interventions in each area of practice (Berkman et al., 1990; McEwan, 2015; Therivel, 2017). As seen in our discussion of the scoping review, a dearth of literature exists to support the call for social work involvement in pain management, which may also contribute to this lack of knowledge.

One reason for the lack of literature and support of social work involvement in pain management may include lack of research skills and support. Teater (2017) identifies barriers to informed research practice among social workers. One of these barriers is the lack of research skills among social workers to produce reliable and precise contributions to literature (Teater, 2017). With insufficient social work-specific research available, social workers do not have access to learning opportunities within their specific profession and would need to expand the search into health sciences literature in general. Developing research with strong skills in the critical analysis must become a priority in the post-secondary education system. This research would require a melding of research with practice to provide appropriate and real-world intervention. Support by managers and educational institutions to provide dedicated time for the development of research knowledge and skills are required to see this change. However, as The Canadian Pain Task Force (2019) indicates, many professionals, not only social work, require further pain education for pain management. Social work advocacy for the advancement of

knowledge and patient care may be emphasized not only for social work but for all health care professionals.

The second theme considered how the CSWHC members have been conditioned to push through pain with a focus on the role of self-reflection. Social workers identified their pain beliefs and awareness of how they approach their own pain. They recognized the need to challenge themselves in their own pain beliefs and how doing so will impact patient interactions. Yip (2016) described the reflective practice in which a "social worker evaluates his or her own performance, thinking, feeling and response in practice" (p. 780); it is a praxis that can be undertaken to scrutinize and develop best practice (Yip, 2016). In our analysis, social workers examined their thoughts and pain beliefs and the impact it has on their practice when given the question and time for reflection. How we respond to our own pain may be remarkably different from how we treat those around us who also experience pain. Marmarosh et al. (2009) examine therapy outcomes based on working alliance, transference and real relationships. In this discussion negative transference as identified by therapists did not influence the clients' observation of the relationship (Marmarosh et al., 2009). There was also indication that the therapists' perspective of treatment outcome was significant (Marmarosh et al., 2009). Examining not only our own beliefs about pain but also how we view our clinical relationships is required in the clinical arena.

As social workers engage in self-reflection and our own reaction to pain is realized, the resolve to assist in advocacy within the workplace for appropriate pain response can be enhanced. Acknowledging and questioning the societal and professional beliefs has been identified by MacDonald (2000) as a requirement in the change for a more responsive healthcare system. The role of social work in advocacy and policy development requires this form of questioning to bring awareness of current and future contributions to the role in pain management.

The third theme identified the importance of social workers expanding pain knowledge to enhance practice, which included access to educational resources for patients to assist in their interactions. Social workers indicated a desire to build and develop their skills and practice and considering ways to enhance patient support by providing educational resources. Providing resources to patients is one way that social workers can help to empower patients in their own medical care experience. Literature supports the idea of empowerment and helping people in

their pain experience. As Brekke (2012) describes, "(T)he scientific domains demarcating the kinds of change we seek to promote empowerment, inclusion, reducing disease, and increasing health" (p. 459). Social workers expressed the intention to provide information and give patients the knowledge they would need in pain management while working with the HTC. At the same time, the social workers noted they themselves would need education and knowledge to assess the quality of resources. Empowerment in the literature encompasses several areas beyond presenting resource material for patients. Key aspects of empowerment include assisting clients to find their voice and to advocate for themselves (MacDonald, 2000; McLaughlin, 2009; Mendenhall, 2003) and the use of behavioural change (MacDonald, 2000). The IASP (2017) includes empowerment in the curriculum guideline with the additional roles of moderating sensitive information between patient, family, and health care professionals; they also note the requisite to assist with language barriers for the empowerment of patients. Further education and familiarity with empowerment for the role of pain management for patients is required for members of the CSWHC. A key finding from the research includes the role of social work to provide pain self-management skills to patients providing them with skills for empowerment.

The fourth and final theme examined how social workers step in and practice in patient care and multidisciplinary teams. High importance has been placed on the multidisciplinary team in the domain of pain management (Duenas et al., 2016; Hruschak & Cochran, 2017; IASP, 2017; The Canadian Pain Task Force, 2019; CSEPM, 2019; van Hecke et al., 2013). In developing the science of social work, Brekke (2012) states the first goal should be multidisciplinary work from "a position of a well-defined scientific identity" (p. 462). Advancing a well-defined methodology, theory, and core constructs (Brekke, 2012), are critical in producing a position in social work to practice well with our patients and our professional teams. In an effort to define our position in science that would examine the role of social workers, this thesis cultivated a full multidisciplinary approach. The science of this project identified the four roles of bleeding disorders, pain, social work, and research as necessary for the overall outcome. Approaching the science of the qualitative research as its own multidisciplinary team has provided a robust examination of the role of social work in each of these areas.

Defining the scope and practice of social work determines the position of social work in the multidisciplinary team. The scoping review identified the role of social work in pain management in three areas: assessment, instrumental services, and counselling. The members of



the CSWHC identified the same roles; the IASP (2017) has identified these roles in the curriculum outline. While these roles were identified by the members in the study, the first theme indicated there was ambiguity of specific pain knowledge and use of pain assessments. Advocating for the social work role and policy development will be difficult with a lack of comprehension in pain assessment and management. Integration of the social work role in multidisciplinary teams in bleeding disorder and pain management will advance as we clearly define our own methods, theories and paradigms.

The four themes presented in this thesis contribute to answering the research questions and portray the current scope of social work practice in pain management within bleeding disorders care and requirements for further education. Social work participants in this study recognized the benefits and importance of implementing pain education and strategies in their practice but also identified a number of barriers to doing so. A lack of resources, time and support contribute to limited practice time in bleeding disorder care and may limit practice of pain management for this population. Finding time to advocate for the social work role and develop further research will persist as the greatest challenge resulting from a lack of dedicated time and support from employers. Browne et al. (2017) support the requirement for health policy courses, skill development and health education for social work students. A shift in priorities, decisions, and funding must be made in order for social workers to meet patient needs in pain management.

### **6.3 Contribution to Research**

The purpose of this research was to examine current knowledge of pain management for patients among social workers and the requirements for further pain education. This project analyzed the literature and qualitative interviews of the CSWHC members to determine the current state and future developments of pain management in bleeding disorders. This thesis outlines the role of social work in pain management with chronic disease and compares it with the qualitative interviews. The analysis indicated an overlap of research and practice in the role. Gaps in the practice of advocacy and policy development were also revealed.

This research has contributed to the identification of specific knowledge gaps and areas where further progress is necessitated. The studies revealed that the CSWHC members require further education in pain assessment, management and language. Advancement in disease specific learning is also required including bleeding types, hemarthrosis and needle pain. It is

indicated that further self-reflection and distinguishing a clear role identification would assist in the establishment of the role in multidisciplinary teams and in patient care. Finally, dedicated resources and learning outcomes focused on advocacy and policy development cannot be ignored.

A recommended education strategy for CSWHC members (Table 6.1) has been developed from the analysis of this research. The broad topics of this proposal are: 1) Specific bleeding disorder information; 2) Pain information; 3) Self-reflection; 4) Role of social work in pain and bleeding disorder multidisciplinary teams; 5) IASP Guidelines; 6) Advocacy and policy development for pain management. These are the core areas identified in the research as future education requirements.

Table 6.1 *Pain Education Outline for CSWHC Members*

Specific bleeding disorder knowledge	Bleeding disorder diagnosis Pain experiences for PwBD Types of bleeding episodes Joint damage Needles and procedures Bidirectional impact of pain and QoL
Pain knowledge/IASP guidelines	Multidimensional nature of pain Definitions Types Dimensions of pain experience Ethical principles Pain assessment and measurement Pain scales Assessment biopsychosocial assessment Biomedical focus Management Medical and pharmacological management Patient support network Barriers Skills and strategies to for enhanced pain relief and self-efficacy Non-pharmacological interventions Resources Empowerment
Self-Reflection	Societal beliefs/myths of pain Impact on practice
Role of social work and bleeding disorders in multidisciplinary teams	Roles
IASP Social Work Curriculum Guideline	Multidimensional nature of pain Pain assessment and measurement Management
Advocacy and policy development	Minimum standards, right to appropriate assessment and treatment Access to care – political, policy, public health

The scoping review indicated a dearth of literature on the practice of social work in pain management for chronic disease and more specifically for bleeding disorder care. The research articles available in our scoping review outlined three key areas of practice, as well as two areas that require further development. The outcome of this research indicates that although there is a call for social workers to participate as a member of the multidisciplinary team specifically in pain management, there is scarce literature to support the practice. Our research has indicated the

gaps between research and positional statements and the neglect of advocacy and policy development discussion. Social work practice requires attention to building sound research in advocacy, education, and policy development to explore the role of social work in pain management among chronic diseases.

The thematic analysis denotes that while social workers believe they have a role to play in pain management in bleeding disorders and that it corresponds closely with the role outlined in the scoping review, an omission of advocacy for the role and policy development has existed. Advocacy and policy development were briefly mentioned in the interviews indicating the need for further discussion and training.

The research in this thesis has provided clarity of the current situation of social work in pain management of CSWHC members and has indicated the requisites for expansion of this topic.

### **6.3.1 Social work practice in non-pharmacological approaches to pain management.**

One potential area for pain management is in the non-pharmacological approaches in pain management are well documented in literature and include the use of self-regulation, reframing pain beliefs, pain acceptance, CBT, and self-management (Reddan & Wager, 2019). Turk et al. (2010) emphasizes the combination of treatment methodologies and recognizes non-pharmaceutical treatment strategies including CBT, supportive counselling, relaxation, and biofeedback. Additionally, mindfulness, CBT, environmental treatment including housing conditions and access to nature, exercise, and physical movement are discussed by Tajerian & Clark (2017). These pain interventions show promising results with time and persistent use. These treatments must be offered as a part of a holistic multidisciplinary team approach, which social workers can support and advocate for.

The call for action on pain management by the IASP (2017), NASW (2017), and The Canadian Pain Task Force (2019) has included the use of non-pharmaceutical treatments and multidisciplinary teams; these recommendations rarely used the term social work. The role of social work is not clearly defined or researched, which could contribute to the deficiency of role integration at the national and international platform. Mendenhall (2003) describes three barriers to effective pain management including inappropriate pain beliefs by professionals, inadequate policies, and stigma around appropriate use of medication for treatment. These are areas in which social work is well suited to address and advocate for (Mendenhall, 2003). Beyond these barriers

the bidirectional effects of pain with mental illness, stress, fatigue, relationships, and finances indicate a role for social workers to provide interventions in pain assessment and management (Duenas et al., 2016; Turk et al., 2010; van Hecke et al., 2013). These effects, however, require further social work education, including knowledge of pain mechanisms and evidence-based approaches to pain management (Therivel, 2017). Phillips et al. (2008) outline several areas that require advocacy and change including adequate pain education, training and support for primary care professionals, providing patients with education and knowledge for self-management, and a closer working liaison between services including employers and occupational health. Until social workers contribute to the development of research, advocacy, and policy development we will not fully comprehend the impact of social work intervention on pain management.

The results of this scoping review indicated the necessity for further development in several dimensions. First, the development and critique of research in pain management for chronic disease is required to support the education and development of the role. Second, advocacy and policy development require a robust examination. Third, the call for social work integration in pain management must be clarified and supported through further research. Education for social workers in assessment, management and general pain knowledge is indicated from this review; further research was required in order to assess the current scope and knowledge of pain practice among CSWHC members.

#### **6.4 General Limitations**

The first consideration of limitations within the thesis is the publication word limits for the submitted chapters (Horsburgh, 2002). In order to comply with the limitations it was difficult to expand on the rationale for discussion. The chapters included for the introduction, research objectives and methods and discussion attempted to expand the process of the research. Subtle analytical details may have been lost in the process of summarization.

The second limitation for purpose of the thesis was to examine the knowledge of pain assessment and management of a specific group of social workers in Canada. Due to the specific nature of this research, it cannot be generalized to other specializations of social work. The recommendations outlined for pain education are intended for the members of the CSWHC. However, by outlining the steps taken for this research a similar research project could be replicated in other specialties. Horsburgh (2002) considers generalizability can be made “to the extent to which theory developed within one study may be exported” (p. 311), for those who are

in situations comparable to the research. Considering our purposive sample was specific to social workers in bleeding disorder care it is difficult to know the extent of generalizability of results. The outline of this research provides a template to replicate the study in situations.

Another general limitation for our research is that although the research was initially developed to examine social work in the context of bleeding disorders, it was necessary to broaden the scope to include chronic disease management. As discussed in the chapter for the scoping review, the restriction on articles relating to chronic disease management rather than on all pain management excluded components of pain management specific to cancer and palliative care in the results. While the articles identified the use of three primary interventions, the strength of the research and outcome measures for these interventions were not assessed for quality. The interpretation of the scoping review can be limited to examining the breadth of research and existing gaps in the literature.

## **6.5 Clinical and Policy Implications**

The scoping review and thematic analysis undertaken both indicate underdevelopment of advocacy and policy; this may reflect the current states of both social work research and education. Brown et al. (2015) examine the state of advocacy and assert that social workers continue to find this an essential aspect of their role; the focus of advocacy in recent years has encompassed professional self-interest rather than for client concerns. We assert that social workers need to advocate in health care, local, and national politics for increased pain management and support. However, if social workers are unaware and uneducated in the practice of pain management, how can they advocate for such change? Advocacy must be established in the professional and patient spheres, parallel to each other in order to advance pain knowledge, assessment, and management in the social work role.

Given the state of social work research on pain management within chronic disease, further research and education must be developed. Without this research, advocating for change in social policy for those who require increased services of evidence-based care will remain unchanged. This thesis calls for an examination of pain education to be offered at an undergraduate level for social workers and for increased resources for researchers to further study the role of social work in pain assessment and management due to the bidirectional impact of pain and impact on vulnerable populations (Duenas et al., 2016; Reddan & Wager, 2019; Turk et al., 2010; van Hecke et al., 2013). As social workers increase their awareness, they will foster

an influential platform to address current policy for access to appropriate treatment (Brekke, 2012; McLaughlin, 2009; Mendenhall, 2003).

Once education for social workers is established, advocacy for increased pain management can begin in the instrumental, educational and practical aspects (McLaughlin, 2009). Instrumental advocacy would focus on benefiting individual client support. Educational advocacy would take on enhancing public and policy maker understanding of pain and clinical requirements in health care, while practical advocacy would assist clients in receiving specific resources that would assist in pain management. Focusing on these three aspects of advocacy with a foundation of pain knowledge would advance the calls to action including better care, better prevention, and education outlined by The Canadian Pain Task Force (2019).

## **6.6 Future Research Recommendations**

The outcomes of our research bring forward four suggestions for future research. The first step would be to conduct a literature review that would include a quality assessment of the articles and a comparison of cancer and palliative pain management. This step would allow a full assessment of the quality of research on the topic of pain within social work practice.

The second recommendation is to study the outcomes for both patients and professionals of the implementation of a pain management course for social workers based on Table 6.1 Pain Education Outline for CSWHC Members. Examining the impact of pain education would provide the profession with practice insight for advocacy and policy development.

Third, the recognition of the value of multidisciplinary care in pain management within bleeding disorders must be advanced. As social workers increase awareness and provision for pain management understanding how this impacts the entire team and recognizing the benefits and potential disconnect in services must be understood. An analysis of team care and expectations within teams would benefit further advancement.

The final recommendation is to conduct a retrospective case study on the impact of previous advocacy work and policy development within bleeding disorder programs and pain management; this would provide social workers with an opportunity to examine previous processes, outcomes, and to generate future developments based on the professional foundation of advocacy. This case study could follow the process of professional, political, and grassroots efforts to develop appropriate and accessible pain clinics.

Evidence-based research in social work practice requires a partnership between academic institutions, health agencies, and practicing social workers. In the author's personal experience, social work research is not encouraged as a part of the role in health care. Social workers, unions and health care managers have a responsibility to advocate for research development in the day to day role of social work. Open conversations related to releasing time from clinical practice for research must detail both benefits and risks of incorporating research into practice. The dearth of information related to social work in pain management in chronic disease necessitates the development of research practice with critical analysis skills in partnership between health care and educational institutions.

## **6.7 Conclusion**

The heart of social work is to support vulnerable and at-risk people to function at the best of their ability with self-autonomy. The bidirectional nature of pain not only increases the state of vulnerability but is also exacerbated by existing vulnerabilities. As such social work has the potential to play a significant role in pain management. This research emphasizes the deficiency in literature for social workers of pain management in chronic disease. Social workers are involved in care at the instrumental, clinical, and assessment interventions and how we care for people impacts pain at the micro, macro and mezzo levels of health care. This care requires further exploration of advocacy and policy development. Care and attention to the uniqueness of social work and how we meet patient requests must be met with attention to critical research and sound practice. Social workers must be advocating for the advancement of research in practice for the profession in order to meet the need of the patient to enhance pain management. Policy development aimed at evidence based multidisciplinary teams requires further attention. Pain education for social workers is indicated by the CSWHC members and indicates future development in order to provide competent practice to those who experience pain. The advancement in pain management for social workers ultimately aims to support those who have indicated it would benefit them in the daily management of their bleeding disorder.



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## APPENDIX A

### Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	35
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	35
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	35-37
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	37-38
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	37-38
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	38-39
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	38-39
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Figure 3.1
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Figure 3.1
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	38
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	38
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	38-40
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Figure 3.1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Table 3.2
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Click here to enter text.
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Table 3.2
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	38-41
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	40-43
Limitations	20	Discuss the limitations of the scoping review process.	44-45
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	43-45
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	35 and 45

JBIG = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

\* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* ;169:467–473. doi: 10.7326/M18-0850

## APPENDIX B

### COnsolidated criteria for REporting Qualitative research Checklist (COREQ)

#### COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	54
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	54
Occupation	3	What was their occupation at the time of the study?	54
Gender	4	Was the researcher male or female?	54
Experience and training	5	What experience or training did the researcher have?	54
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	54
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	54
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	22-24
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	28-29; 55
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	54
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	54
Sample size	12	How many participants were in the study?	55
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	54
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	54
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	56
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	54
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	54
Field notes	20	Were field notes made during and/or after the interview or focus group?	54
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	29; 54



Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	29
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	29-31; 58
Software	27	What software, if applicable, was used to manage the data?	55
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	58-62
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	58-62
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Figure 5.1; 31

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

## APPENDIX C

### Ethics Approval



To: Dr. Donna Goodridge  
Professor, College of Medicine  
Respiratory Research Centre

Student: Jennifer King

Date: May 14, 2018

Re: Beh 18-162

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Thank you for submitting your project entitled *Pain Assessment and Treatment in Bleeding Disorders: The Need for Social Work Specific Education*. The application meets the requirements for exemption status as per **Article 2.5 of the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans, December 2014**, which states "*Quality assurance and quality improvement studies, program evaluation activities, and performance reviews, or testing within normal educational requirements when used exclusively for assessment, management or improvement purposes, do not constitute research for the purposes of this Policy, and do not fall within the scope of REB review.*"

It should be noted that though your project is exempt of ethics review, your project should be conducted in an ethical manner (i.e. in accordance with the information that you submitted). It should also be noted that any deviation from the original methodology and/or research question should be brought to the attention of the Behavioural Research Ethics Board for further review.

**Please revise the consent form to reflect an exemption from the REB or delete the sections regarding REB approval.**

Sincerely,

---

Scott Bell, Chair  
Behavioural Research Ethics Board  
University of Saskatchewan

## APPENDIX D

### Recruitment Poster

Department of Health Sciences,  
University of Saskatchewan



### **PARTICIPANTS NEEDED FOR RESEARCH IN**

### ***Pain Assessment and Treatment in Bleeding Disorders: The Need for Social Work Specific Education.***

As a member of the Canadian Social Workers of Hemophilia Care (CSWHC), you are invited to participate in a study to examine the need for social work specific pain education.

As a participant in this study, you would be asked to: Participate in a phone interview of approximately 1 hour, review the transcript of the interview and be available for a follow up phone call to clarify or discuss new ideas.

Your participation would involve 1 sessions, each of which is approximately 60 minutes.

In appreciation for your time, you will receive a \$100 gift card for Indigo.

For more information about this study, or to volunteer for this study, please contact: Jennifer King

at

306-655-6503

Email: [jennifer.king@saskhealthauthority.ca](mailto:jennifer.king@saskhealthauthority.ca)

**This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.**



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## APPENDIX E

### Consent Form

Consent Form - Pain Assessment and Treatment in Bleeding Disorders:  
The Need for Social Work Specific Education

You are invited to participate in a research study entitled: Pain assessment and treatment in bleeding disorders: The need for social work specific education.

#### Researchers:

Jennifer King Graduate Student, Health Science, College of Medicine, University of Saskatchewan, 1-306-655-6503, [jennifer.king@saskhealthauthority.ca](mailto:jennifer.king@saskhealthauthority.ca)

#### Co-Investigators:

Dr. Susan Tupper PT, PhD, Coordinator Integrated Pain Strategy and Research, Saskatchewan Health Authority, 1-306-655-1041, [susan.tupper@usask.ca](mailto:susan.tupper@usask.ca)

Dr. Kara Fletcher, Faculty University of Regina, Department of Social Work, 1-306-664-7380, [kara.fletcher@uregina.ca](mailto:kara.fletcher@uregina.ca)

Dr. Kelsey Brose, Hematology, University of Saskatchewan Department of medicine, 1-306-655-1483, [kelsey.brose@saskcancer.ca](mailto:kelsey.brose@saskcancer.ca)

#### Supervisor:

Dr. Donna Goodridge, Faculty, College of Medicine, 1-306-966-4209, [donna.goodridge@usask.ca](mailto:donna.goodridge@usask.ca)

#### Purpose(s) and Objective(s) of the Research:

This study will examine the need for social work specific education and the need for skill enhancement in knowledge, assessment and treatment of pain in bleeding disorder patients. A scoping review and qualitative interviews will examine the International Association for the Study of Pain (IASP) Curriculum Outline for Pain in Social Work. The study will examine this question: What specific pain knowledge and training is prioritized by social workers employed in Hemophilia Treatment Centers (HTC's)? This phase of the study will include a minimum of 10 social workers from the Canadian Social Workers in Hemophilia Care (CSWHC).

#### Procedures:

The qualitative portion of the study design will require approximately one and a half hours of interview time with each participant. Transcripts will be available for review before analysis. A follow up interview may be requested for clarification or discussion of new topics that came from the previous interview. All interviews will take place over the phone at a time that suits the participant. Written consent will be obtained prior to the interview and reviewed verbally at the time of the interview.

#### Funded by:

Canadian Hemophilia Society (CHS) Novo Nordisk Canada Psychosocial research project grant.

**Potential Risks:** Risks are minimal.

**Potential Benefits:**

The likely benefits of the research are the development of a specific training program for social workers to support their practice in pain management of patients with hemophilia.

**Compensation:**

The discussion time at the annual meeting, interviews and review of the transcript will add up to between 2-4 hours per participant. We will provide a \$100 gift card to Indigo for participating in the interview, transcript review and any other follow up.

**Confidentiality:**

The researcher will have access to participants' identity due to the nature of the qualitative interview. All measures will be taken to maintain confidentiality in all quotes and analysis presented in papers and presentations. The digital and paper copies of the interviews will be held in a locked cabinet and/or password protected computer files with the supervisor. The paper and digital copies of the interviews will be held for five years and be shredded or deleted after this time.

**Right to Withdraw:**

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Whether you choose to participate will have no effect on your position in the CSWHC or how you will be treated.
- Should you wish to withdraw, please notify the researcher or co-investigators by email. All information previously collected will be destroyed at the time we receive the email.
- Your right to withdraw data from the study will apply until January 2019, when the results are being analyzed. After this date, it is possible that some form of research analysis has been initiated and it may not be possible to withdraw your data.

**Follow up:**

To obtain results from the study, please request by email to the researcher. The results will also be presented to the CSWHC group at the annual meeting in 2019.

**Questions or Concerns:**

Contact the researcher or co-investigators at the top of page 1. This project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306)966-2975. Out of town participants may call toll free (888) 966-2975.

**Consent: Signed Consent**

Your signature below indicates that you have read and understand the description provided. I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

---

*Name of Participant*                      *Signature*                      *Date*

---

*Researchers Signature*                      *Date*

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

## APPENDIX F

### Interview Guide

Jennifer King

Final Interview Guide: SW Knowledge of pain assessment and management in bleeding disorders

April 12/13, 2018

#### Current Practice:

1. Can you describe your work in bleeding disorders care?
2. Can you tell me if, and how you believe pain affects the patients you see with bleeding disorders? What role have you played in helping these individuals? What are barriers to your work in caring for a patient with pain?

#### Current Understanding of Pain:

1. Describe some of the messages you hear about pain from...
  - Your family
  - Society
  - Medical professionals
  - Bleeding disorder patients
2. \*What is acute pain in bleeding disorders?
3. \*What is chronic pain in bleeding disorders?

#### Prioritized Learning:

1. What type of pain education would make an impact on your direct clinical practice?
2. From the following list which is the most important pain topic that would have a direct impact on your practice? (From the IASP Curriculum Outline for Pain in Social Work)
  - Multidimensional Nature of Pain
  - Pain Assessment and Measurement
  - Management of Pain
  - Clinical Conditions
3. How do you respond to the following statement? “Social workers who develop pain-specific knowledge are better able to assess and advocate for appropriate care and employ evidence-informed interventions that contribute to the team management of pain and related suffering” (IASP Curriculum Outline for Pain in Social Work).
4. How would pain education have an impact on the type of care you provide for patients?