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HEALTHCARE PROVIDERS' UNDERSTANDING OF THE LAW: IMPACT ON ADVANCE CARE PLANNING PROCESSES

BY

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Abstract

Health care providers and legal professionals have advocated and supported people through the advance care planning processes for more than a century. These professions have approached advance care planning differently, from within their scope, discipline, and experiences. Neither group fully appreciates the impact their differing standards and practices have on patients and families and the health care they receive. The legal profession focuses on completing advance directive documents and advocates for patients' rights through the courts. Health care providers focus on shared decision making at the time decisions are required. This research, the first of its kind in Canada, will demonstrate the complications that arise for health care providers in the application of advance care planning processes when there are gaps in knowledge and understanding of health law. This study will explore practical suggestions to improve practice.

Keywords: Clinical Competence, Jurisprudence, Advance Care Planning, Advance Directives

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Chapter 1. Introduction

Despite increased attention and importance placed on advance care planning (ACP), uptake remains low, and barriers persist at micro (individual), meso (societal), and macro (government) levels. At the individual level, the public and health care providers' (HCPs) misunderstand the purpose and need for ACP. In society, ACP discussions are not commonplace. At the government level, ACP dedicated resources in health care are rare (Dixon & Knapp, 2019, 2018; Ries et al., 2018, 2016). Also, the completion of legal advance directive documents does not impact the care provided. Directives are inaccessible, insufficient, overruled, or deemed invalid (Noah, 2014; Rhee et al., 2012; Stuart et al., 2017).

The legalities surrounding consent, substitute consent, and advance directive documents are complex and have placed HCPs in a recurring role of interpreting a myriad of legal parameters. For example, during patient interactions, HCPs assess patient capability, determine substitute decision makers (SDMs), ensure SDMs fulfill roles and responsibilities, or validate previous expressed wishes or instructions.

Statement of Problem

Most HCPs do not understand consent, substitute consent, and advance directive legislation (Cartwright et al., 2014; Dixon & Knapp, 2019, 2018; White et al., 2014). The complexity and variability of laws within countries (Carter et al., 2016; Cartwright et al., 2014; Rush, 2005; White et al., 2014) contributes to this misunderstanding. The impact this has on daily clinical practice, and successful ACP implementation is profound. It is my opinion that HCPs' lack of legal understanding contributes to on-going implementation challenges. To successfully implement ACP into routine care practices, HCPs must have both communication and legal competencies. Currently, HCPs' lack of communication skills is cited as a significant barrier to successful ACP implementation (Dixon & Knapp, 2019, 2018; Heyland et al., 2013; Rhee et al., 2012; Rietjens et al., 2017; Silverira, & Rodgers, 2018; Stuart et al., 2017; Vearrier, 2016; You et al., 2014). A critical and rarely explored issue is the impact of HCPs' understanding of legal requirements and obligations as they relate to ACP (Cartwright et al., 2013; White et al., 2014).

Purpose

My primary research purpose is to explore HCPs' understanding of the legal requirements and obligations imposed by British Columbia's laws throughout the ACP processes. The secondary purpose is to identify key factors contributing to implementation challenges and limited system success with informants, provide recommendations, and explore practical solutions. Through this study, I seek to understand how legal obligations contribute to HCPs' ability to support patients and families through the ACP process.

Ethics approvals were sought and obtained by Athabasca University (see Appendix A) and Fraser Health Authority (see Appendix B).

Research Question

What impact does health care providers' understanding of the law have on system-wide ACP implementation?

Definition of Terms

The following definitions guide this research:

1. Advance care planning is a process that supports adults, healthy and not, to think and prepare for their future health care. It takes place over time and may include family, friends, health care providers, and legal professionals (Dhillon et al., 2018; Dixon & Knapp, 2019, 2018; Heyland et al., 2013; Rietjens et al., 2017; Stuart et al., 2017; Sudore et al., 2017).
2. Advance directives are legal planning documents where persons appoint a substitute decision maker, someone who will make health care decisions for them if they cannot, or consent or refuse consent to specific treatment interventions that they do or do not want (Cartwright et al., 2013; Ries et al., 2018, 2016; Rush, 2005; Russell & Detering, 2018; White et al., 2014). In British Columbia (BC), the legislation governing the appointment of substitute decision makers or proxy directive is the *Representation Agreement Act;* consent, temporary substitute decision makers, and instructional directives by the *Health Care (Consent) and Care Facility (Admission) Act*. Note: a power of attorney in BC is for financial and legal matters.
3. Medical Orders for Scope of Treatment (MOST), Goals of Care Designation (GCD), and Physician Orders for Life Sustaining Treatment (POLST) are medical orders made by a health care provider in conjunction with patients or their family and SDMs. They are not consent documents.
4. Health care providers (HCP) refer to disciplines working in health care such as doctors, nurses, social workers, occupational therapists and paramedics.

Chapter 2. Background and Literature Review

Background

At the end of life, 30% of Canadians receive medical interventions that do not align with their wishes (Heyland et al., 2013). Rates of cardiopulmonary resuscitation before death are increasing, and one-fifth of deaths occur in intensive care settings (You et al., 2014). ACP is an effective process to ensure that the medical care patients receive aligns with who they are and what is important to them (Dhillon et al., 2018; Heyland et al., 2013; Rietjens et al., 2017; Stuart et al., 2017). This process supports adults at any stage of health or illness to understand and share their values, life goals, and preferences about future medical care (Sudore et al., 2017).

The benefits of ACP include fewer life-prolonging interventions and hospital admissions, which decrease system costs, better patient-family-HCP communication, and fewer complicated grief outcomes for family members, which results in improved quality of life for the patient and their family (Dhillon et al., 2018; Heyland et al., 2013; Rietjens et al., 2017). Despite these benefits, challenges and barriers exist and include lack of HCP confidence, poor communication skills, lack of time, minimal trust in other disciplines, role confusion, and inaccessible documentation (Dixon & Knapp, 2018).

ACP is a complicated process. It is fraught with a complex medical and legal history resulting in confusion over language and the definition of the term itself locally, within countries, and internationally (Russell & Detering, 2018). This challenge is compounded by varying laws within and between provinces, territories, states, and countries (Rush, 2005; Sabatino, 2010).

Legal History of Advance Care Planning

In Canada and the United States, courts have provided judgments regarding health care consent conflicts and interpreted advance directive documents, or lack thereof, for over a century. The outcome of these cases has significantly shaped clinical practice. This medical and legal history provides insights into the challenges and enablers for current day ACP practices and processes.

Common Law

Although it was not until the 1990s that the term ACP appeared in the literature, I believe a court case from the early 1900s illustrates the early impact of medical and legal intersections. In 1908, Mary Schloendorff was admitted to a New York Hospital, subsequently diagnosed with a tumour. She consented to be examined under anesthesia but withheld consent for surgical removal of the tumour. The doctor disregarded her wishes and removed the tumour. Ms. Schloendorff experienced complications following the surgery and filed a lawsuit against the hospital (Silverira & Rodgers, 2018). The judge presiding in this case, Justice Benjamin Cardozo, wrote in the Court's decision:

> Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. (Schloendorff v Society of New York Hospital, 1914)

Since this case, patients, families, and HCPs have relied on the courts to resolve uncertainty and conflict in health care practices. Several seminal cases provided some legal clarity of capable and incapable patients' legal health care consent rights and SDM rights and responsibilities (Borenko-Hoffmann, 2019). However, legal ambiguity remains, which impacts daily clinical practice. For example, it remains unclear if physicians must provide treatments not medically indicated and whether patients and SDMs can decide on treatments they receive, irrespective of medical opinion (Hillary, 2017).

Advance Directive Legislation

In the 1970s, Ontario and Alberta introduced instructional directive legislation. Due to upcoming government elections, these laws were not passed (Rush, 2005). It was not until the 1990s and 2000s that many Canadian provinces and territories introduced and passed advance directive legislation. As of 2020, all provinces and territories, except Nunavut, have enacted proxy directive legislation, and eight out of thirteen have instructional directive legislation.

Medical Assistance in Dying

In 2016, Bill C-14, An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying or MAID), was enacted by the Parliament of Canada. Eligible Canadians who meet specific criteria have legal rights to request medical assistance in dying. This law's enactment illustrates some Canadian citizens' readiness to challenge and ensure their rights and freedoms related to their health and death. Similarly, limiting eligibility criteria and the rights of HCPs to be conscientious objectors illustrates the need to balance rights and risks for individuals and society. A report commissioned by the federal government to review contentious sections (Council of Canadian Academies, 2018) and two legal rulings illustrate the challenges faced by society, individuals, legal and government institutions.

Literature Review

I conducted literature searches in the following databases: ABI/INFORM, Pubmed, Cochrane, JSTOR, CINAHL, Academic Onefile, PsycInfo, Canadian Legal Information Institute Academic Search Complete, Athabasca University Library, and Google Scholar. The keywords used in this literature search included: ACP and the law, ACP legalities, clinician health law knowledge, and health law. Two articles were identified as relevant and current to the specific topic of ACP and HCPs' knowledge of legal requirements (Cartwright et al., 2014; White et al.,

2014) while eleven others provided supporting evidence of the consequences of the impact HCPs' understanding of the law has on ACP. I reviewed reference lists in chosen articles for additional relevant resources. The literature search was limited to articles written in English. Articles not chosen did not contain information specific to ACP, the law, and HCPs. The majority of research in this area is from North America and Australia.

Reviewing the literature helped identify gaps and develop more insightful questions (Yin, 2018) about HCPs' understanding of ACP and the laws that impact successful implementation. I identified four themes from the literature review. These are discussed below.

Theme One: HCPs Lack Legal Knowledge

A recent theme emerging in the literature is the recognition that there are significant gaps in HCPs' knowledge of the law surrounding the ACP process; however, this is often a small mention and part of a more extensive study (Dixon & Knapp, 2019, 2018). In one Australian survey study, 1000 physicians had critical gaps in legal knowledge. For example, less than half knew how SDMs gained their authority (Cartwright et al., 2014). In another Australian survey study of 867 physicians, the mean knowledge score of the law was less than half (White et al., 2014). The failure to understand and comply with the law has significant consequences for patients. These studies urge improvement for physician knowledge in this area (Cartwright et al., 2014; White et al., 2014). HCPs' lack of understanding of the law is a significant barrier to ACP success (Carter et al., 2016; Cartwright et al., 2014; White et al., 2014), and physicians do not have the necessary skills or competencies to validate advance directives or understand the roles of SDMs (White et al., 2014). Another study suggests that HCPs' understanding of ACP legal underpinning influences how they approach decision makers in their care settings (Blake et al., 2018). Although two studies clearly found HCPs are deficient in their understanding of health law (Cartwright et al., 2014; White et al., 2014), legal barriers such as these remain unknown and under-investigated (Dixon & Knapp, 2018).

Theme Two: Patient Wishes and Instructions Are Not Always Followed

Health care providers' lack of understanding of health law results in patients' verbal and written wishes or instructions not being followed. Many studies suggest patients continue to receive care that is not wanted nor medically indicated (Dhillon et al., 2018; Noah, 2014; Sabatino, 2010) despite recording their instructions in legally binding documents (Stuart et al., 2017; White et al., 2014). Without a comprehensive understanding of health law, providers tend to err on the side of life, initiating and continuing life-sustaining treatments (Dhillon et al., 2018; Noah, 2014; Stuart et al., 2017).

As legal documents are not standardized, and HCPs are not educated about health laws, this adds to the complexity faced by HCPs in clinical practice. HCPs are uncertain how to respond when a person's advance directive is in direct conflict with the family wishes (Blake et al., 2018). Conversely, when there is clarity about advance directives' legal standing, it improves the likelihood that preferences are known, understood, and respected by family and HCPs (Carter et al., 2016).

Theme Three: HCPs Play a Crucial Role in Health and Legal Processes

The technological advances in medicine over the last 50 years have blurred the lines between artificial life and death. Individuals and their families, faced with life prolonged by technology and artificial means who want to discontinue treatments, have turned to the courts. These cases have revolutionized health law and policy and resulted in legislation to support autonomy and choice. However, this has placed HCPs, particularly physicians, in a position where they must be knowledgeable and astutely competent in the area of health law, including consent, substitute consent, and interpreting advance directives (Sabatino, 2010; Vearrier, 2016; White et al., 2014). In BC, two recent court cases illustrate the challenges families and health institutions face when consensus on documented wishes is not reached, and roles and responsibilities of SDMs are unclear (Bentley v Maplewood Seniors Care Society, 2015; Sanders v College of Physicians and Surgeons of British Columbia, 2018). Studies suggest that HCPs are not prepared nor educated for these responsibilities (Cartwright et al., 2014; Rush, 2005; White et al., 2014).

Although it is reported family members accept doctors' recommendations to withhold or withdraw life-sustaining treatment in approximately 98 percent of cases, the remaining cases are contentious and challenged in the court system with increasing frequency (Trask, 2013).

Theme Four: HCPs and Legal Professionals are Not Aligned

The fourth theme identified is a recognition that HCPs and legal professionals are unaware of each other's involvement in ACP and a need for health and legal practices to be better aligned (Berry et al., 2010; Ries et al., 2018, 2016; Vearrier, 2016). Suggestions include joint health and legal clinics, a framework for health and legal collaboration (Ries et al., 2016), legislation revisions (Rush, 2005), or a communications-based approach (Vearrier, 2016).

A Canadian multi-centre ACP study found 30% of ACP conversations taking place with lawyers, versus 8% with nurses (Heyland et al., 2013). Other studies report lawyers’ active involvement in ACP (Goodridge et al., 2013; Ries et al., 2018). For example, in Saskatchewan, half of the respondents to a public survey reported support from a lawyer, versus 5% from a physician, to complete ACP documents (Goodridge et al., 2013). In an Alberta study, 70% of lawyers state they support people to complete advance directives daily or weekly, 30% monthly, yet were unaware if the documents made were useful to future medical situations (Ries et al., 2018). Social media is a means to direct attention to this topic. A recent blog by a physician states that the language of legal documents needs to change and suggests that advance medical decisions should not occur in law offices (Heyland, 2019).

Changing ACP Literature Landscape

The number of ACP research studies has significantly increased in the last decade. For example, a search of the term ACP in CINAHL garnered one study in 1990; in 2019, this increased to 650. Some, but not all studies, have reported positive benefits of ACP. Consequently, some researchers question the utility of ACP. Two commentary editorial articles recommend eliminating ACP with new approaches and terminology (Heyland, 2020; Morrison, 2020). The ACP research landscape is changing. Authors of a recent scoping review on ACP randomized controlled trials on interventions and outcomes urge future research to explore the complex interdependent socio-ecological systems that impact ACP success (McMahan et al., 2020). This study further concludes that, to date, researchers are conducting very little research at the meso or macro levels such as community, health care system or policy. Conversely, most research has taken place at the micro or patient and SDM level (McMahan et al., 2020). This article proposes future research consider addressing at least six pillars of inter-reliant socio-ecological ACP systems and suggests that each pillar requires standardized measurements to further the field of ACP.

Summary

Advance care planning history illuminates that clinical medical practices are directly influenced by advance directives, consent, and substitute consent legislation, and common law. To date, the literature has focused at the micro level, notably HCPs' communication skills and public interest as significant barriers to success. My literature review revealed two articles

(Cartwright et al., 2014; White et al., 2014) specific to the topic of ACP and the law, posing additional challenges. My study, the first of its kind in Canada, will, through interviews with ACP experts, review of health authority documents and policies, and my retrospective observations, uncover the impact this knowledge gap has on daily patient-clinician interactions.

Chapter 3. Methods

Introduction

Case study is a research methodology increasingly utilized in health policy analysis (Yin, 2018). While a challenging endeavour for experienced and novice researchers due to its lack of unified structure, it was the best method to achieve my research goals. Yin's (2018) application and procedures were the primary source of guidance in my research. For example, during the data analysis phase, I manipulated participants' key points and reflected on themes and sub-themes for several weeks. Though my propositions shaped my research, I intentionally followed an inductive strategy allowing the data to lead to concepts not previously known to me.

Part 1: Case Study Research

Case study research shares some general features with other qualitative approaches and has some unique features. Characteristics of case study utilized in my research include:

1. In-depth analysis of complex case and study questions: A unique feature of case study is its specific focus. Case study provides an in-depth analysis of a complex real-life case (Bhatta, 2018; Creswell & Poth, 2018; Yin, 2018). A fundamental principle is a belief that a better understanding of the issue is gained by focusing on a part, not the whole (Creswell & Poth, 2018; Gerring, 2004). Further, as with other qualitative methodologies, there is a fundamental belief that experiences are socially constructed based on individual socialization, experiences, and mental processing; this research tries to understand these experiences in real-time (Ridder, 2017). As such, case study research is an iterative process answering the “how” and “why” questions (Yin, 2018). This research topic is complex, and the phenomena of ACP processes within the context of HCPs varied

personal, professional, educational, and institutional factors add to this already existing complexity.

2. Single bounded case: Additional principles of this methodology are that it typically involves small bounded cases, and the goal is not to generalize but to better understand the studied person, persons, problem, or issue (Creswell & Poth, 2018; Yin, 2018). A single case design was utilized in this research because it is:
    a. Critical – the impact of HCPs knowledge of health law on ACP could help refocus current educational programs within and outside of degree programs and promote future research investigations
    b. Extreme or unusual – this is an area not yet explored in BC or Canada nor with HCPs other than Australian physicians, and the values of the study could impact current ACP processes, education, and future research
    c. Common - although this is an unknown area, this issue impacts daily clinical practice
3. Multiple sources of data: Another unique feature and foundation of case study is its depth of understanding of the case, which means many forms of intensive data collection and multiple sources of evidence, such as interviews, observations, and the review of policies or other supporting documentation, are required (Bhatta, 2018; Creswell & Poth, 2018; Yin, 2018). My research utilized multiple sources of data.
    a) Interviews. Interviews were completed with convenience, non-randomized BC ACP experts who hold regional positions within their organization and have experience developing, delivering, and supporting clinicians to understand ACP processes. Participants interviewed were from various disciplines and included a

social worker, a physician, and two nurses. Prior to the interview, potential participants were provided an Invitation to Participate (see Appendix C) and Letter of Information/Consent Form (see Appendix D). Sample interview questions were utilized (see Appendix E).

b) Documents**.** Relevant policies and educational content from the provincial health authority and five regional health authorities were reviewed and provided further insights into how HCPs learn about ACP, consent, substitute consent, and advance directives. I reviewed data from Fraser Health Authority in-class education surveys and consult services.

c) Direct observations. I created a two-page document of my retrospective professional observations from teaching ACP to over 6,000 health care providers and public members (see Appendix F). Additionally, my regional, provincial and national experiences of engaging and teaching alongside other health authorities, profit, and non-profit organizations, and various non-health sectors such as lawyers and financial planners added to the richness of this observational data.

4. Linking data to propositions: I have worked in ACP for 15 years at a systems level in a regional health authority. I am an ACP expert, devoted to implementing ACP within and outside of health systems and recognized as an ACP leader provincially, nationally, and internationally. I have observed the challenges experienced in clinical, community, and organization areas first-hand. One of my reasons for choosing this topic is my belief that HCPs lack an understanding of the various laws that intersect with ACP processes. I assumed that if HCPs understood these laws, challenges experienced between family members and family members and the health care team would decrease. My goal was to

better understand the reasons for this lack of understanding while formulating potential solutions.

Part 2: Data Analysis

I followed the data analysis spiral (Creswell & Poth, 2018) to analyze the data. The spiral helped to remind me that the analysis process is circular rather than linear. Each interview was listened to several times during transcription. As I began to explore possible themes, transcripts were read and re-read. This process took place over several weeks, primarily between May 11 and June 5, 2020.

I wrote participants' critical points on desk size yellow sticky notes and placed large wall post-its on office walls. I placed common key points on separate wall post-it notes before generating concrete themes. I then reviewed and moved the participants' critical points around until themes began to unfold and make sense to me. As with other qualitative research methods, I generated themes to uncover case findings. I identified four themes.

Once I identified the themes on paper, I moved the data to a computer-based program, NVivo, where further analysis took place. In this program, I collated the data into nodes with the number of files and references identified. For example, the number of files on each data source states how many of the participants said a particular theme, and the number of references indicates the number of times participants said a particular theme. The data organization provided clear and accurate qualitative data for me to review.

Participant word vignettes are used throughout the results to align with case study research (Creswell & Poth, 2018) and ensure the participants' voices and views are forefront. A detailed description of the case, including context, historical and organizational information, and interpretation of the themes that emerge are included. The research findings dictate the document's organization, grouped in similarities and differences (Creswell & Poth, 2018). The case study's final features conclude with detailed descriptions of the patterns and themes and general lessons learned (Creswell & Poth, 2018). This typical case study research reporting process supports my decision to use case study methodology.

Secondary data sources, including six health authorities' policies, Fraser Health consults, surveys, and the researcher's two-page retrospective observational data were imported into NVivo. Throughout the analysis, I ensured time for reflection and incorporated different ways to explore the data. Transcripts were re-read many times to ensure views were not under-estimated or under-reported. For example, one participant had different views than the other three participants on a few topic areas. Therefore, I re-read this transcript on multiple occasions.

Data analysis was inductive and thematic (Yin, 2018). For example, I continuously explored and re-explored common themes, and as I wrote each chapter, data was re-reviewed.

Other case study experts emphasize that readers of the case study play an essential role in generalizing. It is up to them to decide if the resulting themes resonate with their lived experiences (Stake, 2010). I provided a detailed description of the study context (Creswell & Poth, 2018; Pearson et al., 2015) to provide space for the reader to determine generality and transferability.

Summary

Case study research was the best method to meet my goals due to its unique characteristics. It is a methodology that scientifically explores and provides an in-depth understanding of a real-life case, issue, or problem (Creswell & Poth, 2018; Mohammed, 2018; Yin, 2018). I determined that multiple sources of data would be required to explore this complex issue adequately. Therefore, I conducted interviews, reviewed relevant documents, and categorized observations. The impact of HCPs' understanding of the law is critical to clinical practice, will potentially refocus educational programs, and transform patient and family experiences. Yin's (2018) application and procedures were the primary source of guidance for data analysis.

Chapter 4. Results

Introduction

Despite the increasing attention and importance placed on ACP, barriers persist at the clinical, community, and organizational levels. Reasons for these barriers identified in the literature and clinical practice include lack of HCPs' communication skills and lack of patients' engagement in the process (Dixon & Knapp, 2019, 2018; Heyland et al., 2013; Rhee et al., 2012; Rietjens et al., 2017; Silverira, & Rodgers, 2018; Stuart et al., 2017; Vearrier, 2016; You et al., 2014). A reason unexplored is HCPs' understanding of health laws that intersect with ACP and its impact on patients and families.

To explore this issue, I conducted interviews, reviewed documents, and categorized retrospective observations. I analyzed and themed the data. This data constitutes the basis for this chapter, and analytical results that is divided into the following sections:

- Section 1: Interviews,
- Section 2: Documents, and
- Section 3: Observations.

Section 1: Interviews

Four interviews took place between March 7, 2020, and April 20, 2020. Two were in-person, and two virtually on Skype. Of the two virtual interviews, one participant chose audio recording and one video recording. Interviews lasted between 30-46 minutes, with an average of 40 minutes. I chose participants for their ACP implementation expertise within complex regional health care systems in BC. Participant demographic information is listed below (Table 1).

Table 1

Participant Demographics

Participant	Employer	Current Role	Previous Specialty
Registered Nurse 1	Fraser Health	Regional Nurse Clinician, ACP	Cardiac Services
Registered Nurse 2	First Nations Health	Clinical Nurse Specialist, End of Life and Palliative Care	Long-term Care
Medical Doctor	Alberta Health (Formerly Fraser Health)	Palliative Care Consultant	Program Medical Lead, PC General Practice
Registered Social Worker	Providence Health	Leader, ACP	Renal Services

Note: To distinguish participants, I have identified them by their discipline: Registered Nurse 1, Registered Nurse 2, Medical Doctor, and Registered Social Worker.

I identified four key themes: 1) all HCPs need to know the law; 2) Canadian and BC laws are complex; 3) ACP and health law are not adequately covered in HCPs' degree education, and 4) closing the knowledge gaps is multi-faceted. Participant salient quotes illustrate main points with my bolding added for further emphasis. I discuss four main themes below.

Theme One: All HCPs Need to Know the Law

In addition to the above central theme, I have drawn three subsequent sub-categories from the interviews:

a) Foundational basics: HCPs need foundational knowledge of advance directives, consent, substitute consent, and roles of substitute decision makers in order to support and encourage the ACP processes effectively;

b) Professional disciplines and setting of care: HCPs require this foundational knowledge irrespective of professional disciplines and setting of care; and

c) ACP is a misunderstood and unrecognized skill: HCPs are unaware when they do not uphold the law as it is not a core education or clinical skill.

a) *Foundational Basics*

All participants stated all HCPs, regardless of the clinical care setting they work in, need to know the fundamental basics of health law. Participants said HCPs need this knowledge to effectively support and encourage patients to begin the ACP process, provide on-going assistance, support within that process, and enact any expressed wishes or instructions. Specifically, all participants commented that all HCPs needed to know how to support patients to make an advance care plan, create a medically indicated and legal advance directive, appoint a substitute decision maker, interpret documents and translate documents into medical orders. They stated all HCPs needed knowledge in all areas. For example, one participant said:

> I think there's a basic foundational level of understanding around legislation that should be required for all health care providers, regardless of [the] setting of care [they work in] …**even a family doc who has a predominantly young population**. I would want them to start preaching around advance care planning early (Medical Doctor).

b) *Professional Disciplines and Setting of Care*

All participants said they did not believe that different health care disciplines - nurses, and physicians, for example - need to know different aspects of consent, substitute consent, and roles of substitute decision makers. Conversely, all stated HCPs needed to be knowledgeable in all areas of the ACP processes. Further, all participants said HCPs who work in different care settings, such as community or hospital, need to be aware of and competent in all ACP processes. When I asked if HCPs experience legal challenges differently in different care settings, one participant stated, “I think it's the same knowledge challenges because the legislation is legislation that's never going to change, but what's always changing is the medical context” (Registered Nurse 1).

This participant and another participant articulated that conversations differ when a patient is capable or incapable. For example, one participant said:

> ...somebody who is capable and can express their wishes…the advocacy role [for the HCP] is just encouraging the person to express their wishes... [whereas when a person is incapable] …**it’s uncomfortable to go against what the family are saying** and say ‘that’s not what I think your mother or father would want’ (Registered Nurse 2).

Additionally, all participants said the ACP conversations change depending on a person's health status, which often aligns with where they are residing. For example, most people living at home can engage in ACP conversations and create documents. Many people living in long-term care cannot make their own decisions; therefore, HCPs interact and take direction from SDMs. One participant noted, “…different health care providers have different roles and responsibilities… depending on where they are meeting and working with the patient in their health journey” (Registered Social Worker).

Participants further noted the importance of being aware of who is providing health care, as this is changing. One participant included speech therapists and occupational therapists when discussing HCPs (Medical Doctor). Another participant mentioned physiotherapists and pharmacists (Registered Nurse 1). A third participant commented that paramedics are also providing health care and delivering it in new ways, such as providing palliative care to patients in their homes rather than transferring them to hospital care (Registered Nurse 2). This HCP worried that paramedics only receive clinical training such as pain and symptom management and not ACP education.

Nonetheless, all participants re-iterated that a universal ACP understanding is essential for all HCPs, whether physicians, nurses, social workers, or other health care providers.

c) *ACP is a Misunderstood and Unrecognized Skill*

Two participants stated it took them five years of direct care practice to be competent with clinical tasks such as starting a transfusion or intravenous. During this time, they did not know about or practice ACP. All participants said, as ACP is unknown, HCPs are unaware when they do not uphold the law, such as when a SDM is not fulfilling their role. As a result, HCPs are unaware of when they should reach out to supportive internal resources such as risk management, legal services, or ACP teams. Participants noted this lack of knowledge exists as ACP is not a core competency in those first years of practice. One participant said, “My biggest worry is that people don't even realize that they're in a situation. So, they don't know that they need to reach out and ask for help” (Registered Nurse 2). Three of the four participants said medical and legal errors are common, occurring daily, mainly when a HCP believes that patients or SDMs independently decide what medical treatments they should receive. Another participant went further and stated, “I think a lot of people are just simply not aware. I don't think it’s a purposeful intention [getting]…consent from the wrong person…” (Registered Nurse 1). Another participant noted:

> I think there's significant confounding differences between what situations are ethical considerations versus legal considerations. And I think if we as a culture start to talk more about legal aspects, not fear of litigation…**the more we are able to arm ourselves with correct legal understanding, we may not be so fearful of threats of legal action** because we have a deeper appreciation of the law" (Medical Doctor).

Participants said ACP is not accurately understood. They stated this is a further reason for all HCPs to know about all ACP processes and the law's importance throughout this context. All participants stated, before they began to engage with ACP experts in their practice, they misunderstood ACP. For example, one participant said:

> I think I had always had a more general understanding of advance care planning as a patient's choice to choose to, in advance, consent or refuse certain treatments that may or may not come down the line and that it was almost like **a menu of choices** (Medical Doctor).

Another participant stated: "I thought, oh, it [ACP] was just the patient choosing the things that they want or don't want, and we document them. And then, as I started to develop workshops, **I realized how integral the legal pieces were**" (Registered Nurse 1).

A third participant said, "I think what we need to strive for is that there is a deep an equal understanding of the law across all sectors around advance care planning" (Registered Social Worker).

All participants commented, regardless of the care setting in which HCPs work or their specific discipline, all HCPs need to know the foundational basics of ACP. All participants said that because ACP is a misunderstood and unrecognized concept and skill, this further reinforced a need for a universal understanding.

Theme Two: Canadian and BC Laws are Complex

I identified a second theme from the analysis of interview data: Canadian and BC laws are complex. I grouped participant data further as follows:

a) HCPs misinterpret consent;

b) HCPs are unaware of substitute decision makers' roles and responsibilities;

c) HCPs misunderstand legal standing of advance directives; and

d) Lack of federal laws increases confusion of consent, substitute consent and advance directives.

All participants said they were unaware how profoundly health laws affected their daily clinical practice until they specialized in ACP. However, all participants commented that once they began to understand ACP, the laws' complexities were increasingly predominant. One participant stated:

> …even for myself, **it has been an evolving area of deeper and deeper understanding** in terms of where the legal nuances, especially around the consent legislation for BC, intersects with decision making when a patient has capacity and especially important when a patient loses capacity, and, ultimately advance care planning is about making medical choices in a time of incapacity, so the two are intrinsically linked (Medical Doctor).

As previously noted, all participants commented that ACP is misunderstood. Another participant said, "…we think that advance care planning is simple…it's just about having a conversation. But then, as we engage in advance care planning, we realize that there are these layers of complexity related in part to the legislation (Registered Social Worker).

Another participant spoke to teaching ACP to HCPs and the importance of linking the legalities into the curriculum:

> … [as a] facilitator for…[ACP] workshops where we teach other clinicians about the fundamentals of advance care planning, all of the pieces of legislation and law that surround it and influence advance care planning and then…how do we take that and... put it into real-life experiences? How do we have conversations using various tools… [after workshops] clinicians…reach out…for advice on practice implementation (Registered Nurse 1).

a) HCPs Misinterpret Consent

Three participants termed the laws in BC as having “nuances.” When asked to explain further, they noted that consent, in theory, seems to be and is presented in school and practice as relatively simple. One participant stated, “We know we're supposed to get informed consent. Everybody knows that and every medical student can say that you need informed consent, but…I'm not sure there are universal standards of what that looks like, what that means…” (Medical Doctor).

During the interviews, each participant spoke about HCPs' lack of understanding that consent is only required by patients or SDMs for medically indicated and offered treatments. In an interview, this concept was stated: “We think we need informed consent when we're not offering something” (Medical Doctor).

b) HCPs are Unaware of Substitute Decision Makers Roles and Responsibilities

Three participants spoke about how treatment and care plans are often made by whoever is present at the time these discussions take place. They noted that HCPs do not clarify if they meet the legal SDM criteria or adequately fulfill their SDM responsibilities. They obtain consent from who is “at the bedside.” One participant stated:

> They [HCPs] have the wrong language. They talk about next of kin, or...proxy, or I've even heard clinicians say power of attorney. All incorrect and potentially they could be getting consent from the wrong person… ignorance is huge, and they **[HCPs] don't know what they don't know**. But these things have consequences for patients (Registered Nurse 1).

All participants noted that HCPs are often unaware that SDMs, legally appointed or not, must decide based on the person’s previously expressed wishes and instructions. In practice, this has repercussions for patients, as illustrated by this participant’s comment:

> …the other piece…we're not paying enough attention [to is], that regardless of whether it's a representative...or a temporary substitute decision maker, the person making substitute consent...has to make a decision based on the patient's best interests...that's...the law...[but] people don't respect that either. They ask the wrong questions and, our substitute decision makers end up making decisions for themselves...**we're not guiding them in the right way to make the best decisions [the one the patient would make for themselves]** (Registered Nurse 2).

The roles and responsibilities of SDMs are clear, written into BC law, yet many HCPs are unaware or unsure how to put this into practice. One participant discussed how many nurses, in particular, are relieved when they learn that the law outlines qualifications to be an SDM, such as contact in the last year with the person. This participant said:

> Nurses talk about having a plan for a client...then a family member comes into the situation that wasn't previously involved ... sabotaging the plan …when [they]...don't have the right to sabotage that plan. Nurses generally don't know that and are quite relieved when I tell them that... **But they didn't know to ask, 'Who do I listen to?'** (Registered Nurse 2).

c) HCPs Misunderstand Legal Standing of Advance Directives

Additionally, HCPs often misunderstand legal documents. For example, if a person has a legal document naming them as the SDM (Representation Agreement in BC), HCPs feel that they cannot speak to anyone else. One participant commented:

> ...there's a lack of understanding...if there is a representation agreement, who deserves to have information...there's a misinterpretation...health care providers will say, 'I will only now give information to the representative and not give information to anybody else'… (Medical Doctor).

d) Lack of Federal Laws Increases Confusion of Consent, Substitute Consent and Advance Directives

Three participants noted that adding to already existing complexity provincially, the laws differ across the country, which adds to the confusion. One participant said:

> "… [there are] too many pieces of legislation. It's not intuitive…And I think... on top of that...the provinces and territories are different in Canada. [There is a] need for a federal – simple, simple, straightforward piece of legislation" (Registered Social Worker).

All participants said this has an impact on HCPs, community members, and communities in general. Another participant commented, "…what I'm coming across is Indigenous Peoples who live in eastern Canada see advance care planning and how to have those conversations in a different, slightly different way than how we're seeing it in BC" (Registered Nurse 2).

This participant further noted many First Nations communities have lived under federal jurisdiction. As a result, there has been minimal exposure to provincial laws: "…when the consent law came into BC, the nurses…working in First Nations communities…were working under Health Canada...there was no education for them around a provincial consent law because their employer was federal (Registered Nurse 2).

All participants stated that the laws in this area are difficult to understand, and three noted that the lack of federal uniformity adds to the complexity. All participants said that when they realized the laws of consent, substitute consent, and advance directives impacted care provided to patients, it changed their clinical practice and how they teach other HCPs about ACP.

Theme Three: ACP and Health Law Are Not Adequately Covered in HCP Degree Education

None of the participants felt that their university nursing, social work, or medical degree program prepared them for ACP conversations or to understand the laws that intersect with ACP. All participants stated that HCPs learn about ACP in practice, alongside colleagues who often do not accurately understand ACP or the laws that affected this process. All spoke that early in their careers, they viewed and understood ACP solely as a patient's choice and autonomy. For example, one participant said:

> I [thought]…ACP… was a patient's… menu of choices… 'I never want dialysis. I never want to have a tube feed,' and I suppose in the back of my mind, I knew that consent had to

> do with it. But it wasn't until I started to practice palliative care, did I start to realize that the **legislation was a key component of it and that I needed to have an understanding of the legislation**...that probably happened? Maybe five, six years after starting my palliative care career (Medical Doctor).

All participants commented that ACP is not a core competency for HCP education, noting that several years' focus is to learn medical treatment tasks. Two participants said that ACP is seen as a “soft skill” or a “nice to have” at some point in their career. One participant said, “I think what we find is people… [think] advance care planning is just about a conversation. Sometimes it takes years for people to get it” (Registered Social Worker).

As HCPs do not receive education before beginning their career, I was interested to learn from the participants regarding how much knowledge they believed their colleagues had about ACP. I asked participants to rate, on a Likert scale of one to five, HCPs’ understanding of three areas: a) consent, b) substitute consent, and c) advance directives. I also asked participants to think about their discipline, specifically, as well as other HCPs. Though not all, many chose to break down the rating into discipline groups to illustrate their perspective variations. All participants noted that ACP knowledge drastically varies from person to person, so they stated it was challenging to provide answers. Three noted that as new graduates from any discipline receive minimal training, their rating would be lower, but two also said that some seasoned HCPs were unaware.

a) HCPs' Understanding of Consent

In terms of HCPs' understanding of consent, the participants' responses were quite varied. Overall, participants said social workers had a greater understanding of consent laws, followed by nurses and physicians.

One participant stated, "… overall, I'd say it's fairly poor. I don't know, two, maybe" (Registered Nurse 1). Another participant said, "physicians…around one or two… social workers I would think maybe closer to four. Other health care providers again, one to two" (Medical Doctor). A third participant felt there were differences between nurses who work in particular settings, attended education, or traditionally had worked under federal laws.

> …thanks to...sessions that have been held by experts in advance care planning. I think we've [First Nations Health Authority] moved the [nurses] from a zero to a one or two… [nurses working in long-term care] I think I would give a three, they'd definitely be higher" (Registered Nurse 2).

Another participant said, "So I would say we're more at kind of an overall four out of five, just generally…at least in my organization… nurses are, are closer to a four… social workers would be a five and doctors a four-point five" (Registered Social Worker).

b) HCPs' Understanding of Substitute Consent

HCPs, according to participants, have a poor understanding of substitute consent laws and consequently SDMs' roles and responsibilities. All participants commented that, in their experience, social workers have a better understanding than nurses or physicians.

When asked on a scale of one to five how much HCPs understand about substitute consent, one participant stated, "only one or two…or less… giving more credit to social work as opposed to nursing…I was one of those people, and I would give myself a one or two" (Registered Nurse 1). Another participant recounted a personal story that occurred six months ago. This person explained substitute consent legislation to a surgeon and nurse in a large BC teaching hospital after being told she was not a SDM to her temporarily incapable adult child, as he was over the age of 19. This participant stated, overall HCPs understand substitute consent laws "…less than one [out of five] (Registered Nurse 2). Another participant said:

> …to some [physicians] two, some, one… as a palliative care consultant [I am frequently] asked to assist with cases where substitute consent is required. And more frequently than not, I'm noticing the lack of documentation…and discovery made around the existence of a representation agreement or existence of previous ACP documents or advance directives? There's often a convenience factor in terms of who's at the bedside (Medical Doctor).

In contrast, one participant stated, "overall knowledge [of substitute consent laws] three to four amongst all healthcare providers…nurses two or three…social workers…more of four, or five, and physicians would be a three and a four" (Registered Social Worker).

c) HCPs' Understanding of Advance Directives

HCPs' understanding of pre-planning tools such as advance care plans, representation agreements, or advance directives was the lowest ranking by all participants. One participant commented that everyone needs to know about ACP tools. They said, "It's not just health care providers. It's all people need to know this so that they can advocate for themselves knowing what their rights are…but I would put HCPs' understanding as a point five" (Registered Nurse 2). Another participant stated HCPs' understanding in this area is "Pretty low. Very low. Alarmingly low. Alarmingly" and ranked HCPs understanding as "One to two, depending on the individual"

(Medical Doctor). One participant noted how difficult it was to provide an overall ranking in this area, stating:

> …experiences or the area of their practice makes a big difference. I don't think it has to do with [their] age. So palliative care tends to know a lot more. It's also the type of person…how much they really value individuals…**nurses overall struggle to learn the nuances of incapacity planning**, so they are a two to three… [physicians] somewhere between the three and four. I think **some physicians know nothing**, or... very little…**social workers, I think have the expertise** around this, but...I still get called from social workers asking for clarification around particular nuance of things. So, it's not a five it's maybe four point five (Registered Social Worker).

All participants described their health care education and early careers as devoid and inadequate of ACP, health care consent, and substitute consent, including roles and responsibilities of SDMs, and advance directives. All stated that they learned about these topic areas in practice. When asked to rate their colleagues' understanding of the consent, substitute consent, and incapacity planning tools, three of four participants rated all but social workers as two or less in all categories.

Theme Four: Closing the Knowledge Gaps is Multi-faceted

Participants shared various thoughts and ideas regarding how to close the knowledge gaps. All commented, many times, that the approaches needed to be creative, on-going, and inclusive. Specifically, all participants noted that closing the knowledge gaps needs to include multiple organizations and partners within and outside university or health settings, involve public campaigns, and two strongly felt that HCPs had a professional responsibility to ensure their practice included ACP. Categories described include specific participant ideas and perceived needs:

> a) Collaboration between medical and legal practitioners;
>
> b) Inclusion in university education;
>
> c) Education and support, including on-going, in-the-moment coaching;
>
> d) Personal and professional responsibility; and
>
> e) Public campaigns.

a) ***Collaboration Between Medical and Legal Practitioners***

All participants said medical and legal communities do not work with one another; one does not necessarily know what the other is doing in this area. The relationship is often adversarial. Participants commented:

> ...the physician is taking the medical piece and the lawyers taking the lawyer piece and doing their independent work, and **they never quite come together**. I think there needs to be some massive, probably provincial, or maybe national processes that need to come together to smooth out some of these wrinkles that are...causing a huge impact (Registered Nurse 1).

> ...when [lawyers are] involved with…health care, a lot of lawyers are acting or representing the public against the health care organization. Health care has done something wrong...they're involved in **litigation against health care**. So that's part of the dynamic… (Registered Social Work).

All participants advocated for collaboration with legal partners. One participant said legal opinions should occur earlier than they currently are, another participant suggested creative ways of learning together through joint communities of practice. This participant said:

> I like the idea of case studies where people present a situation, and then there's a **community of practice** that can discuss it and learn from it…but having conversations with multiple professions, including the legal profession, so that everybody learns from that going forward (Registered Nurse 2).

Another participant said:

> …formalized processes [are needed] to bring the law perspective into our clinical decision making…we need to get legal opinions earlier when we have challenging cases, bring them into the room. [as well as] …**dialogue, mutual learning, and sharing of experiences**…reaching out to law societies and society of notary publics and asking them what their practices are… (Medical Doctor).

b) ***Inclusion in University Education***

All participants felt that HCPs' university degree programs need to include ACP education, but one participant noted there is only so much a non-practicing professional will understand; therefore, front line practice support is imperative. "It's a pretty overwhelming process learning an entire profession, in four years" (Registered Nurse 1).

c) ***Education and Support, Including On-going, In-the-moment Coaching***

All participants stated that health care organizations or employers should be required to provide education in this area. However, three participants noted that education alone does not impact practice; therefore, they suggested additional solutions. "So, …education is huge, but I also see education happening in various areas in health care all the time, and it doesn't...impact practice” (Registered Nurse 1). Another participant noted: “The standard way for education is through conferences, and webinars. But I think we have done that. And clearly, we need something different as well” (Registered Social Worker).

The nurse participants’ spoke about how mentors and “in-the-moment” coaching is imperative to shift nursing practice. One participant stated how important this was for them. One commented, “I also needed a lot of mentorship, which I was lucky enough to receive so that I could continue my learning as different cases came up, different situations came up. So, I see that as being...important” (Registered Nurse 2).

One participant explained how this plays out in clinical settings and how important coaching is.

> I'm an emerg nurse, someone has rolled in the door, we're in the trauma bay, we're intubating. Someone tells me to call family. So, what does that look like? ...how do I know the right person to call...who are my go-to’s, and where do we keep everything? ...the practicalities around the actual execution of where's the rep agreement? Who do we call, who's the substitute decision maker? (Registered Nurse 1).

This participant noted that it is vital for organizations to have someone or a department to call when they are unsure and in this situation.

One participant stated that organizations need to provide education, but they need to provide adequate time and space to illustrate ACP’s importance. Some specific ideas included:

> **A simple phrase posted** around...wards like 'Ensure you're following consent legislation' …[and]… **designated quiet spaces** for advance care planning and goals of care conversations, so that there is privacy...we don't feel so rushed …[then]…we're are sending the message that this is as important as falls, as important as sterility on the surgical site (Medical Doctor).

d) *Personal and Professional Responsibility*

Three participants commented that engaging in personal ACP supports learning and understanding of ACP processes and they advocate for other HCPs to do the same. One participant said, “I didn't...fully understand...what a representation agreement meant until...[I] was doing a representation agreement for myself...I think **all health care providers...should do their own advance care planning**” (Registered Nurse 2).

Participants commented that all professions have annual regulatory college fees, and all must report on yearly education learning and competencies. Therefore, they felt HCPs had a professional responsibility to maintain current in their practice, ACP being a substantial piece.

Two participants noted that regulatory provincial and territorial colleges had a role in supporting ACP. One said:

> I think it will be wonderful for each individual college for physicians and surgeons to create guidelines and policies around the requirements of understanding consent legislation...[similarly], we are getting emails from colleges around proper charting and patient confidentiality. More recently, issues around medical assistance in dying and exercise of conscientious objection, **I very rarely get an email brief around consent legislation** (Medical Doctor).

e) *Public Campaigns*

Two participants said that public campaigns would be crucial to any successful approach. As one participant stated: “Grassroots pressure, where health care providers will then say, I need to know this stuff, because I'm going to be asked about it. My patients are going to ask about this. So, I need to understand this” (Registered Nurse 2).

Participants commented on increasing HCPs’ ACP knowledge, and closing the knowledge gaps would require long-term, on-going, and inclusive solutions. All participants provided ideas that included collaboration between sectors and organizations, including the ACP curriculum in degree programs and widespread targeted campaigns.

Section 1: Summary

Four BC ACP experts were interviewed and provided rich information about ACP from their experiences. From this data, I identified and discussed four key themes. Prominent findings included:

- Due to participants’ retrospective insights and current understanding of ACP, all commented that ACP is a skill that all health care disciplines, regardless of the setting they work, need competency.
- Participants noted that as they began to appreciate the complexity of ACP and the laws that intersect, they commented that an approach that included various levels of government, policy, community, and the public will be required.
- Despite the discipline of participants, all stated that in hindsight, they were unprepared through their education to identify and resolve ACP challenges in clinical practice.

Section 2: Documents

Relevant documents from the provincial health services authority (PHSA) and five regional health authorities were reviewed and provide further insights into how HCPs learn about ACP, consent, substitute consent, and incapacity planning documents. Specific documents reviewed include a) health authority policies, b) health authority education content, c) Fraser Health Authority in-class education surveys, and d) Fraser Health consultative services.

a) Health Authority Policies

The provincial and regional health authorities in BC have distinct policies, procedures, and documents for ACP. I reviewed consent and ACP policies from Fraser Health Authority, Vancouver Coastal Health Authority, Island Health Authority, Interior Health Authority, Providence Health, and Provincial Health Services. Three health authorities combine ACP with Medical Orders for Scope of Treatment (MOST) and various conversation tools such as serious illness and goals of care conversations; two health authorities separate ACP from medical orders. All have separate consent policies (Island Health is in the process of removing ACP from the Consent Policy), and all relevant policies refer to each other.

Fraser Health's Medical Orders for Scope of Treatment (MOST) and ACP Policy include serious illness and goals of care conversations, and there is a separate consent policy. Interior Health's policy structure is the same as Fraser Health. Providence Health has ACP and serious illness combined in policy, and a separate Options for Care (equivalent to MOST) policy. Island Health Authority has consent and ACP policy in addition to a MOST and ACP Policy. The intention is to remove ACP from the consent policy and have it only in MOST and ACP.

b) *Health Authorities Education Content*

I reviewed Fraser Health Authority, Vancouver Coastal Health Authority, Island Health Authority, Interior Health Authority, Providence Health, and Provincial Health Services education content from on-line modules available in the Learning Hub (a web-based platform administered by the Provincial Health Services Authority (PHSA) on behalf of Health Organizations in BC) and classroom session objectives. I note that completion of the modules and attendance to classroom session are not stated as mandatory.

The learning objectives from five health authorities on-line ACP modules include a general overview and understanding of ACP conversations, documentation options, consent, and substitute consent.

c) *Fraser Health Education Survey Data*

Fraser Health has offered in-person six-hour HCP ACP education since the mid-2000s. Attendance is optional, although some managers have mandated attendance, such as some home health offices. A 30-minute online module is a pre-requisite for sessions. Pre and post evaluations from these sessions were completed from April 2019 to February 2020, with a 100% completion rate. Facilitators asked participants to rate on a Likert Scale of 1-5, the following question pre and post education: “I understand key legal and ethical obligations as it relates to ACP.” There was a significant increase in post-class. Before the class, HCPs stated they understood ACP and health law 62% of the time, and post-session, there was an increase to 89%. The statistical significance is $p = .000$ (see Table 2 and Table 3).

Table 2

Fraser Health Education Survey Paired Samples Statistics

	Mean	N	Std. Deviation	Std. Error Mean
I understand key legal and ethical obligations as it relates to ACP PRE	3.102	244	1.0111	.0647
I understand key legal and ethical obligations as it relates to ACP POST	4.455	244	.6103	.0391

**p=.000

Table 3

Fraser Health Education Survey Paired Samples Correlations

	N	Correlation	Sig.
I understand key legal and ethical obligations as it relates to ACP PRE & I understand key legal and ethical obligations as it relates to ACP POST	244	.384	.000

**p=.000

d) Fraser Health Consultative Services

The ACP team at Fraser Health provides consultative support across the region. HCPs are encouraged to reach out for support should they have questions about understanding SDMs' responsibilities, applying documents or stated wishes into a current health context, supporting patients to execute legally binding documents, or navigating family conflict. HCPs typically connect with the ACP team when there is family conflict. Examples include when SDMs ask for treatments not offered, such as cardio-pulmonary resuscitation, or when SDMs decline to consent to pain medication when medically indicated. In some cases, patients have made their wishes clear, completed documents, and SDMs refuse to honour those wishes. HCPs are often unaware that SDMs have responsibilities, and can be legally disqualified, if they do not fulfill their legal role and responsibilities.

An internal Fraser Health database document noted, between April 2019 and May 2020, HCPs contacted the ACP team 111 times. Forty-eight percent or 54 of the calls were legal. For example, I coded calls as legal when HCPs inquired about SDMs' roles and responsibilities, questioned content of representation agreements, or required clarification about consent laws. Of these, 55% or 25 were from acute care settings, and 35% or 19 from the community. Long-term care, outpatient clinics, and palliative care clinicians also utilized this service. Various disciplines utilize these consult services, including nurses, social workers, physicians, and leadership, such as managers or directors.

Section 2: Summary

I reviewed health authority policies and education content, Fraser Health Authority education surveys, and consultative support. This data provided further insights into HCPs' learning about ACP, consent, substitute consent, and incapacity planning documents.

Section 3: Direct observations

I wrote a two-page point-form document of my retrospective professional observations from teaching ACP to over 6,000 health care providers. Categories included Fraser Health clinicians, Fraser Health ethics, Fraser Health executive leadership, Fraser Health communications, Fraser Health integrated risk management, and national committees. I noted that all stakeholders held a superficial, not comprehensive understanding of ACP; therefore, the messaging about ACP continued the misunderstanding and misperceptions of ACP.

Internal departments that Fraser Health ACP commonly interacts with include executive leadership, ethics, communications, integrated risk management, and direct care providers. From my experience, these departments often agree in principle that ACP needs to be up-stream and is for healthy adults, yet in practice, they link palliative care with ACP. For example, Fraser Health communications regularly ask for stories dealing with dying patients and has declined publishing stories about younger healthy persons. Recently, an executive leader requested all ACP move to the intranet under specialized seniors' services. Additionally, Fraser Health's ethics discussion framework does not explicitly include the law, nor do they routinely include ACP, risk management, or legal services in a co-consulting capacity.

ACP has a national platform supported by Health Canada and managed by the Canadian Hospice Palliative Care Association. Although ACP is a separate subsidiary, until a year ago, the national logo tag line was: Speak Up: start the conversation about end of life care. Social media posts have, at times, been focused solely on palliative and end of life care. Some nationally funded ACP projects include one specific sector of care, for example, long-term care or home care, rather than patients' journeys through these systems.

Throughout the last 15 years in my regional ACP leadership role, physicians have stated they either did not know the law or, if they were aware, were not willing to go against family and SDMs’ demands due to fear of litigation. Physicians often request an ethics consult rather than involve risk management, legal services, or ACP clinical support. Other HCPs have commented that this is frustrating for them as they know the additional support these resources can provide yet feel that they cannot reach out without the physician’s approval.

Section 3: Summary

My direct observations working in Fraser Health ACP for 15 years have placed me in a unique position to interact with executive leadership, ethics, communications, integrated risk management, and direct care providers. All agree in principle that ACP is for healthy adults and those facing illnesses, yet their actions often default to only seniors or those with an incurable illness.

Chapter 5. Discussion

Introduction

My primary research purpose was to explore HCPs' understanding of the legal requirements and obligations imposed by British Columbia's health laws that intersect with ACP processes: consent, substitute consent, and advance directives. The secondary purpose was to identify key factors contributing to implementation challenges and limited system success and provide recommendations and explore practical solutions. Through this study, I sought to understand how legal obligations contribute to HCPs' ability to support patients and families through the ACP process. The following research question guided this study: what impact does health care providers' understanding of laws have on system-wide ACP implementation?

I conducted four interviews, reviewed health authority policies and education content, analyzed Fraser Health's education survey and consult data, and categorized my retrospective observations. I identified four themes from the interviews. Documents and observations provided further insights into the challenges HCPs encounter as they seek to understand the laws of consent, substitute consent, including roles and responsibilities, and advance directives that interface with ACP system-wide implementation.

This chapter discusses interview themes, supplementary health authority documentation, limitations, and recommendations from my lens. It includes how my research contributes to the current research and supports addressing gaps in the literature. COVID-19 was not part of the intended research; however, I have included it as it has impacted individuals' and organizations' current and future ACP outlooks.

Section 1: Interviews and Themes

a) *Theme 1: All HCPs Need to Know the Law*

All participants stated that HCPs, irrespective of their discipline or setting of work, need to understand all ACP processes. These processes include consent, substitute consent, including roles and responsibilities of SDMs, and support for the creation and interpretation of advance directives. This contradicts previous findings that different skills were needed to, for example, support the creation of advance care plans in comparison to interpreting documentation (Cartwright et al., 2014; White et al., 2014). These studies were limited to one country, Australia, and one discipline, physicians. The differences in my study may be due to the inclusion of nursing and social work perspectives. It may also be that ACP expert knowledge has expanded, changed, and grown over the last six years.

The participants in my study acknowledged that the disciplines providing health care are changing. As a result, HCPs who require ACP knowledge have expanded from solely health authority nurses, physicians, and allied staff to community-based pharmacists and paramedics. I recognize that HCPs outside of health authorities are often overlooked as important ACP stakeholders and contribute to the success of system-wide ACP implementation.

I was not surprised that participants stated ACP was a misunderstood, undervalued, and unrecognized clinical skill. However, I was surprised to learn that two participants stated the focus for the first five years of their nursing and physician practice was only mastering medical tasks. Until ACP is recognized as necessary as other medical skill sets and seen as an intervention and sub-specialty, the challenges of ACP implementation will continue.

A recent article highlights that there has been a shift from defining ACP as a legal documentation process to an on-going communication intervention (McMahan et al., 2020). This shift may support the recognition of ACP as a key clinical skill for all HCPs.

b) *Theme 2: Canadian and BC Laws are Complex*

In Canada, we have a publicly funded federal health care system. The federal government is responsible for setting national principles. The provinces and territories are responsible for delivering care. Consent, substitute consent, and advance directive laws are provincial and territorial responsibilities. Therefore, each province and territory have different legal terms assigned to substitute decision makers, and not all have advance directive legislation. Unlike Medical Assistance in Dying (MAID) legislation, the laws that may intersect with consent, substitute consent, and advance directives are not federal.

In BC, six different laws and regulations are interconnected with ACP and include the *Mental Health Act*; the *Patients Property Act*; *Health Care (Consent) and Care Facility (Admission) Act*; the *Representation Act*; the *Infants Act*; and the *Adult Guardianship Act*. These laws were initially passed at different times by various government ministries, and revisions made intermittently and independent of each other. For example, the *Patients Property Act*, which details the authority of a Committee of the Person (highest SDM ranking in BC), was initially enacted in 1965 and revised to its current version in 1996. Also, the Ministry of Health is responsible for the *Health Care (Consent) and Care Facility (Admission) Act,* which includes the advance directive form, and the Ministry of Attorney General is responsible for the *Representation Agreement Act*, which includes representation agreement forms. Having different government departments responsible for singular pieces of the ACP processes has resulted and perpetuated the unlinked approaches that affect ACP.

I believe that these laws are disjointed and add to the complexity and confusion experienced by HCPs. In clinical practice, HCPs require a working knowledge of all six laws to effectively engage in ACP with patients and their families. However, this seems an impossible task.

The Uniform Law Conference of Canada, an organization with nationally appointed commissioners, has been hosting annual conferences since 1918 to promote uniform legislation among the provinces and territories. This institution does not mandate the implementation of proposed laws but provides a forum for provincial and territorial governments to harmonize laws (Uniform Law Conference of Canada, n.d.). For example, in 2016, they adopted the *Uniform Interjurisdictional Recognition of Substitute Decision-Making Documents Act*. In 2018 and 2019, the Alberta Law Reform Institute recommended adoption, but this has not occurred (MacKenzie, 2019). This aligns with other research that argues harmonizing laws across countries, Canada and Australia for example, would increase ACP uptake and success (Carter et al., 2016; Cartwright et al., 2014; Rush, 2005; White et al., 2014).

A recent Ontario case, Wawrzyniak v. Livingstone, provides further clarity regarding when consent is not required and may influence jurisdictions outside of Ontario (Downar et al., 2019). In this 2019 judgment, the Ontario Superior Court of Justice stated that physicians do not need consent for a treatment not offered (Downar et al., 2019). Therefore, consent is needed to perform resuscitation (CPR), but consent is not needed if the order is not to resuscitate (DNR). In this case, Judge Cavanagh ruled that neither patients nor their SDMs can insist or demand treatments that are deemed by HCPs as medically unindicated (Downar et al., 2019). Participants discussed these issues during interviews. Case law and articles such as Downar provide additional clinical clarity about consent and transference of judgments for HCPs in the future.

c) *Theme 3: ACP and Health Law Are Not Adequately Covered in Degree Education*

All participants stated that HCPs learn about consent, substitute consent, and advance directives while in clinical practice from colleagues who may or may not understand these domains. University curricula do not include this education. I was not surprised by this finding and believe that HCPs' knowledge of the laws is low, in part, because of inadequate academic preparation.

To help resolve HCPs' gaps in communication skills and ACP training, health care organizations have created various solutions. Some health care organizations have developed in-house education programs (Aasmul et al., 2018; Tilburgs et al., 2019). Reputable institutions such as Ariadne Labs (collaborative with Brigham and Women’s Hospital and Harvard T.H. Chan School of Public Health) have created and promote organizations to implement the Serious Illness Conversation Program (Ariadne Labs, n.d.). The need to create these programs illustrate HCPs’ lack of preparation through academia.

Participants stated they found it difficult to rate HCPs' understanding of ACP legal areas as the individual knowledge base is not easily generalized. Overall, participants said social workers knew health care laws better than other disciplines. One stated that palliative medicine clinicians are also more knowledgeable. Unless there are concerted provincial efforts to address curriculum needs, HCPs’ introduction to ACP and health care laws will continue to take place haphazardly in clinical settings.

One participant rated HCP’s knowledge of the laws higher in all categories in comparison to other participants. Participants' scope and size of organizations vary, which may contribute to these differences. For example, one of the participants works at a single site with 4 000 employees, two other participants are responsible for 12 communities and 30 000 employees, and another participant services 200 communities throughout the province with 130 medical centres (St. Pauls, n.d.; First Nations Health Authority, n.d.; and Fraser Health Authority, n.d.). An organization's size difference may indicate that healthcare institutions with smaller numbers of employees may have increased ACP implementation success.

d) Theme 4: Closing the Knowledge Gaps is Multi-faceted

All participants stated that to support HCPs to become competent in the laws that affect ACP, approaches within legal settings, academic institutions, health authorities, and colleges need to be consistent, transparent, and coordinated.

Participants' ideas to close the knowledge gaps included micro, meso, and macro-level collaborative strategies. I agree that without a unified approach, the challenges for ACP implementation will continue. As previously and continuously reported in the literature, ACP is inherently complex (Blake et al., 2018; Dhillon et al., 2018; Russell & Detering, 2018; Stuart et al., 2017). Solutions will therefore be complex and this complexity needs to be taken into consideration for future research (McMahan et al., 2020). The need for medical-legal collaboration, one of my findings, is beginning to be recognized as noted in a recent study that identified strategies to improve and align practices with these professions (Hooper et al., 2020).

One of Health Canada's Action Plan on Palliative Care goals is to "Raise Awareness and Understanding of How Advance Care Planning and Palliative Care Can Improve Quality of Life Until the End of Life" (Health Canada, 2019). Health Canada recognizes that combined efforts of governments, stakeholders, health care providers, caregivers, and communities are needed to achieve this goal.

A recent ACP study indicates agreement with my findings and Health Canada's suggestion for combined efforts while expanding the stakeholders' list. For example, this study proposes six inter-reliant stakeholders, noting that all six must work in tandem for ACP to succeed. Stakeholders include patients, surrogates, community, health systems, and policy (McMahan et al., 2020). In this analogy, the study states that a patient's wishes will be remiss if HCPs' are untrained, systems unprepared, and legislation inadequate.

To adequately address the identified gap of HCPs' knowledge of the law, local, regional, provincial, and federal efforts will be required. Participants identified various practical approaches, and Health Canada and ACP experts acknowledged that it must include multiple stakeholders to be successful.

Section 2: Documents

I reviewed five regional health authorities and the provincial health authority policies and education content that relate to ACP. These documents provided further insights into how BC health authorities understand ACP and may indicate how HCPs understand it.

a) Health Authority Policies

A provincial policy for ACP does not exist. Each health authority has distinct clinical protocols and guidelines. Three health authorities incorporate HCP communication tools such as serious illness, goals of care, and medical orders into regional ACP policies while two health authorities do not. All health authorities refer to ACP policies in their stand-alone consent policies. The inclusion and exclusion of content within ACP policies may perpetuate the issue brought up by participants. Many HCPs see ACP as conversations unlinked from the health laws.

Policy documents reviewed align with the view that all HCPs have a role in ACP conversations. For example, the BC Cancer states under Responsibilities and Compliance in their ACP Policy:

> All Health Care Providers: 1. Document advance care planning conversations in the medical record. 2. Use the serious illness conversation guide to facilitate communication with patients/SDM. 3. Refer to the BC Cancer Introduction to Advance Care Planning learning hub course (BC Cancer Agency ACP Policy, 2019).

b) Health Authority Education

The learning objectives from five health authorities on-line ACP modules indicate that HCPs need a general overview and understanding of ACP conversations, documentation options, consent, and substitute consent. All modules include these as objectives. Modules had various titles, and some language or content appeared outdated. Health authority modules were created at different times and did not cohesively flow, except Fraser Health. For example, Vancouver Island's 2014 “Advance Care Planning and Health Care Consent” did not link to their 2016 “Medical Orders for Scope of Treatment.” In contrast, Fraser Health has an “Advance Care Planning Curriculum Module,” which includes all ACP modules, such as MOST and serious illness. Provincial Health Services “Obtaining Informed Consent: An On-line Guidebook for Healthcare Professionals” lacked practical clinical content.

The education modules and content from five health authorities on-line ACP modules may contribute to confusion about ACP and how ACP resources, tools, and processes link together.

Relevant policies and educational content from the provincial health authority and five regional health authorities may inadvertently contribute to HCPs' lack of understanding and linking of ACP to health laws.

c) Direct Observations

Within my role and experience, the need for regional, provincial, and national organizations to understand ACP, provide consistent messaging with ACP, and work collaboratively is imperative for success. I note that while many organizations and individuals working in them articulate that ACP is for all adults, healthy and with chronic illnesses, ACP is often associated with palliative care, end of life, or dying. Unlinking this ingrained perception will take concerted efforts at all levels, achieved through regular consistent messaging for HCPs and the public.

Fraser Health has provided HCP consultative support across the continuum of care. This service provides coaching and mentoring for HCPs while in the moment of challenging situations with patients and families. Nursing participants commented on how this level of support profoundly impacted their own clinical experiences and noted how it continues to impact clinicians at Fraser Health positively.

My direct observations regionally, provincially, and nationally provided additional supporting data for this research. These observations aligned with the participants’ insights.

Impact of COVID-19 on Advance Care Planning

The COVID-19 global pandemic has changed the world, communities, families, health care systems, and HCPs in profound ways. The emphasis this has placed on ACP can be considered a silver lining. For example, a retrospective study reported a significant increase in visits to an ACP web site and completion of documents (Auriemma et al., 2020). The rapid tool and resource development by international experts and renowned organizations, and numerous webinars hosted and attended, illustrates this new ACP focus. New resources include but are not limited to:

- Respecting Choices: Proactive Planning Resources in the Context of Covid-19 (Respecting Choices, 2020)
- Ariadne Labs: COVID-19 Response Toolkit (Ariadne Labs, 2020)
- Vital Talks: COVID Resources, videos, scripts (Vital Talks, 2020)
- Health Quality and Safety Commission New Zealand: talking COVID (HQSC, 2020)
- Providence Health: COVID Serious Illness Conversations and Treatments (Providence Health, 2020)

COVID-19 has highlighted that older persons and those with chronic illnesses need to plan for their future health care and engage in ACP before a crisis, before a positive COVID-19 diagnosis. Additionally, the pandemic forced HCPs to be more explicit about the health risks associated with age, illness, and the limitations of life-saving treatments. Call to action articles reinforces in the current time, ACP should be a priority for individuals, families, and HCPs (Block et al., 2020; Curtis et al., 2020). As COVID-19 continues, healthy adults and younger adults are becoming infected at increasing rates. These adults may not die from COVID-19 but may become unable to make their own health care decisions for a period of time. The essence of ACP is to provide support to healthy adults, adults with chronic illnesses, and those closer to the end of life. ACP is, therefore, a process to assist patients and HCPs during COVID-19.

Fraser Health's ACP COVID-19 Response

Fraser Health's ACP team responded to the pandemic by developing new tools and resources and ensuring previously existing resources were easily accessible. Within a month, this organization moved to virtual education platforms for HCPs and the public.

In Fraser Health, over 800 HCPs attended virtual education in the areas of consent, substitute consent, serious illness, and goals of care conversations from April 2020 to July 2020.

Organizations outside of Fraser Health are eager to co-host information sessions. Fraser Health ACP presented with national or provincial associations hosting, including Pallium Canada; Canadian Association of Retired Persons (CARP); Canadian Association of Social Workers (CASW); British Columbia Association of Social Workers (BCASW); and BC Patient Safety and Quality Council (BCPSQC).

Fraser Health's ACP web site page view and download data illustrate the impact COVID-19 has had on the general public's interest in advance health care planning.

- Fraser Health's external public ACP site, pageview data: From January 2019 to July 2019 compared to January 2020 to July 2020, there is an increase of 1521.93% or 15 times.
- Downloads of Fraser Health's ACP companion workbook from April 1, 2019, to March 31, 2020, compared to four months, April 1, 2020-July 31, 2020, is 3.4 times increased.

COVID-19 will continue to push ourselves, our families, communities, health care systems, and providers to support future health care planning. This study further demonstrates the need for clarity of ACP and early ACP conversations.

Limitations

This study's limitations are the small sample size, four interviews, from one province, BC, whose views may be homogeneous. It is important to note that this case study research goal was not to generalize but to gain insight, generate or build theories and concepts (Creswell & Poth, 2018; Potter et al., 2010). The purpose of this case study research was to provide an opportunity to shed light on the impact HCPs' understanding of consent, substitute consent, and incapacity planning documents has on system-wide ACP implementation, and generalize at a conceptual level which leads to greater "how" and "why" insight (Yin, 2018). However, this study provided opportunities to explore this uninvestigated issue.

Recommendations to Improve HCPs' Understanding of Health Laws

To support patients and families throughout the ACP processes and ensure patients previously expressed wishes and instructions are known and honoured, HCPs must better understand consent, substitute consent, and advance directive documents. Changes must be made simultaneously at all system levels: national, provincial, and territorial, regional and organizational, and individual, to achieve this. As a result of my study, including a review of health authority documents and interviews with participants, the following recommendations are suggested to improve HCPs understanding of ACP and health laws:

- Explore provincial, territorial, and federal jurisdictional responsibilities for consent, substitute consent and advance directive laws.
    - Consider harmonizing laws to standardize language.
- Explore the benefits and challenges of standardizing provincial and territorial health authority policies, procedures, and forms.

    - Consider centralizing provincial and territorial ACP programs, policies, procedures, and forms.
- Explore ways to make ACP an understood and recognized intervention and skill within academia and health care institutions.
- Integrate stakeholders outside of health care in ACP partnerships.
- Engage stakeholders within health care, such as colleges and professional associations.
- Involve non-clinician department stakeholders within health care in understanding ACP—for example, communications and ethics.
- Co-create campaigns in collaboration with community, legal, financial, and health organizations.
- Fund teams of ACP experts in all health authorities to provide standardized systems-level support, on-going coaching, and mentoring for the public and HCPs.
- Invite medical-legal collaboration and co-present at public and HCP education.
- Support HCPs to engage in ACP processes for themselves.
- Provide quiet spaces in health care for conversations.
- Create standardized simple poster campaigns that promote legal understanding for HCPs.

Recommendations for Future Research

As recommended in other ACP studies and as my finding suggests, future research should consider the interplay between stakeholders at micro, meso and macro levels (McMahon et al., 2020; Walczak et al., 2016). McMahon et al. (2020) suggest six pillars of ACP: patients, surrogates, community, clinicians, health systems and policy. Therefore, a future study could explore the impact provincial health laws have on 1) health systems, 2) patients, 3) surrogates/SDM 4) community, and 5) clinicians.

Based on the insights and themes identified, additional future research could include:

- Review this research in the context of the proposed six pillars of ACP and support standardized outcomes.
- Replicate this study in other Canadian jurisdictions to gain a broader pan-Canadian perspective.
- Include rural and urban jurisdictions to explore if geographical locations may be a factor.
- Include organizations and communities across Canada that have well-established ACP programs and those that do not, to explore if foundational ACP work may or may not be a contributing factor.
- Ensure that all health care providers providing health care are included in future studies.

Chapter 6. Conclusion

I used case study methodology and spiral analysis to explore the impact of health care providers' understanding of health laws have on system-wide advance care planning implementation. I utilized multiple sources of data and conducted non-randomized interviews. Policies and educational content from five health authorities were reviewed, education surveys and consult reports from Fraser Health Authority were analyzed, and retrospective observations were categorized.

Interviews took place with two registered nurses, one medical doctor and a registered social worker from three health authorities. The inclusion of multiple disciplines and organizations added to the richness of various perspectives and experiences. Their insights and recommendations developed into four themes: all HCPs need to know the law; Canadian and BC laws are complex; ACP and health law are not adequately covered in HCPs’ degree education, and closing the knowledge gaps is multi-faceted.

The various relevant health authority policies and educational content documents indicated an uncoordinated provincial approach to advance care planning policies, education and programs. All documents provide further insights into how health care providers learn about health law.

The current global pandemic is a catalyst to reframe health care systems, promote the integration of earlier advance care planning conversations, and embed advance care planning processes at micro, meso and macro levels.

This research is the first of its kind in Canada. It has provided the opportunity to learn how health care providers understand health laws and identified a possible key factor contributing to limited implementation success: lack of knowledge of health laws. Through practical recommendations, this research supports the following key considerations: reviewing federal, provincial and territorial legislative responsibilities, exploring centralization of advance care planning programs, policies and forms; refocusing current educational and clinical processes and practices within and outside of health systems, and promotes future national research.

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Appendix A: Athabasca University Research Ethics Approval

Athabasca University
RESEARCH CENTRE

CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: 23799

Principal Investigator:
Ms. Cari Borenko Hoffmann, Graduate Student
Faculty of Health Disciplines\Master of Health Studies

Supervisor:
Dr. Karen Cook (Supervisor)
Dr. Kathleen Leslie (Co-Supervisor)

Project Title:
Healthcare Providers' Understanding of the Law: Impact on Advance Care Planning Processes

Effective Date: February 24, 2020 **Expiry Date**: February 23, 2021

Restrictions:

Any modification or amendment to the approved research must be submitted to the AUREB for approval.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

A Project Completion (Final) Report must be submitted when the research is complete *(i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable))* or the research is terminated.

Approved by: **Date: February 24, 2020**

Barbara Wilson-Keates, Chair
Faculty of Health Disciplines, Departmental Ethics Review Committee

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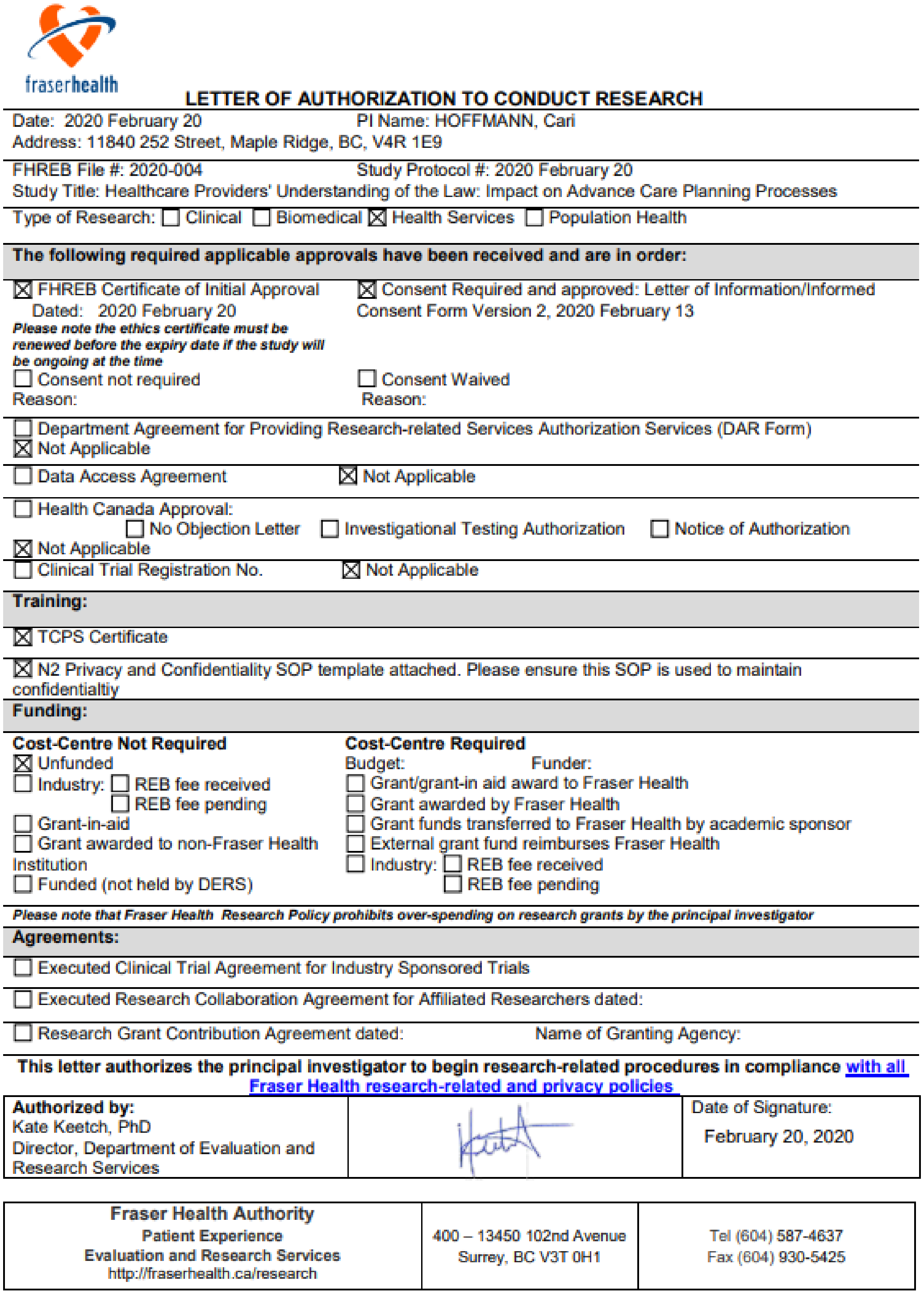
Athabasca University Research Ethics Board
University Research Services, Research Centre
1 University Drive, Athabasca AB Canada T9S 3A3
E-mail rebsec@athabascau.ca
Telephone: 780.675.6718

Appendix B: Fraser Health Research Ethics Approval



fraserhealth

LETTER OF AUTHORIZATION TO CONDUCT RESEARCH

Date: 2020 February 20 PI Name: HOFFMANN, Cari
Address: 11840 252 Street, Maple Ridge, BC, V4R 1E9

FHREB File #: 2020-004 Study Protocol #: 2020 February 20
Study Title: Healthcare Providers' Understanding of the Law: Impact on Advance Care Planning Processes

Type of Research: ☐ Clinical ☐ Biomedical ☒ Health Services ☐ Population Health

The following required applicable approvals have been received and are in order:

☒ FHREB Certificate of Initial Approval
Dated: 2020 February 20
Please note the ethics certificate must be renewed before the expiry date if the study will be ongoing at the time

☒ Consent Required and approved: Letter of Information/Informed Consent Form Version 2, 2020 February 13

☐ Consent not required
Reason:

☐ Consent Waived
Reason:

☐ Department Agreement for Providing Research-related Services Authorization Services (DAR Form)
☒ Not Applicable

☐ Data Access Agreement ☒ Not Applicable

☐ Health Canada Approval:
☐ No Objection Letter ☐ Investigational Testing Authorization ☐ Notice of Authorization
☒ Not Applicable

☐ Clinical Trial Registration No. ☒ Not Applicable

Training:

☒ TCPS Certificate

☒ N2 Privacy and Confidentiality SOP template attached. Please ensure this SOP is used to maintain confidentialtiy

Funding:

Cost-Centre Not Required
☒ Unfunded
☐ Industry: ☐ REB fee received
☐ REB fee pending
☐ Grant-in-aid
☐ Grant awarded to non-Fraser Health Institution
☐ Funded (not held by DERS)

Cost-Centre Required
Budget: Funder:
☐ Grant/grant-in aid award to Fraser Health
☐ Grant awarded by Fraser Health
☐ Grant funds transferred to Fraser Health by academic sponsor
☐ External grant fund reimburses Fraser Health
☐ Industry: ☐ REB fee received
☐ REB fee pending

Please note that Fraser Health Research Policy prohibits over-spending on research grants by the principal investigator

Agreements:

☐ Executed Clinical Trial Agreement for Industry Sponsored Trials

☐ Executed Research Collaboration Agreement for Affiliated Researchers dated:

☐ Research Grant Contribution Agreement dated: Name of Granting Agency:

This letter authorizes the principal investigator to begin research-related procedures in compliance with all Fraser Health research-related and privacy policies

Authorized by: Kate Keetch, PhD Director, Department of Evaluation and Research Services		Date of Signature: February 20, 2020

Fraser Health Authority **Patient Experience** **Evaluation and Research Services** http://fraserhealth.ca/research	400 – 13450 102nd Avenue Surrey, BC V3T 0H1	Tel (604) 587-4637 Fax (604) 930-5425

Appendix C: Invitation to Participate

INVITATION TO PARTICIPATE

Healthcare Providers' Understanding of the Law: Impact on Advance Care Planning

February 15, 2020

Principal Investigator (Researcher):
Cari Borenko Hoffmann
Cariborenkohoffmann1@athabasca.edu
Lead, Advance Care Planning
Fraser Health Authority
400-13450 102nd Street
Surrey, BC V3T 0H1

Supervisors:
Karen Cook, PhD, RN
kcook@athabascau.ca

Kathleen Leslie, PhD, JD, RN
kleslie@athabascau.ca

My name is Cari Borenko Hoffmann and I am a Masters of Health Studies student at Athabasca University. As a requirement to complete my degree, I am conducting research to explore healthcare providers' understanding of the role of consent, substitute consent and interpretation of advance directive documents impact advance care planning processes. I am conducting this project under the supervision of Drs Karen Cook and Kathleen Leslie. I am employed at Fraser Health Authority as the Lead for Advance Care Planning.

I invite you to participate in this project because you have regional responsibility for advance care planning, and experience supporting healthcare providers implement advance care planning into practice.

The purpose of this research project is to explore the impact of healthcare providers' understanding of the legal requirements and obligations imposed by the laws of consent, substitute consent and advance directives throughout advance care planning processes.

Your participation in this project would involve a 30-60 minute in-person or phone interview. The interview will be audio recorded on a secure encrypted laptop, saved with de-identifiers, and transcribed verbatim on an encrypted secure hard drive. The interview will be arranged for a time and place that is convenient to your schedule between the dates of February 15 and September 30, 2020. A set of standard and clarifying or follow-up questions will be asked. In the event that further information would be useful to capture your perspectives, an additional second interview may be arranged, with agreement of both the participant and primary researcher.

The research has indirect benefits for clinicians and organizations involved in advance care planning implementation, and educational delivery and development today and in the future. It may help to unearth a limitation not yet researched in Canada or British

Columbia and consequently recommend solutions that will positively impact healthcare systems, administrators, government and clinicians to further develop knowledge, knowledge translation and change in this area.

The risk associated with this research is, due to the small advance care planning community in Canada and British Columbia and small sample size, your confidentiality cannot be guaranteed. To address this, the researcher will ensure interviews are quickly transcribed, coded and themed, and a numeric de-identifier applied.

Thank you for considering this invitation. If you have any questions or would like more information, please contact me, (the principal investigator) by e-mail cariborenkohoffmann1@athabasca.edu or my supervisors by kcook@athabascau.ca or kleslie@athabascau.ca

Thank you.

Cari Borenko Hoffmann

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718.

Appendix D: Letter of Information/Informed Consent Form

LETTER OF INFORMATION / INFORMED CONSENT FORM

Healthcare Providers' Understanding of the Law: Impact on Advance Care Planning

February 15, 2020

Principal Investigator (Researcher):
Cari Borenko Hoffmann, BA, BSW, RSW
Masters of Health Studies, Student
Faculty of Health Disciplines
Athabasca University
cariborenkohoffmann1@athabasca.edu
Lead, Advance Care Planning
Fraser Health Authority
400-13450 102nd Street
Surrey, BC V3T 0H1

Supervisors:
Karen Cook, PhD, RN
Assistant Professor
Faculty of Health Disciplines
Athabasca University
kcook@athabascau.ca

Kathleen Leslie, PhD, JD, RN
Assistant Professor
Faculty of Health Disciplines
Athabasca University
kleslie@athabascau.ca

Invitation

You are invited to take part in a research project entitled '*Healthcare Providers' Understanding of the Law: Impact on Advance Care Planning*'.

This form is part of the process of informed consent. The information presented should give you the basic idea of what this research is about and what your participation will involve, should you choose to participate. It also describes your right to withdraw from the project. In order to decide whether you wish to participate in this research project, you should understand enough about its risks, benefits and what it requires of you to be able to make an informed decision. This is the informed consent process. Take time to read this carefully as it is important that you understand the information given to you. Please contact the principal investigator, Cari Borenko Hoffmann if you have any questions about the project or would like more information before you consent to participate.

It is entirely up to you whether or not you take part in this research. If you choose not to take part, or if you decide to withdraw from the research once it has started, there will be no negative consequences for you now, or in the future.

Introduction
My name is Cari Borenko Hoffmann and I am a Masters of Health Studies student at Athabasca University. As a requirement to complete my degree, I am conducting a research project to explore how healthcare providers' understanding of the role of consent, responsibilities of substitute consent and interpretation of advance directive documents impact advance care planning processes. I am conducting this project under the supervision of Drs Karen Cook and Kathleen Leslie. I am employed at Fraser Health Authority as the Lead for Advance Care Planning.

Why are you being asked to take part in this research project?
You are being invited to participate in this project because you have regional responsibility for advance care planning, experience supporting healthcare providers implement advance care planning into practice, and insight into understanding how healthcare providers understand the laws that impact advance care planning processes.

What is the purpose of this research project?
The purpose of this research project is to explore the impact of healthcare providers' understanding of the legal requirements and obligations imposed by the laws of consent, substitute consent and advance directives throughout advance care planning processes. The researcher's goal is to determine if this is a significant limitation to successful advance care planning implementation and explore possible solutions.

What will you be asked to do?
As a participant in this research, you will be asked to participate in an in-person or phone interview with the primary researcher, Cari Borenko Hoffmann. Interviews are anticipated to take 30-60 minutes. The interview will be audio recorded on a secure encrypted laptop, saved with de-identifiers, and transcribed verbatim on an encrypted secure hard drive. During the interview, you will be asked open-ended questions to describe your experiences and insights into healthcare providers understanding of the laws that impact advance care planning. A set of standard questions will be asked of all participants, as well as clarifying or follow-up questions when needed. In the event that clarification or further information would be useful to capture your perspectives, an additional second interview may be arranged, with agreement of both the participant and primary researcher.

The interview will be arranged for a time and place that is convenient to your schedule between the dates of February 15 and September 30, 2020. No personal expenses are anticipated. A $25 coffee gift card will be provided as a token of appreciation.

What are the risks and benefits?
This research has indirect potential benefits for clinicians and organizations involved in advance care planning implementation, educational delivery and development today and in the future. It may help to unearth a limitation not yet researched in Canada or British Columbia and consequently recommend solutions that will positively impact healthcare systems, administrators, government and clinicians to further develop knowledge, knowledge translation and change in this area.

The risk associated with this research is, due to the small advance care planning community in Canada and British Columbia and small sample size, your confidentiality cannot be guaranteed. To address this, the researcher will ensure interviews are de-identified, quickly transcribed, coded and themed, and a numeric applied.

Do you have to take part in this project?

As stated earlier in this letter, involvement in this project is entirely voluntary. Participants can end or stop participating at any time, for example, during or after the interview. Any data collected prior to analysis will be used only with permission from the withdrawing participant. Otherwise, the data will be deleted and destroyed. Should participants withdraw after analysis, it cannot be guaranteed that the withdrawing participants' data can be removed due to the de-identifying of transcripts and coding that will be employed. It is anticipated that transcribing and coding will be take place shortly after each interview, for example, 2 weeks.

How will your privacy and confidentiality be protected?

The ethical duty of confidentiality includes safeguarding participants' identities, personal information, and data from unauthorized access, use or disclosure.

- Each participant's privacy and confidentiality will be maintained through intentional actions on behalf of the researcher to separate and secure identifying information, such as that obtained for the purposes of consent, from the interview data collected. Transcripts of the interviews will be re-labelled with non-identifying codes (e.g., A07) and pseudonyms will replace any names or identifiers (i.e., employment organization) that might connect the data to the original participant. Due to the connections of the interviewees and small sample size, there are challenges with guaranteeing complete privacy and confidentiality for participants that may already know one another. Participants may choose to decline consent to participate should this be a concern for them.
- All information will be held confidential, except when legislation or a professional code of conduct requires that it be reported.

Your confidentiality will be respected. However, research records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the Fraser Health Research Ethics Board.

Every reasonable effort will be made to ensure your confidentiality; you will not be identified in publications without your explicit permission. Your data will be reported without identifiers. Your personal identifiers such as name will not be included in reports.

How will the data collected be stored?

- Interviews will be audio recorded on an encrypted secure laptop computer. Once the interviews are transcribed by the researcher, they will be deleted from the laptop. Transcriptions will be kept for 5 years as per University of Athabasca policy. At this time, they will be deleted from the encrypted hard drive.

- Locked filing cabinets will be utilized for any hard copy data, such as consent forms.
- Supervisors will have access, upon request, to the data collected. Supervisors may be involved in coding and theming de-identified transcripts.
- Should this data be requested for further secondary use, REB approval would be sought.

Who will receive the results of the research project?

- The existence of the research will be listed in an abstract posted online at the Athabasca University Library's Digital Thesis and Project Room and the final research paper will be publicly available.
- This research will be presented at relevant conferences in oral and written form and available on the researchers e-portfolio.
- The results of this research will be summarized. Direct quotes will be integrated into research reports without personal identifying information.
- All participants will be provided an executive summary by email from the researcher. It will also be available on the researcher's e-portfolio. All participants will be invited to a presentation of this research once results are finalized.

Who can you contact for more information or to indicate your interest in participating in the research project?

Thank you for considering this invitation. If you have any questions or would like more information, please contact me, Cari Borenko Hoffmann by e-mail cariborenkohoffmann1@athabasca.edu or my supervisors as listed above, kcook@athabascau.ca and kleslie@athabascau.ca

If you are ready to participate in this project, please contact me. You can complete and sign the attached Consent Form and return it to me, Cari Borenko Hoffmann, in paper copy within one week of receipt. I would be happy to pick it up from you. Alternately, it can be provided to me prior to the interview.

Thank you.

Cari Borenko Hoffmann

This project has been reviewed by the Athabasca University Research Ethics Board. Should you have any comments or concerns regarding your treatment as a participant in this project, please contact the Research Ethics Office by e-mail at rebsec@athabascau.ca or by telephone at 1-800-788-9041, ext. 6718. You many also contact Fraser Health Research Ethics Board by calling 604 587-4681. You may discuss these rights with one of the co-chairs of the Fraser Health REB.

Informed Consent:
Your signature on this form means that:

- You have read the information about the research project.
- You have been able to ask questions about this project.
- You are satisfied with the answers to any questions you may have had.
- You understand what the research project is about and what you will be asked to do.
- You understand that you are free to withdraw your participation in the research project without having to give a reason, and that doing so will not affect you now, or in the future.
- You understand that if you choose to end your participation **during** data collection, any data collected from you up to that point will be retained by the researcher, unless you indicate otherwise.
- You understand that your data is being collected confidentiality, and therefore cannot be removed once the data collection has ended.

	YES	**NO**
I agree to be audio-recorded	○	○
I agree to the use of direct quotations	○	○
I allow data collected from me to be archived on the researchers' personal phone & computer until coded and themed	○	○
I am willing to be contacted following the interview to verify that my comments are accurately reflected in the transcript.	○	○

Your signature confirms:

- You have read what this research project is about and understood the risks and benefits. You have had time to think about participating in the project and had the opportunity to ask questions and have those questions answered to your satisfaction.
- You understand that participating in the project is entirely voluntary and that you may end your participation at any time without any penalty or negative consequences.
- You have been given a copy of this Informed Consent form for your records; and
- You agree to participate in this research project.

By signing this consent form, you are not giving up any of your legal rights.

Signature of Participant Date

Principal Investigator's Signature:

I have explained this project to the best of my ability. I invited questions and responded to any that were asked. I believe that the participant fully understands what is involved in participating in the research project, any potential risks and that he or she has freely chosen to participate.

Signature of Principal Investigator Date

Appendix E: Interview Questions

Set up Interview:

- Review and summarize the research study
- Review consent form, acknowledge participant/researcher prior relationship and voluntary nature of participating
- Sign consent, if interview is taking place
- Discuss confidentiality and anonymity

Prior to engaging in questions:

- Review definitions used in research to ensure mutual understanding
    - Advance care planning
    - Advance directives (incapacity planning tools)
        - Proxy
        - Instructional
    - Medical Order for Scope of Treatment (MOST)

1. From your experience, how much knowledge do clinicians have about the laws that affect and interact with all phases of advance care planning? On a scale from 1-5. For example:
    a. consent laws
    b. substitute consent laws
    c. incapacity planning tools (or pre-planning tools)

2. Tell me about your experiences with advance care planning in terms of supporting other clinicians to implement these processes into practice? Would you say that the legalities are a knowledge gap area? Why or why not?

3. From your perspective, what are some of the key challenges clinicians face throughout the advance care planning processes, specifically in the area of law. For example:
    a. When initiating conversations with a capable adult
        i. living in community (their home, at a clinic setting)
        ii. residing in hospital, experiencing a health event
    b. When having conversations with a person’s substitute decision maker while their loved ones are:
        i. Living in community (their home, at a clinic setting)
        ii. Residing in hospital, experiencing a health event
        iii. In a critical care setting, experiencing a life limiting illness

4. In your opinion, what are some strategies that could be employed to close the knowledge gap for health care providers knowledge of the law that affect ACP? For example:

  a. Within their educational degree training
  b. Following the completion of their degree
    i. Within their work place
    ii. Within their colleges, unions or associations
5. In your opinion, what strategies could support minimizing the gap between and with the medical and legal communities?

Appendix F: Retrospective Observations

Cari's Observations ACP & the Law

Fraser Health Clinicians

- Increase in understanding – evidence: not the majority main reasons for attending education
- Difference between HA staff -? FH dedicated resources over 17 years?
- Still issues however, nuances
  - When there is difference/conflict with what HCP team is recommending/offering vs what SDM is asking/demanding. Not always an escalation of ask/demand.
  - Seems unaware of roles & responsibilities to honour prior wishes or how to enact that piece.
  - Legal documents are a quandary for many.
- Physicians anecdotally seem to lack most skills – as reported by other HCP; they often want an ethics consult not ACP or IRM
- Very individual, challenge to make any generalization between sectors ie home health is better than acute or vice versa
- Education isn't really changing practice
- Interest has not waived in all these years – waitlist for education therefore they see as a need?

Fraser Health Ethics

- Lack of understanding of ACP especially the legalities
- Not part of their Framework
- Feel it is EOL only by their actions not spoken words
- irregularly include us in consults they receive
- Have their own modules/education. Not really integrated
- Often ask for speakers outside of FH which adds to confusion

Fraser Health Executive Leadership

- Lack of wholesome understanding of ACP
- Articulate its importance
- COVID has made this increasingly important
- Relates ACP to PC and dying
- Have not made education mandatory across the board
- Repeatedly ask for meeting

Fraser Health Communications

- Lack of understanding re who is it for
- Often packages with Palliative Care (is this due to organizational structure?)
- ACP is a small part of their role, importance appears minimal
- Challenging to gain support/attention

Fraser Health IRM

- Have a good handle though is individual specific
- Not all want to take it on, feel it's not their job?
- ACP involves them +
- We do not often hear from them

National Tables

- Articulate differences of EOL, PC and need for upstream yet…social media can get very EOL focused as can messaging
- Clear understanding of the legal differences as illustrated on web site
- Non clinical staff
- Continue to support/see siloed approaches ie LTC toolkit, Home Care Toolkit. Yet we see the same people throughout their journey?

Summary

- Same/similar challenges with these groups as the public/community