PREVENTION OF RHD ALLOIMMUNIZATION IN NORTHERN BRITISH COLUMBIA

by

Trina Marie Fyfe

B.A., University of Waterloo, 1999
M.I.St., University of Toronto, 2001

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Abstract

Despite best practice guidelines, international evidence suggests that the provision of anti-D prophylaxis to RhD negative pregnant women is suboptimal. Missing from the literature is research exploring the factors that perpetuate suboptimal care and continue to put RhD negative pregnant women at risk for RhD alloimmunization. The purpose of this study was to understand why RhD negative pregnant women continue to be at risk for RhD alloimmunization in northern BC. The specific research questions were: How do healthcare providers make decisions regarding the care of RhD negative pregnancies in northern BC? How do RhD negative women in northern BC experience pregnancy?

A qualitative approach utilizing interpretive description was used to address the need for the development of rural centric clinical guidelines. Interviews were conducted with RhD negative women about pregnancy and healthcare providers' experiences in caring for RhD negative pregnancies in northern BC. A Stakeholder Committee guided the research process and provided insight into data analysis to ensure applicability to practice. A qualitative approach with these two populations has provided a greater understanding into the depth of quality of care for RhD negative pregnancies and the decisions that inform patient safety by revealing nuances of care that lead to potential miscommunication and near misses. Recommendations into guideline adaptation, decision-making and health literacy in rural healthcare settings are presented.

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Glossary

AC	-	Accreditation Canada
ACC	-	Accident Compensation Corporation
ADAPTE	-	Appraisal of Guidelines Research and Evaluation
BC	-	British Columbia
BMJ	-	British Medical Journal
CBL	-	Case-Based Learning
CCL	-	Canadian Council on Learning
CDA	-	Canadian Diabetes Association
CFPC	-	College of Family Physicians of Canada
CIHI	-	Canadian Institute for Health Information
CME	-	Canadian Medical Education
CMIRPS	-	Canadian Medication Incident Reporting and Prevention System
CMPA	-	Canadian Medical Protective Association
CNA	-	Canadian Nurses Association
CPG	-	Clinical Practice Guidelines
CPHA -	-	Canadian Public Health Association
CPSI	-	Canadian Patient Safety Institute
D&C	-	Dilation and curettage
EBM	-	Evidence-Based Medicine
GRADE	-	Grading of Recommendations Assessment, Development and Evaluation
GUIDE-IT	-	Guideline Implementability Tool
HDFN	-	Hemolytic Disease of the Fetus/Newborn

IOM	-	Institute of Medicine
ICPS	-	International Classification for Patient Safety
IKT	-	Integrated Knowledge Translation
KT	-	Knowledge Translation
LDR	-	Labour and Delivery
MORE^{OB}	-	Managing Obstetrical Risk Efficiently
NH	-	Northern Health
NHS	-	National Health Service
NMP	-	Northern Medical Program
NSIR	-	National System for Incident Reporting
OECD	-	Organization for Economic Co-operation and Development
PFPSC	-	Patients for Patients Safety Canada
RAADP	-	Routine Antenatal Anti-D Prophylaxis
RANZCOG	-	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCPSC	-	Royal College of Physicians and Surgeons of Canada
RhD	-	Rhesus
RhIG	-	Rh immune globulin
QHRC	-	Qualitative Health Research Conference
SLS	-	Safety Learning System
SOGC	-	Society of Obstetricians & Gynaecologists of Canada
SRPC	-	Society of Rural Physicians of Canada
UBC	-	University of British Columbia
UNBC	-	University of Northern British Columbia

US	-	United States
WHO	-	World Health Organization

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Chapter One: Introduction and Background

Introduction

Patient safety incidents are a significant issue within contemporary healthcare. The 2004 (Baker et al.) Canadian Adverse Events Study found that 7.5% of acute care patients experience patient safety incidents, 36.9% of these incidents were considered preventable. More than a decade later, Canadians still experience harm. In a 2016 report, 5.6% of hospitalized patients experience patient safety incidents; this translates as 1 in every 18 patients (Canadian Institute for Health Information & Canadian Patient Safety Institute, 2016). Of the 5.6% of patients that experience harm, 11.7% are neonatal and obstetrical patients.

The impact of a patient safety incident can have devastating effects on patients, families and healthcare providers (Blendon et al., 2002; Gallagher & Levinson, 2005; Gallagher, Waterman, Ebers, Fraser, & Levinson, 2003; Iedema et al., 2011; Mazor, Goff, Dodd, Velten, & Walsh, 2010; O'Connor, Coates, Yardley, & Wu, 2010; Witman, Park, & Hardin, 1996). After a patient safety incident, patients and their families may experience a multitude of feelings including, emotional trauma, a need for information about the event, a lack of empathy and support, and may want an apology and/or acknowledgement of accountability for the incident (Blendon et al., 2002; Gallagher & Levinson, 2005; Gallagher et al., 2003; Iedema et al., 2011; Mazor et al., 2010; O'Connor et al., 2010; Witman et al., 1996). The way in which these experiences are dealt with are often the deciding factor between whether the patient and/or family members file a complaint and/or medical malpractice claim (Mazor et al., 2010; Witman et al., 1996). Healthcare providers are often

deemed the "second-victims" (Coughlan, Powell, & Higgins, 2017; Wu, 2000) of patient safety incidents because of the detrimental emotional effects of causing and/or witnessing preventable harm or near misses, and the blame and shame that follow such events (Wu et al., 2017). When patient safety incidents are reported it often instigates an investigation, regulatory bodies may be involved and the healthcare providers may face legal action (Wu et al., 2017).

Patient safety incidents result from individual decisions made in the context of a complex system (Schubert, Winslow, Montgomery, & Jadalla, 2012). The decision-making process involves the decision-makers(s) acknowledging that an issue has risen, the identification of the specific problem, the creation of goals that will lead to a resolution, the exploration of possible solutions, decision-making, followed by the assessment of actions taken throughout the process (WHO Study Group on the Role of Research and Information Systems in Decision-Making for the Development of Human Resources for Health & Organization, 1990). If a healthcare provider does not identify that an issue has arisen or a problem exists, there is no opportunity to resolve the issue leading to a potential patient safety incident. One area of concern, are clinical situations that healthcare providers are not faced with often. Low occurrence clinical situations have the potential to result in patient safety incidents and/or near misses because of the infrequent nature of exposure. An example of low occurrence clinical situations are Rhesus (RhD) negative pregnancies, particularly when sensitizing events occur.

The purpose of this study is to explore decision-making amongst healthcare providers and patients regarding a low occurrence medical event, the prevention of RhD alloimmunization, in northern British Columbia (BC). A deeper understanding of the decision-making processes amongst various stakeholders, their roles in the process, the

factors that influence decision-making and the complexity of making decisions about low occurrence events may prove useful in the delivery of care. Focusing on an aspect of perinatal care, RhD negative pregnancies, that has the potential to cause harm, will provide the opportunity to examine decision-making in situations where guidelines/evidence may, or may not be, applicable or helpful, and where adherence to such guidelines or protocols might prove to be problematic, particularly in a diverse geographical landscape like northern BC. Following the recommendations made in the Fyfe et al. (2014)'s scoping review, the continued risk of RhD alloimmunization in pregnancy needs to be explored. In a scoping review of the literature, Fyfe et al (2014) suggested that research exploring the experiences of RhD negative women with pregnancy and further insight into healthcare provider experiences in the delivery of care may provide guidance into this problem. These suggestions provided direction for this study, specifically informing the following research questions:

- Why do RhD negative women continue to be at risk for developing D antibodies in pregnancy?
    - How do healthcare providers make decisions regarding the care of RhD negative pregnancies in northern British Columbia?
    - How do RhD negative women in northern British Columbia experience pregnancy?

The researcher used a qualitative approach utilizing interpretive description methodology and the research was conducted in northern BC.

The researcher developed this study, initially, from personal experience with RhD alloimmunization, due to mismanagement in care. This experience led to questions about the

healthcare system, healthcare provider decision-making and RhD negative pregnant women's experiences. After an informal complaint was made to the regional health authority, Northern Health (NH), the questions being asked led to the development of a stakeholder team of decision-makers at NH. This team conducted a scoping review (Fyfe et al., 2014) focused on adherence to RhD alloimmunization prevention guidelines. The scoping review provided the opportunity to further this project by asking questions that were derived from gaps in the literature.

The dissertation is presented into sections and chapters that allow for the examination the prevention of RhD alloimmunization in northern BC. A historical discussion of the discovery of RhD alloimmunization is subsequently provided. The story of the identification and clinical management of RhD alloimmunization is an example of successful knowledge translation; a prophylaxis was developed and implemented thereby drastically reducing RhD alloimmunization and its harmful consequences within a few decades (Joseph, 2013). Following the brief historical discussion, current clinical management will be outlined and contextualized within Canadian and provincial practice.

Background

The background will provide a historical narrative of RhD alloimmunization and the current prevention program, including the management of RhD alloimmunization during pregnancy. Included in this section is the description of concepts deemed by the research to be important to the discussion of RhD alloimmunization, such as sensitizing events. The section concludes with a brief discussion of RhD alloimmunization prevention within Canadian and provincial, specifically BC, contexts.

History and discovery

RhD alloimmunization (also referred to as RhD sensitization) and hemolytic disease of the fetus/newborn (HDFN), previously referred to as erythroblastosis fetalis, remained unsolved for centuries, with the first reported incidence of HDFN in 1609 by a French midwife (Bowman, 2003). In just four decades within the last century, scientists made great breakthroughs in the area of RhD alloimmunization and HDFN. In this section, the story of the discovery of the pathophysiology and subsequent prevention and management programs of both HDFN and RhD alloimmunization will be provided (Bowman, 2003).

The unfortunate death of an infant due to kernicterus in 1938 caused pathologist Ruth Darrow to question cause of the infant's death (Bowman, 2003). Darrow hypothesized that the fetus' blood had somehow passed into the mother's circulatory system causing her to develop antibodies; the maternal antibodies then crossed the placenta back into the fetal circulatory system and destroyed the infant's red blood cells. This important discovery identified the initial pathology of HDFN, except she had pinpointed the incorrect antigen. The following year, 1939, Levine and Stetson discovered the RhD antigen (Urbaniak & Greiss, 2000) after observing a blood transfusion of a pregnant woman with blood from the woman's husband. Not long after the transfusion, the pregnant woman gave birth to a stillborn infant that had suffered from HDFN (Urbaniak & Greiss, 2000). Levine and Stetson concluded "that the infant had inherited a red cell agglutinogen from the father which was foreign to the mother" (Urbaniak & Greiss, 2000, p. 45), RhD alloimmunization, an important discovery.

This discovery led to further work identifying the causes of HDFN (Bowman, 2003). It became evident that RhD alloimmunization does not develop if the fetus is also RhD negative because both maternal and fetal blood do not carry the RhD antigen. Therefore,

RhD positive pregnant women are not at risk of RhD alloimmunization. If the fetus is Rh-positive and a sensitizing event occurs, thus exposing the mother to fetal blood, the mother will develop D antibodies (Dean, 2005) causing HDFN and RhD alloimmunization (Urbaniak & Greiss, 2000). HDFN may involve hyperbilirubinemia causing kernicterus and anemia (Dean, 2005). These situations can lead to life-long conditions, such as cerebral palsy. This was an important discovery leading to the advancement of research focused on the clinical identification and management RhD alloimmunization (Bowman, 2003; Charles & Friedman, 1969; Clarke, 1975; Urbaniak & Greiss, 2000).

Further work was conducted to enhance the understanding of maternal-fetal circulatory systems, maternal antibody development, and the relationship between bilirubin and kernicterus in the 1950s (Charles & Friedman, 1969). One important discovery was the observation of a fetal-maternal hemorrhage (FMH) in the pregnancy of an RhD negative woman that proved FMH events can cause RhD alloimmunization (Urbaniak & Greiss, 2000).

Any event that can cause a FMH is considered a sensitizing event. These clinical significant clinical events can lead to the potential development of D antibodies in an RhD negative pregnancy (Fyfe et al., 2014). The list of sensitizing events is substantial:

- Delivery of an RhD positive infant (or if the infant's Rh type is unknown)
- Abortion
    - Therapeutic termination of pregnancy
    - Spontaneous abortion followed by instrumentation
    - Spontaneous complete or incomplete abortion after 12 weeks gestation
    - Threatened abortion before 12 weeks (when bleeding is heavy or repeated or is associated with abdominal pain)
    - Threatened abortion after 12 weeks (when bleeding continues intermittently after 12 weeks gestation)
- Invasive prenatal diagnosis
    - Amniocentesis
    - Chorionic villus sampling (CVS)

    - Cordocentesis
    - Fetal blood sampling (FBS)
- Other intrauterine procedures
    - Insertion of shunts
    - Embryo reduction
    - Transfusions
    - Surgery
    - Laser
- Intra-operative cell salvage
- Antepartum hemorrhage (APH)/Uterine (PV) bleeding in pregnancy
- External cephalic version
- Abdominal trauma
- Ectopic pregnancy
- Molar pregnancy
- Intrauterine death (IUD)
- Stillbirth (Fyfe et al., 2014, p. Additional File 1)

The identification of the RhD antigen and the increased understanding of the maternal-fetal circulatory system led to the development of prevention and management in the 1960s. In just one decade, scientists found ways to effectively treat HDFN and prevent alloimmunization (Zimmerman, 1973). By 1963, fetuses with expected HDFN could be effectively treated with intrauterine blood transfusions (Charles & Friedman, 1969) which remains critical in clinical management even today (Moise & Argoti, 2012).

The second great achievement of the 1960s was the development of a prophylaxis to prevent RhD alloimmunization amongst RhD negative pregnant women based on clinical trial data from the United States (US), United Kingdom (UK) and Canada (Bowman, 2003). The trials involved giving RhD negative men RhD positive red blood cells to simulate sensitizing events (like a FMH between a RhD negative mother and a RhD positive fetus). The participants were then administered plasma with high levels of anti-D, hypothesizing that this would prevent RhD alloimmunization (Bowman, 2003). The development of anti-D immunoglobulin was being done with plasmapheresis to extract plasma with anti-D that could then be injected into RhD negative pregnant women (World Health Organization,

1971). By 1968, a prophylaxis, RhD immune globulin (RhIG), was approved and being utilized in Europe and North America (Bowman, 2003).

Current clinical management

A person's RhD status indicates the presence or the absence of the D antigen on red blood cells (Canadian Blood Services, 2013). In the case of RhD negative blood types, such as A-, B-, O- and AB-, the red blood cells do not carry the D antigen. Knowing a person's Rh factor is important when matching people for blood transfusions and, in some cases, during pregnancy. It is estimated that 15-16% of the general population is RhD negative (Roman, 2013), Caucasians accounting for 85% of all cases (Dean, 2005).

In pregnancy, a woman's RhD negative status is an important element in the care and management of pregnancy. It is of particular concern if the woman is carrying a RhD positive infant because the infant carries the D antigen. If the woman is RhD negative she requires RhIG at 28 weeks (Fung Kee Fung et al., 2003). Clinical guidelines suggest dividing the administration of anti-D immunoglobulin into two dosages, one at at 28 and the second at 34 weeks, and once again after delivery if the infant is RhD positive (UK Guidelines, National Institute for Health and Clinical Excellence, 2008). This prophylaxis will prevent the woman from developing antibodies and becoming RhD alloimmunized (Bowman, 2003). Despite this, the rate of RhD alloimmunization remains 6.7/1000 live births (Martin et al., 2003).

Prophylaxis, RhIG, remains the gold standard in the prevention of RhD alloimmunization (Pilgrim, Lloyd-Jones, & Rees, 2009; Turner et al., 2012). Even with the availability of RhIG, RhD negative women are still developing D-antibodies in pregnancy. Fyfe et al. (2014), found that in various healthcare settings opportunities for RhD alloimmunization exist because of mismanagement of care; for example, the prophylaxis is

not given and/or not given at the right time when a sensitizing event occurs. Absent from the literature are the reasons behind the occurrence risks of this patient safety incident. Furthermore, Koby et al. (2012) hypothesize that the potential reasons for patient safety incidents to occur in sensitizing situations (or in routine care) is either human or systemic. The system approach may lack "protocols, a team approach, and an active outreach strategy", whereas the human aspect would involve the healthcare provider not recognizing that prophylaxis is required or the patient (RhD negative pregnant women) not understanding the importance of RhD factor in pregnancy (health literacy), or perhaps refusing treatment due to cultural or religious beliefs (Koby et al., 2012, p. 432).

In Canada, the Society of Obstetrician and Gynecologists of Canada's (SOGC) prevention of RhD alloimmunization guidelines provide recommendations for the delivery of anti-D prophylaxis to RhD negative pregnant women (Fung Kee Fung et al., 2003). Clinical practice guidelines (CPGs) in the UK, the US and Australia have similar recommendations in their guidelines (American Congress of Obstetricians and Gynecologists, 1999; National Health and Medical Research Council, 2003; National Institute for Health and Clinical Excellence, 2008; Prices et al., 2011). Despite the recommendations for antenatal prophylaxis RhD negative pregnant women are not consistently being protected from the risk of developing anti-D antibodies (Fyfe et al., 2014).

In BC, the RhD alloimmunization prevention CPG has been incorporated into BC's Perinatal Services maternal care pathway (British Columbia Perinatal Health Program, 2010). The detailed national guideline is summarized into a few sentences on the routine screening of RhD status and the administration of prophylaxis. A link to the national guideline was provided within the pathway in each instance where administration of prophylaxis is indicated. Absent from this pathway is the use of anti-D prophylaxis when sensitizing events

occurs. CPGs are synthesized documents that make recommendations for consistency of care (further defined in the literature review section). In this instance, the CPG has been further summarized and perhaps omits information critical to the prevention of RhD alloimmunization.

Despite guidelines, RhD alloimmunization continues to occur and there is limited information regarding the prevalence of RhD sensitized women in BC. Canadian Blood Services in BC does provide the incidence of RhD sensitized women in an annual report; for example, in 2014 the incidence of RhD negative women developing D antibodies was 44 but no descriptive information about the population is available (Canadian Blood Services, 2014). Likewise, a recent retrospective study conducted in northern Alberta identified that the prevalence of anti-D was 6.8% from 2006 to 2010 and was associated with the severe adverse outcomes for the fetus or newborn (Zwingerman, Jain, Hannon, Zwingerman, & Clarke, 2015). The reasons for continued RhD alloimmunization need to be explored and understood. There have been only two retrospective studies undertaken in a Canadian context, one prior to the national 2003 CPG and one after, both showing that there are discrepancies in the care of RhD negative pregnant women (Grant & Hyslop, 1992; Koby et al., 2012). These studies provide a look at the delivery of prophylaxis to RhD negative pregnant women within clinically controlled environments (i.e. – an RhD negative woman gives birth to a RhD positive newborn and the prophylaxis is given). The findings are helpful in that they provide policy makers and healthcare providers with evidence that quality improvement is needed.

In April 2017, the SOGC published updated recommendations regarding the prevention program of RhD alloimmunization. These recommendations, if adopted, provide guidelines to improve the way RhD negative pregnancies are managed (Johnson,

MacDonald, Clarke, & Skoll, 2017). The primary change in the recommendation is that only women pregnant with a RhD positive fetus will be given prophylaxis. The recommendation states:

> it is no longer considered appropriate to treat all D-negative [sic] pregnant women with human plasma derivatives when there are no benefits to her or to the fetus in a substantial percentage of cases. (Johnson et al., 2017, p. 367)

It is now, more than ever, important to explore the current state of the existing RhD alloimmunization prevention program before the recommendations are adopted and current unknowns become larger unknowns.

Despite a broad literature base, gaps in knowledge about RhD alloimmunization pervade. A scoping review published in 2014 (Fyfe et al.) on the provision of RhIG, found that there is a need to identify if there is a knowledge gap amongst general practitioners, emergency physicians and other healthcare providers regarding the care of RhD negative pregnancies. Fyfe et al (2014) found that in the 18 included studies (Bolton-Maggs, Davies, Poles, & Cohen, 2013; Chaffe, Ford, & Bills, 2007; Fox, Savage, Evans, & Moore, 1999; Ghosh & Murphy, 1994; Grant & Hyslop, 1992; Griffey, Chen, & Krehbiel, 2012; Howard, Martlew, McFadyen, & Clarke, 1997; Huggon & Watson, 1993; Hughes, Craig, Murphy, & Greer, 1994; Koby et al., 2012; MacKenzie et al., 1999; MacKenzie, Findlay, Thompson, & Roseman, 2006; Mayne, Parker, Harden, Dodds, & Beale, 1997; McLaren & Shelley, 2002; McSweeny, Kirkham, Vinall, & Flanagan, 1998; Rennie, Smith, Smith, Rawlinson, & Clark, 2001; Thorp, 2008; Weinberg, 2001) contributing factors, such as access to health services in rural areas, or if this is a rural issue, that may or may not influence care were not accounted for. Norman (2010) suggested that existing RhD negative research has not identified the perhaps reasons for nonadherence by providers, and which providers find it difficult to follow guidelines. The paucity of research focusing on adherence to RhD alloimmunization

guidelines leads to many questions: there is a need to clarify and/or understand factors that influence CPGs interpretation by healthcare providers? How do rural healthcare providers or emergency physicians ensure that RhD negative pregnant women receive consistent care? Although there are guidelines to manage care in these instances, what is not known is whether or not healthcare providers are aware of the guidelines, whether they have insights into their own knowledge limitations, or whether they have ready access to prophylaxis. In addition, there is a lack of literature on the experiences of RhD negative women with pregnancy. There is no evidence to illustrate the impact of the women's knowledge and understanding on the decision-making process regarding the care of their RhD negative pregnancy. To date, research has yet to explore the experiences of RhD negative women that have developed anti-D antibodies in pregnancy. The development of new SOGC recommendations and the gap in knowledge about the care for RhD negative pregnant women needs to be explored in order to ensure quality care.

In the next Chapter, a literature review will provide context, evidence and inform the research questions outlined in the previous paragraph. The first section of the chapter will update the 2014 (Fyfe et al.) scoping review that sparked this research. The literature review section is structured into two components: (1) The first component will focus on the use of evidence by healthcare providers in the decision-making process, including conversations about the development, implementation and adaptation of CPGs, and decision-making in a rural context; (2) The second component will discuss decision-making processes that involve patients. The literature regarding health literacy, information behaviour and shared decision-making will be used to inform and contextualize the final research questions:

- Why do RhD negative women continue to be at risk for developing D antibodies in pregnancy?

- How do healthcare providers make decisions regarding the care of RhD negative pregnancies in northern British Columbia?
- How do RhD negative women in northern British Columbia experience pregnancy?

Chapter Two: Scoping and Literature Reviews

The research questions that frame this study aim to fill gaps in knowledge informing the provision of RhIG during pregnancy identified in the scoping review conducted by the researcher and stakeholders at NH (Fyfe et al., 2014). This Chapter is structured into two components: (1) a summary of the findings from the 2014 scoping review is provided to support the need and situate the research questions for this doctoral research study. In addition, an update to the original scoping review to ensure new research on the topic is included and explored; and (2) based on the findings of the scoping review and the research questions for this study, the literature review focuses on healthcare provider and patient decision-making processes in healthcare. The vast geography of northern BC will be defined and framed throughout the literature review to provide the context for the research study. Existing research will be used to define concepts that further inform the research.

Scoping Review

The Fyfe at al. (2014) scoping review provides the background and methodology for this section (Appendix A). The purpose of the original scoping review was to "review the literature on healthcare provider provision of anti-D prophylaxis to RhD negative pregnant women in appropriate clinical situations in various healthcare settings" (Fyfe et al., 2014, p. 2). The original review followed Levac, Colquhoun and O'Brien's (2010) scoping review methodology to ensure all the literature on a specific question, determining its breadth and nature within existing evidence is examined for applicability.

The searches completed in 2013 found 301 articles after duplicates were removed. After title and abstract screening, 35 articles were selected for full review. Two reviewers independently read each article and applied inclusion and exclusion criteria; discrepancies

amongst reviewers were resolved by a third reviewer. Articles were excluded if the study described how RhIG is administered and/or dosage of RhIG in pregnancy. Articles were included if they focused on the delivery of RhIG in routine and/or sensitizing events during pregnancy. After reviewers fully reviewed the 35 articles, 18 articles met the inclusion criteria (Bolton-Maggs et al., 2013; Chaffe et al., 2007; Fox et al., 1999; Ghosh & Murphy, 1994; Grant & Hyslop, 1992; Griffey et al., 2012; Howard et al., 1997; Huggon & Watson, 1993; Hughes et al., 1994; Koby et al., 2012; MacKenzie et al., 1999; MacKenzie et al., 2006; Mayne et al., 1997; McLaren & Shelley, 2002; McSweeny et al., 1998; Rennie et al., 2001; Thorp, 2008; Weinberg, 2001).

Findings from the review included a need for quality improvement regarding the care for RhD negative pregnancy as it relates to the delivery of RhIG:

> RhD negative women are not being consistently tested for their RhD status in clinically significant situations and are consequently not provided anti-D immunoglobulin when required. (Fyfe et al., 2014)

The reviewers framed the analysis on four areas for improvement: practice, policy, education and research. The original review themes of practice and policy concluded that in controlled environments, such as labour and delivery (LDR) and post-delivery units, routine RhIG administration is provided most of the time. The original review found that outside of controlled environments and situations, such as sensitizing events in pregnancy, RhIG administration is not provided consistently, hypothesizing that systems and communication failures were the potential cause of RhD alloimmunization. It was recommended that intervention-based quality improvement initiatives should be implemented and evaluated for effectiveness in reducing the potential for RhD alloimmunization in sensitizing event clinical situations. These quality improvement initiatives should include strategies for education and communicating with RhD negative women about being RhD negative and pregnant (Fyfe et

al., 2014). The review found studies that encouraged increased education amongst healthcare providers about the prevention of RhD alloimmunization in pregnancy.

Retrospective cohort studies were the most utilized method by the included articles in the original scoping review (Fyfe et al., 2014). Although these studies identified that there is inconsistency in the delivery of RhIG to RhD negative pregnant women during sensitizing events, reasons for not identifying RhD factor or providing RhIG were not identified. The review recommended larger multi-centered prospective studies be conducted and studies that explore RhD negative women's experiences with pregnancy.

Scoping Review Update

A further review of the literature published subsequent to the Fyfe et al (2014) paper was completed. This section gives a brief overview of the methods and includes a discussion of the pertinent articles. The articles will be discussed in the context of the original scoping review recommendations and how these articles support the need for further research in prevention RhD alloimmunization.

Methods

Levac et al.'s (2010) scoping review framework provided the methodology for updating the original scoping review in this dissertation. Each search string created for the 2014 review was re-run in the databases that were originally searched: Medline OVIDSP, EBM Reviews OVIDSP, Embase OVIDSP, CINAHL EBSCO, and Web of Science ISI. The Medline OVIDSP search strategy can be found in Appendix B. The search was limited to English language and publication years 2013 to 2018, ending on February 10, 2018. The publication years of 2013 to February 10, 2018 was selected to ensure that articles published, but not yet indexed at the time the original search was concluded, were not omitted.

The citations from each database were exported to Endnote and duplicates were identified and deleted. The titles and abstracts were then screened for relevancy. Identical inclusion and exclusion criteria were applied as in the original scoping review. The inclusion criteria were broad to ensure that the nature and depth of existing literature was captured. An article was included if it

> addressed the provision of prophylaxis in routine and/or sensitizing situations within healthcare settings. Articles that explored dosage and/or the administration of anti-D immunoglobulin practices were excluded. (Fyfe et al., 2014, p. 2)

In the process of updating the original scoping review, the researcher was the only person to review each article for inclusion and exclusion. During the screening process the researcher hesitated to discard anything that looked like it potentially might meet the inclusion criteria. It was suspected that this lead to a large amount of conference abstracts that were not weeded out during the screening process but were excluded when reviewing the full-text articles.

Results

The updated searches identified 92 citations for review for the period of 2013 to 2018. After duplicates were removed, 84 citations remained for screening. The researcher removed 44 citations in the screening process, leaving 40 for full article review. The original scoping review inclusion and exclusion's criteria was applied to each article, after full review only 3 articles met the criteria.

Of the citations that were removed during the review process 21 were conference abstracts. The abstracts were examined to determine if each of these had been published as a full paper, perhaps missed by the search strategy, however none of the abstracts were published as full papers as of February 10, 2018. Although the abstracts were relevant to the purpose of this review they were excluded because full text papers were not found.

One of the three studies included in this updated scoping review is a 2014 study conducted in New Zealand. The purpose of the retrospective study was to find the incidence of maternal RhD alloimmunization over an 8-year time span, 2005 and 2012 (Badami, Parker, Kenny, & Warrington, 2014). Along with the identification of sensitization, the researchers identified the reason for the development of RhD alloimmunization. They found the incidence of RhD alloimmunization in Christchurch, New Zealand, is 1.1%. Forty-four newborns required intervention, intrauterine transfusions and exchange transfusions. Of the mothers that were sensitized, the authors found that half were consequences of providers not following existing guidelines. The guidelines referred to are that of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists routine antenatal anti-D prophylaxis (RAADP; (The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2015). Although this guideline is endorsed by the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), the Ministry of New Zealand, as of 2014, did not endorse the guideline (Badami et al., 2014).

The second article included in the update describes research completed in Malaysia. The purpose of the prospective study was to find the prevalence of D antibodies and consequences of RhD alloimmunization in Malay pregnant women (Hassan, Mohd Nor, Noor, Sukri, & Mustafa, 2015). This article would have been excluded in the original scoping review because the Malaysian guidelines were not included in the original review; this occurred because Malaysian guidelines were not located at the time. The article is included here because the article fits meets the criteria for inclusion. The researchers found that the prevalence of RCB alloimmunization was less than 1%, 0.99%. This is consistent with other studies of prevalence (Badami et al., 2014). The authors suspected that the reason for continued alloimmunization was due to lack of adherence to prevention guidelines, not

providing the correct amount of RhIG and not identifying RhD negative status early enough in pregnancy (Hassan et al., 2015). The authors concluded that because alloimmunization is a rare occurrence they recommend to only screen for antibodies in those that are at risk of alloimmunization.

The most recent study to be included in the updated review comes from Northern Ireland (McCauley, Morris, & Maguire, 2017). A retrospective study examining the adherence to RhD alloimmunization guidelines was performed, spanning 2010 to 2015. The strength of this study is that its population spanned the entirety of Northern Ireland, making it a large cohort. The researchers found 67 cases of RhD alloimmunization and 97% adherence to guidelines. The three incidents of nonadherence were around sensitizing events, such as trauma and the omittance of screening for antibodies after birth. The authors recommended that future guidelines include an increase in the amount of RhIG administered to women after the delivery of an RhD positive infant and to further explore fetal molecular RhD genotyping to confirm if a fetus' RhD status early on in pregnancy.

Discussion

The three included articles in this review provide further evidence that RhD alloimmunization continues to occur in RhD negative pregnant women globally. These articles support the original thesis and confirm that RhD negative women are receiving inconsistent care, and if not rectified within the healthcare system, can have harmful consequences.

The New Zealand researchers demonstrate the struggle amongst updated policy by government, adherence to guidelines, and rare occurrences (Badami et al., 2014). This article adds to the original review's discussion themes of quality improvement in practice and

policy. The authors identified opportunities to work with the RANZCOG and the Ministry of Health in New Zealand to adapt and endorse RAADP guidelines to further prevent RhD alloimmunization. They conclude that once RAADP is the recommended and accepted guideline there will be opportunities for the education of providers, RhD negative pregnant women and laboratory staff. Further research could be conducted to investigate the impact the RAADP guideline has on RhD alloimmunization and stakeholder understanding and knowledge.

The Malaysian study has contradictory conclusions to most articles on prevalence of RhD alloimmunization (Hassan et al., 2015). They recommend that only those at risk of developing antibodies be screened for antibody development, this is similar to the recent SOGC recommendations (Johnson et al., 2017). As highlighted in the original review, this is in contrast to international guidelines that state that all RhD negative pregnant women should be screened during pregnancy and not just those at risk (Fyfe et al., 2014).

The recommendations in the Northern Ireland study to move to a fetal molecular RhD genotyping system in early pregnancy are similar to the new SOGC recommendations published in 2017 (Johnson et al., 2017; McCauley et al., 2017). Both suggest that using fetal molecular RhD genotyping may increase the prevention rate of RhD alloimmunization. The fetal molecular RhD genotyping can detect the fetus' RhD status using cell-free DNA. If the non-invasive text confirms the fetus' RhD status to be RhD positive, then the mother would be followed for routine RhIG. If the fetus' RhD status was confirmed RhD negative, the mother would then not require RhIG throughout the pregnancy. In Canada, these recommendations have not yet been implemented into practice.

These three articles provide further evidence that there is a need to understand and explore the reasons for RhD negative women to not receive RhIG when required. There

continues to be a need to explore the experiences of RhD negative women with pregnancy in order to get a clearer understanding of what is currently occurring in routine and non-routine prevention of RhD alloimmunization.

Conclusion

Three important studies have been published since the 2014 (Fyfe et al.) scoping review. Since this update, another study, based in Northern Ireland, was published that found only a small percentage, 4%, of RhD alloimmunized women was due to the lack of adherence to prevention protocols (McCauley et al., 2017). The articles provide further evidence that RhD negative pregnant women receive inconsistent care. None of these studies tell us why inconsistent and suboptimal care continues to occur, further supporting the need for the study outlined in this dissertation.

Literature Review

This component of the Chapter presents a review of relevant literature pertaining to key concepts in existing research, the purpose of which is to further refine the focus of this study. The utilization of guidelines in the decision-making process of healthcare providers requires checking applicability and adaptation. In large health authorities, such as NH, vast geographical landscapes add an additional layer of complexity to guideline implementation use and decision-making. This Chapter will begin with defining and describing the contexts that frame this study, such as rural, low occurrence clinical events and patient safety incidents. From there, an examination of evidence-based decision-making, from theory to critiques, knowledge creation, implementation, adaptation and the ways in which decision-making is influenced by geographic areas, such rural contexts will be described. The evidence-based decision-making discussion will involve a critical examination of existing

CPGs related to the prevention of RhD alloimmunization. From there, the review will revert to a discussion about shared decision-making between healthcare providers and patients/family members and the challenges of health literacy and information behaviour.

Defining Rural

Approximately 19% of the Canadian population lives in rural areas (Statistics Canada, 2011), yet a common definition of rural continues to challenge Canadian researchers. The difficulty lies in the various ways in which rural has been defined (du Plessis, Beshir, Bollman, & Clemenson, 2001). Rural healthcare studies often do not define or describe the regions they are investigating (Pitblado et al., 1999). One study that defined rural utilized the "rural and small town" definition to define the population because of its inclusion of community patterns (Macleod et al., 2008). The use of this definition is based on recommendations in a Statistics Canada's 2001 report entitled *Definitions of Rural* that looked at six different definitions of rural. In that report, du Plessis, Beshiri, Bollman, and Clemenson examined various rural definitions put forth by Statistics Canada and the Organization for Economic Co-operation and Development (OECD):

- Census "rural areas"
- "Rural and small town" (RST) and "metropolitan area and census agglomeration influenced zones" (MIZ)
- OECD "rural communities"
- OECD "predominantly rural regions"
- "Non-metropolitan regions" (modified Beale codes)
- "Rural" postal codes (Statistics Canada, 2011, p. 4)

The report looked at each definition individually in order to extrapolate unique differences. The report further examined each definition by comparing the factors that affect the definitions; such as size of the rural population, the overlap of the population, and socio-economic indicator results. The authors instructed the readers to respect each definition's

individual features yet recognize that characteristics for each definition are different and may have an impact on the way in which the definition is understood, thus making the process of defining contentious. The report recommended that researchers use the definition that best fits the research question but suggests that the "rural and small town" definition is appropriate in most instances:

> This is the population living in towns and municipalities outside the commuting zone of larger urban centres (i.e. outside the commuting zone of centres with population of 10,000 or more). (du Plessis et al., 2001, p. 8)

This definition includes urban centres that have populations less than 10,000, but remains outside of the community zone of larger urban centres with a population of more than 10,000. This definition is widely used in rural research in Canada. Other researchers have used definitions put forth by regulatory bodies, geographic isolation, limited to clinical settings without trainees, and rural communities identified through Canadian Census postal codes (Dharmar, Kuppermann, et al., 2013; Dharmar, Romano, et al., 2013; Green et al., 2013; Macleod et al., 2008). For the purposes of this dissertation, the <10,000 is not a sufficient definition of rural.

The definition of rural used in this study incorporates multiple criteria (Hearns et al., 2010), including geographic isolation, limited access to specialists, accessibility to services, resource availability, diminishing populations, struggling economies, cultural diversity, includes First Nations communities, and communities that struggle to recruit and retain healthcare providers. The following section will focus on the delivery of healthcare in all healthcare settings within rural environments that fit into one of the aforementioned criteria.

Defining Low Occurrences

Several terms are often used to describe low occurrences, such as low frequency, low-volume, small-volume, and limited experience (Dharmar, Kuppermann, et al., 2013; Heath, Salerno, Hopkins, Hertzig, & Caputo, 2009; Joint Position Paper Working Group, 2012; Marcin et al., 2007). Although rare diseases are often associated with low occurrence it will not be included in this definition. This study will use the term low occurrences when referring to clinical events that healthcare providers have limited exposure to within clinical settings. A clinical event is defined as the problem the patient presents with at the clinical setting. A clinical setting is considered any setting that a patient may visit with a health problem, particularly those in rural areas; such as, but limited to, hospitals, outposts, nursing stations, and physician/nurse practitioner offices. The focus of this section will be on low occurrences in rural clinical settings.

Defining Patient Safety Incidents

Without continuous exposure to clinical events a healthcare provider's knowledge, skills, and confidence may decrease over time (MacKinnon, 2010). If this is true, then rural healthcare providers confronted with low occurrences run the risk of their decisions resulting in harm to the patient. Based on this assumption, the term patient safety incident will be used to describe these situations and is further defined in the next few paragraphs.

The term patient safety incident has changed over the past two decades. In 2000, the Institute of Medicine (IOM) published a report entitled *To Err is Human,* using the term adverse events to describe patient safety incidents (Kohn, Corrigan, & Donaldson, 2000). An adverse event was defined as an incident for which injuries occurred due to medical mismanagement and not as the result of an underlying medical condition (Kohn et al., 2000).

This report and definition were created in response to major patient safety studies that emerged in the 1990s. Using the IOM definition of adverse events, the Harvard Medical Practice Study found that adverse events occurred in 3.7% of all hospital visits in the US, and 27.6% of the adverse events occurred as a direct result of negligent behaviour (Brennan et al., 1991). Negligent behaviour was defined as "care that fell below the standard expected of physicians in their community" (Brennan et al., 1991, p. 370).

The Canadian Adverse Events Study (Baker et al., 2004) was the first of its kind and showed that 7.5% of patients admitted to Canadian hospitals in 2000 experienced an adverse event. Much like the benchmark Harvard study, the Canadian study defined adverse events as "an unintended injury or complication that results in disability at the time of discharge, death or prolonged hospital stay and that is caused by healthcare management rather than by the patient's underlying disease process" (Baker et al., 2004, p. 1679). In the Canadian study, healthcare management included the broader systems, which is not defined in the Harvard study. In addition, the Harvard study used the term negligence. Instead, the terms "acts of omission (failure to diagnose or treat) and acts of commission (incorrect diagnosis or treatment, or poor performance)" were used (Baker et al., 2004, p. 1679). These two landmark studies provided the landscape for which adverse events were defined, categorized and realized in both Canada and the US.

In 2009, the World Health Organization (WHO) developed an International Classification for Patient Safety (ICPS) (World Health Organization, 2009; Wu et al., 2017). The ICPS used the term patient safety incident instead of adverse event. The ICPS defined a patient safety incident as "an event or circumstance that could have resulted, or did result, in unnecessary harm to a patient" (World Health Organization, 2009, pp. 15-16). Others, such as the Canadian Patient Safety Institute (CPSI), have adopted this language. The CPSI's most

recent disclosure guidelines uses the ICPS definition of patient safety incident (Disclosure Working Group, 2011). The intent of ICPS and the CPSI definitions of patient safety incidents is to set standard definitions that can be implemented within local contexts (Disclosure Working Group, 2011; World Health Organization, 2009). This only works if the definitions can and are adapted locally. There is a gap in knowledge as to how rural healthcare settings adapt the definition and criteria outlining patient safety incidents. The concept of knowledge uptake will be discussed further in the next section.

Patients/family members might include healthcare providers' lack of interpersonal skills and poor service in their definition of patient safety incidents, and although these additional factors may seem out of place, patients are likely to attach them to patient safety because they are unable to classify them elsewhere (O'Connor et al., 2010). In the UK, researchers interviewed 38 patients about their understanding of patient safety (Rhodes, Campbell, & Sanders, 2015). The participants in the Rhodes et al study (Rhodes et al., 2015), were not provided with a definition of patient safety. They were asked broad questions about patient safety and were prompted that no right answer existed. The themes that emerged from the interviews was that patients identified trust and social interactions between providers and patients as factors in patient safety. The second theme to emerge from the interviews was choice and continuity in the relationship between patient and provider. The third theme identified was that patients attached systems-level issues to patient safety. These tensions ranged from trouble booking appointments to lost test results. These components of a patient/family member's view on patient safety incidents are integral to developing a broader definition that encompasses healthcare systems, service delivery, and trust.

The term error is rarely used in regards to healthcare because it promotes a culture of failure and blame. The ICPS defines error as

> a failure to carry out a planned action as intended or application of an incorrect plan. Errors may manifest by doing the wrong thing (commission) or by failing to do the right thing (omission), at either the planning or execution phase. (World Health Organization, 2009)

This kind of language resonates with Reason's work on human and system error. Reason (1990) considers an error to be the result of an action that did not result in the desired outcome, yet if the unwanted outcome was due to external factors then it would not be considered an error. For example, if the unwanted outcome was the result of an underlying disease or condition, or an adverse reaction to a medication, then the action would not be considered an error (Brennan et al., 1991), however in some instances the outcome defines the error. For example, if a negative outcome occurred due to an error then it is deemed an error, yet if that same error did not have a negative outcome it will likely not be considered an error (Espin, Levinson, Regehr, Baker, & Lingard, 2006). Schubert, Winslow, Montgomery, and Jadalla capture the complexity of error in a well-rounded definition: "errors are embedded in human, organizational, and technical factors which, acting alone or in concert, are the causes of failure" (Schubert et al., 2012, p. 38).

Low Occurrences in Rural Settings

Rural settings have their own set of ethical dilemmas regarding patient safety incidents, such as relationships between patients and providers, lack of resources, privacy and confidentiality and shared decision-making (Nelson, 2009). There continues to be a paucity of research looking at patient safety incidents in rural healthcare (Coburn et al., 2004; Wholey, Moscovice, Hietpas, & Holtzman, 2004), yet a growing body of literature is exploring the management of low occurrences in rural healthcare (Dharmar, Kuppermann, et al., 2013; Dharmar, Romano, et al., 2013; Marcin et al., 2007). Understanding low

occurrences in a rural setting and the relationship to patient safety incidents may be helpful in developing interventions to prevent patient safety incidents from happening.

Not all physicians in rural areas manage pregnancies, or at least not many pregnancies, therefore one may question whether or not that limited experience with pregnancy has an effect on the physicians' competency, specifically the ability to recognize and respond to adverse conditions. Maternal care is an example of low occurrence in rural health, from a provider perspective where not many do maternity care. The SOGC states that many factors challenge the delivery of maternal care in rural environments:

> Rural maternity care providers have identified many challenges including determining and accepting risk, obtaining and maintaining competencies in low-volume environments, and balancing women's needs against the realities of rural practice (Joint Position Paper Working Group, 2012, p. 136; Miller et al., 2012, p. 985).

There is limited evidence regarding low occurrences and competency, particularly in rural maternity. This could be a direct result of obstetrical services not being offered in rural communities due to centralization, lack of resources, and/or the decision not to offer the services because of the small number of births per year (Hearns et al., 2010; Johnson & Jin, 2002). A policy statement developed by the SOGC, the College of Family Physicians of Canada (CFPC), and the Society of Rural Physicians of Canada (SRPC) refutes the idea of competency linked to low occurrence (Society of Obstetricians and Gynaecologists of Canada, 2002). In 2002, a study was published that looked at delivery volume of family physicians and maternal and neonatal outcomes at BC Women's Hospital and Health Centre in Vancouver (Klein, Spence, Kaczorowski, Kelly, & Grzybowski, 2002; Society of Obstetricians and Gynaecologists of Canada, 2002). This study found that there was no direct correlation between number of deliveries and maternal/neonatal outcomes that occurred at BC Women's Hospital and Health Centre from April 1997 to August 1998. The study did

find that family physicians who managed small numbers of pregnancies referred patients to obstetrician more frequently. It must be noted that this study was conducted in a resource intensive hospital; therefore, it is not truly reflective, nor can it be applied to a rural setting for which resources are often limited. In addition, this study did not ask physicians with a lower number of pregnancy interactions why they referred their patients to obstetricians more frequently. This information would helpful to understand this phenomenon.

Another example of low occurrence in rural settings is that of pediatric trauma and/or critical illness presenting to emergency departments. Several researches in the US have conducted studies on medication incidents (that may impact patient safety) in rural emergency department with a focus on critically ill and injured pediatric patients (Dharmar, Kuppermann, et al., 2013; Dharmar, Romano, et al., 2013; Marcin et al., 2007). The series of studies found that medication incidents are significant in rural US emergency departments treating children. The first study looked at the incidence, type of, and outcomes of medication errors. Through a three-year retrospective chart review, the researchers found that 39% of the pediatric patients experienced at least one medication error (Marcin et al., 2007). The errors identified fall into the range of incorrect dosage (most common physician-related error), incorrect administration, incorrect drug for the condition, drug ordered but not given, or the drug was given but not ordered (Marcin et al., 2007).

Low occurrences leading to patient safety incidents

The research that does exist on rural patient safety incidents covers a broad range of topics, such as implementation of patient safety and reporting, and community member perspectives of patient safety incidents (Demiris, Patrick, & Austin Boren, 2004; Klingner, Moscovice, Tupper, Coburn, & Wakefield, 2009). The majority of rural patient safety

incident studies have been conducted in the US (Coburn et al., 2004; Cook, Hoas, Guttmannova, & Joyner, 2004; Demiris et al., 2004; Klingner et al., 2009; Van Vorst et al., 2007; Wholey et al., 2004) and only one has been found in Canada (O'Beirne, Sterling, Zwicker, Hebert, & Norton, 2011). Absent from the literature is research looking at the experiences of those involved, healthcare providers and patients, in incidents of low occurrences leading to patient safety incidents in rural areas. In addition to a lack of research, the definition of rural has not been actively used in the included studies. For example, a 2011 study conducted in Calgary, Alberta (O'Beirne et al.) focused on the use of Safety Learning Systems (SLS) in 19 family practice clinics. Included in these clinics were 15 urban clinics and four rural clinics. Neither urban nor rural were defined in the study making it the reader's prerogative to define each term. In addition, the analysis did not differentiate between urban and rural family practice clinics. Consequently, no conclusion was drawn between patient safety incidents and rural clinics, something that is much needed. Without knowledge of the frequency of patient safety incidents within rural areas, decision-makers and researchers are not able to address the problem.

Unique elements regarding patient safety incidents have emerged from the literature, changing the way it is defined based on a rural context. Campbell and Croskerry (2003) conducted a review of the literature with the purpose of exploring what was known about patient safety incidents in rural practice settings. Based on this review there are many unique aspects to rural practice that can lead to patient safety incidents:

1. Broader scope or practice
2. Increased reliance on clinical judgement [sic]
3. Relative isolation
4. Continuing medical education (CME) opportunity limitations
5. Decreased specialist availability
6. Variations in local admission criteria
7. Increased familiarity with patients

8. Inadequate feedback
9. Differing patient characteristics/expectations
10. Differing physician coping mechanisms

(Campbell & Croskerry, 2003, p. 34)

In a 2012 review article, the authors repeatedly remarked that the environment/context for which a patient safety incident occurs can shape its impact (Schubert et al., 2012). As discussed previously, dealing with low occurrences increases the chance of patient safety incident occurring (Dharmar, Kuppermann, et al., 2013; Dharmar, Romano, et al., 2013; Marcin et al., 2007).

In another study, Wholey, Moscovice, Heitpas, and Holtzman (2004) found several factors that contribute to potential rural low occurrences:

- fewer staff and healthcare providers
- fewer available services across the continuum of care
- less financial resources
- lower patient volume
- patients bypassing local healthcare provider
- lack of information sharing in order to address quality issues
- distance and geographic barriers
- limited electronic information systems for clinical work and quality improvement

Further to these unique factors, Wholey et al. (2004) suggest that rural physicians have different decision-making factors and processes, compared to that of urban physicians, that need to be considered in defining patient safety incidents. The authors provide an example that involves assessing a patient for an acute myocardial infarction in a rural emergency room. The rural physician needs to include many more steps in the decision-making process including: the discussion of the possible transfer of patient with family members to a larger centre, the assessment of weather conditions for safe transfer, telephone the centre where the patient is being transferred to communicate with the transfer team, the reassessment of the patient prior to transfer, all of this being pursued while dealing with other patients that are

also being admitted to the emergency room. At each point in this process a slip, lapse or mistake could occur[1]. With more steps, such as in the case of the rural emergency department, more processes exist in the decision-making process that increases the risk for patient safety incidents to occur.

Another factor of rural healthcare that may influence decision-making is relationship between the healthcare provider and the community. "Social embeddedness" is considered a unique factor in rural environments (Wholey et al., 2004). Embeddedness refers to the healthcare staff and providers knowing patients as patients and as members of the community. Wholey et al. (2004) state that this dynamic relationship has both positive and negative aspects. The positive aspect of social embeddedness is the ability to share information between healthcare provider and patient due to the relationship they have beyond the healthcare relationship, making discussions between the patient and healthcare provider, or staff, more meaningful and anomalous results might be spotted easier if the patient is known. On the negative side, complacency may occur, such as one healthcare provider assuming the other provider has knowledge of the patient's health status because they know each other personally from the community.

Further research is needed in the area of patient safety incidents in rural areas in order to gain a better understanding of the impact it has on those involved and the potential this impact could have on the community at large. It would be helpful to further explore social

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[1] James Reason coined the terms *slip, lapse and mistake*. Slips are errors that do not go as planned; i.e. slip of the tongue. Lapses are errors that often involve failure of the retrieval of information from memory. A mistake involves actions that are not appropriate due to "failures in the judgemental [sic] and/or inferential processes involved in the selection of an objective or in the specification of the means to achieve it, irrespective of whether or not the actions directed by the decision-scheme run according to plan" (Reason, 1990, p. 9).

embeddedness, cognitive bias and process, and other mitigating factors that lead to and influence the way patient safety incidents are managed and/or to understand why they occurred.

Managing low occurrences

Managing low occurrences presents many challenges in rural healthcare settings and many innovations and interventions have been explored to mitigate risks and to support clinical decision-making. The most common interventions described in the literature are telemedicine, targeted continuing education, quality improvement programs, and shared care. These interventions have been implemented as a means of providing support and education to rural healthcare providers. For the purpose of this dissertation, telemedicine, targeted continuing education and quality improvement programs will be explored in relation to previous examples already used in this section.

Managing Obstetrical Risk Efficiently (MORE^{OB}) is a quality improvement and patient safety approach targeted toward improving obstetrical care, quality and safety. This program has been implemented in many areas across Canada, including Northern Health Authority in BC (Salus Global, 2012). An Alberta based study found that MORE^{OB} improved maternal and neonatal outcomes after the implementation of the team-based program (Thanh, Jacobs, Wanke, Hense, & Sauve, 2010). A study looking at differences where MORE^{OB} is implemented amongst rural and urban healthcare centres within a centralized/regionalized health system is needed[2].

[2] It is assumed that this occurs within internal reports.

Telemedicine has been utilized in supporting the management of low occurrences in rural areas. Only three studies were found that support or consider the use of telemedicine as a tool to facilitate healthcare provider discussion with specialists when dealing with low occurrences (Dharmar, Kuppermann, et al., 2013; Dharmar, Romano, et al., 2013; Heath et al., 2009). The low occurrence studies focusing on pediatric patients presenting to emergency departments, (Dharmar, Kuppermann, et al., 2013; Dharmar, Romano, et al., 2013) were retrospective and involved eight rural emergency departments in northern California over a 6-year period. The Heath et al. (2009) study was conducted prospectively across two states and involved 19 rural emergency departments. These studies have found that utilizing technology to overcome geographic and lack of specialist barriers is effective in managing low occurrences and reducing patient safety incidents. One of the limitations of the Dharmar, Kuppermann et al (2013) study, was that they were limited to medication misuse, consequently, other types of patient safety incidents were not considered. The Heath et al. (2009) article followed the use of telemedicine for two years and was able to identify challenges and the use of telemedicine that may overcome accessibility and other resource implications.

There is a risk of patient safety incidents in rural healthcare settings were low occurrences of obstetrical and pediatric occur. Although there is some evidence that MORE^{OB} and telemedicine can help to mitigate such risks, there are other factors that may not yet be known. Without a better understanding of the types of low occurrences that occur in rural settings, management and/or prevention strategies may not be effectively implemented.

Managing patient safety incidents

Policies are emerging that provide guidance for the disclosure, management and reporting of patient safety incidents. There is limited information on models that are specific to patient safety incidents in rural settings. This section will explore the three aspects of patient safety incidents (disclosure, reporting and management) through a rural lens.

Disclosure

In healthcare, disclosure is the act by which the patient and/or family member(s) is told by a healthcare provider, administrator, or other that a patient safety incident has occurred. There is a growing body of literature regarding disclosure of patient safety incidents. Disclosure remains the critical component in the management of low occurrences because patients are affected in the following ways:

1. Accountability, acknowledgement and apology
2. Emotions
3. Information
4. Lack of empathy
5. Lack of support
6. Reporting
7. Trust

(Blendon et al., 2002; Gallagher & Levinson, 2005; Gallagher et al., 2003; Iedema et al., 2011; Mazor et al., 2010; O'Connor et al., 2010; Witman et al., 1996). Each will be discussed in turn.

Accountability, acknowledgement and apology

Studies show that patients/family members want to know details of patient safety incidents, for example, what happened, how it happened and why it occurred (O'Connor et al., 2010). In the majority of the studies included in this section, patients and family members wanted an apology after a patient safety incident (Gallagher et al., 2003; Iedema et al., 2011;

Mazor et al., 2010; O'Connor et al., 2010; Witman et al., 1996). Often an apology for a patient safety incident is the deciding factor between a patient's/family members' decision to file a complaint and/or medical malpractice claim regarding the incident (Mazor et al., 2010; Witman et al., 1996). Mazor et al (2010) undertook a qualitative study to explore parents' experience with patient safety incidents. Thirty-five parents were interviewed and following analysis over half of the participants stated that not one individual provided any information about the incident nor did anyone take responsibility. The lack of accountability and information influenced the response of the parents to the patient safety incident. It remains unknown how patient safety incidents are managed in rural areas and if disclosure might be easier or harder amongst close colleagues and patients/family members due to social embeddedness.

Emotions

Patients and family members may be angry, anxious, sad, and depressed after experiencing a patient safety incident (Gallagher et al., 2003; O'Connor et al., 2010). Physicians can also experience strong emotions when patient safety incidents occur. The most common emotion that emerged in the literature amongst healthcare providers is that of fear: the fear that they harmed a patient, the fear that apologizing or taking responsibility for a patient safety incident may lead to litigation and the fear of damage to one's career (Gallagher & Levinson, 2005; Gallagher et al., 2003; O'Connor et al., 2010). These studies do not focus on rural environments. It is not apparent if emotions run higher amongst the patient/family member or healthcare provider when patient safety incidents occur in rural areas due to social embeddedness factors. There is a gap in the literature on the emotional impact a patient safety incident has on patients/family members and healthcare providers in

rural healthcare settings. Bridging this gap may help to understand the impact social embeddedness has on rural healthcare.

Information

Following a patient safety incident, patients and family members often seek information about the event. A national qualitative study conducted in Australia interviewed 100 patients and family members about disclosure, found that participants did not want information to be one-directional (Iedema et al., 2011). These individuals wanted to be able to ask questions about the incident in order to satisfy their information needs, which lead to closure. This is an important finding because it relates to the principles of shared decision-making, which will be discussed in a later section. In this instance, just as in a "normal" physician-patient encounter, the patients wished to be part of the process that involved the sharing of information.

The Australian study (Iedema et al., 2011) found that patients use information as a means of coping and gaining closure. This resonates with the monitors-blunters stress coping theory, which will be discussed in more detail in a later section of this chapter. When faced with traumatic events, active seekers will attempt to acquire as much information as possible in order to make sense of the situation and use the information to cope with the consequences of the event (Miller, Brody, & Summerton, 1988). When patients or family members are not satisfied with the information provided and/or the way in which it is communicated they may decide to pursue this information through other means, such as legal action (Gallagher & Levinson, 2005; Mazor et al., 2010).

Lack of empathy and support

Patients and family members want to feel that healthcare providers and administrators are empathetic to the situation and genuinely care (Mazor et al., 2010). In addition to empathy, patients/family members want to be supported in this process. The Australian study cited above (Iedema et al., 2011) found that patients/family members who were offered a support person throughout the disclosure process felt this was important in understanding and moving through the process.

Conversely, physicians may also feel a lack of support. In a study conducted in the US, physicians at six health institutions were asked to complete a survey on error disclosure culture (Etchegaray, Gallagher, Bell, Dunlap, & Thomas, 2012). This study found that if a physician believes that they are not supported by the organization for which they work, the physician is less likely to disclose a patient safety incident. This important work found that general error and trust culture were the most important factors in the disclosure of patient safety incidents. Further, the study validated an important assessment tool for healthcare systems to assess the state of the disclosure culture within the system. Based on these findings, the authors argue that organizations should measure the disclosure culture in order to improve the processes in place to deal with patient safety incidents and identify educational needs. Improving the culture of disclosure improves the trust, both within the healthcare system and with its patients.

Trust

Each of the themes (reporting will be covered next) regarding disclosure could arguably lead to trust issues. Two papers state that patients/family members have an increase of trust with their healthcare provider if a patient safety incident has been disclosed

(Gallagher et al., 2003; O'Connor et al., 2010); therefore, trust is part of their definition of patient safety incidents (Rhodes et al., 2015). A culture of trust within a healthcare institution can lead to an increased willingness to disclose patient safety incidents because healthcare professionals and staff feel supported in reporting within the institution (Etchegaray et al., 2012).

Models of disclosure and reporting

Managing patient safety incidents begins with acknowledgement and disclosure. As discussed in the previous section disclosure is complicated, requires a great deal of thought and sensitivity, and has many factors that can influence its outcome(s). This next section will explore the international literature on models of managing patient safety incidents. These models will be described and explored using a rural lens.

In 2008 the CPSI disseminated its first set of Disclosure Guidelines, which were updated in 2011. These guidelines were widely disseminated and supported by such groups as the Canadian Medical Protective Association (CMPA) and Accreditation Canada (AC) (Disclosure Working Group, 2011). A recent review of international policy regarding the disclosure of patient safety incidents found that despite the CMPA and AC's efforts to educate and disseminate the information there is no evidence of what the impact the Disclosure Guidelines has had in the management of patient safety incidents (Wu et al., 2017).

The international review described the National Health Service's (NHS) policy entitled *Being Open* implemented nationally in both England and Wales in 2005 (Wu et al., 2017). Unlike the Canadian model, an evaluation of the uptake of the policy was conducted two years after the policy was put into effect. Although the intentions were in the right place,

the study found that “36% of physicians held unfavorable attitudes toward the policy” (Wu et al., 2017, p. 2) and that there were many obstacles to the uptake of policy. These barriers included a culture of blame, a lack of the communication skills required to effectively disclose, a perceived lack of support from the organization, and a perception of an environment that is not safe to disclose.

As previously discussed, the apology is a critical component in the disclosure process. There is a growing trend around apology legislation. In Canada, as of April 2013, eight provinces and one territory had passed apology legislation: Alberta, British Columbia, Manitoba, Ontario, Newfoundland and Labrador, Nova Scotia, Prince Edward Island, Saskatchewan, and Nunavut (Wu et al., 2017). According to CMPA, the purpose of apology legislation is to encourage healthcare providers to apologize and address the concerns about the apology being used against them in legal action (Canadian Medical Protective Association, 2013). As an example, the BC Apology Act states that an apology is not an admission of fault and cannot be used in court ("Apology Act," 2006). In addition to apology legislation in Canada, each province and territory’s quality improvement protection legislation safeguards information derived from quality improvement discussions, records, and other related documents from being included in legal proceedings (Canadian Medical Protective Association, 2013).

In Australia, open disclosure “requires doctors to inform patients that an adverse event has occurred” (Finlay, Stewart, & Parker, 2013, p. 445). As in Canada, there is no national regulation regarding the disclosure of patient safety incidents. Instead there are open disclosure policies and apology laws in each state and territory in Australia (Finlay et al., 2013). In 2003, the Australian Commission on Safety and Quality in Healthcare was the first world-wide to adopt national open disclosure standards; however, these standards were

replaced with an open disclosure framework in 2014 (Finlay et al., 2013). As with the Canadian apology laws, in Australia the laws are different across the states and territories in regards to what kind of statement of apology will and will not be protected. Understandably, this leads to confusion and scripted insincere apologies (Australian Commission on Safety and Quality in Health Care, 2013).

Reporting

Reporting patient safety incidents is the act of recording the incident in a structured and uniform system. This reporting system could be a local patient safety initiative, a regionalized system or a national system put in place to collect patient safety data across a country. Safety Learning Systems (SLS) are localized systems implemented by health authorizes and/or hospitals to record patient safety incidents with the goals of quality improvement and learning (Finlay et al., 2013). Patients/family members report patient safety incidents because they want to be reassured that the incident they, or their loved one, experienced will not occur again (Iedema et al., 2011; Mazor et al., 2010; Witman et al., 1996). In addition to knowing, patients and family member(s) want to be involved in ensuring that prevention and quality improvement takes place (Witman et al., 1996).

In 2005, the WHO published draft guidelines encouraging countries to implement reporting systems. The guidelines were based on four key principles:

- The fundamental role of patient safety reporting systems is to enhance patient safety by learning from failures of the health-care system.
- Reporting must be safe. Individuals who report incidents must not be punished or suffer other ill effects from reporting.
- Reporting is only of value if it leads to a constructive response. At a minimum, this entails feedback of findings from data analysis. Ideally, it also includes recommendations for changes in processes and systems of health care.
- Meaningful analysis, learning, and dissemination of lessons learned requires expertise and other human financial resources. The agency that receives

> reports must be capable of disseminating information, making recommendations for changes, and informing the development of solutions. (World Health Organization, 2005, p. 10)

Almost 10 years later, national patient safety incident reporting systems are still being established in Canada.

Canada does not have a mandatory and regulated patient safety incident reporting system as demonstrated in a systematic review published in 2010 (Kingston-Riechers et al., 2010). The Canadian Institute for Health Information's (CIHI) National System for Incident Reporting (NSIR) is a voluntary reporting system established to collect medication/ intravenous fluid incidents (Canadian Institute for Health Information, 2014). The data collected in the NSIR is provided to the Canadian Medication Incident Reporting and Prevention System (CMIRPS) (Canadian Institute for Health Information, 2014). The mandate for CMIRPS is to prevent medical incidents in Canada.

Data about complaints can be found from Physician and Surgeon Colleges, such as BC College of Physicians and Surgeons complaint annual reports, and likewise, the CMPA does collect data on medical malpractice claims, but this information is by request. In a policy briefing report, the CMPA recommended that "legislation that mandates incident/occurrence reporting and policies that clearly specify the conditions under which such reporting is to take place" is required (Canadian Medical Protective Association, 2009). In a review article, Kalra, Kalra and Baniak (2013) found that Colleges of Physicians and Surgeons in several provinces have implemented disclosure guidelines (Saskatchewan, Manitoba, Ontario, Newfoundland, Nova Scotia). Disclosure guidelines are also included in the Quebec code of ethics. BC does not have disclosure guidelines but, as discussed previously, does have apology legislation.

Compensation

A discussion of national reporting is often coupled with models of compensation. It could be argued that disclosure guidelines, apology legislation, and reporting systems are not enough. Each of the components of patient safety is isolated without a national structure in place to provide it structure, legitimacy, and effective management. Several countries (such as Sweden, Norway, Denmark and New Zealand) have national patient safety incident compensation programs (Andreasen, Backe, Jorstad, & Oian, 2012; Kachalia, Mello, Brennan, & Studdert, 2008). Implementing programs to compensate patients who experienced patient safety incidents is a global challenge because of the "presence or absence of a centralized health authority, the way in which health care is funded, and litigation laws and culture in different settings" (Wu et al., 2017, p. 3).

New Zealand has one of the longest running compensation programs in the world and will be explored as a model for dealing with patient safety incidents. In 1967, the government implemented extended coverage for persons experiencing accidental injury, followed by the Accident Compensation Corporation (ACC) implementing a no-fault compensation program in 1974 that grew to include harm due to medical misadventures (Kachalia et al., 2008). Wu et al.'s (2017) review describes the program as a means of providing compensation to patients that experienced harm as the result of healthcare and eliminated medical practice claims. Further to this, the authors note that the ACC deals with the complaints through health provider regulation boards. This process progressed to a "duty of candor" law in 2002. As a consequence, all hospitals in New Zealand have local disclosure policies yet nothing specific for rural areas. Little research has been conducted to evaluate this program. One study looked at claims data from the mid-1990s and found that the compensation program in New Zealand did not alleviate low-level claims (claims that did not fit patient safety incident

criteria and are not compensated) (Davis et al., 2002). In addition, a qualitative examination of patient/family member satisfaction and healthcare provider perspectives would be helpful in understanding if this type of compensation process is effective.

Summary

This section has examined the management of low occurrences in rural healthcare. Several themes emerged from the research presented in this section. Many definitions of rural exist in health research, no one definition is perfect and most omit important aspects of rural context. Low occurrences are described in the literature but further research is needed to understand the management of low occurrences in rural health.

Although some research describing barriers and challenges to working in rural areas exists it is not clear how these barriers and challenges impact decision-making. Furthermore, there is a paucity of research on the impact of decision-making processes in the management of low occurrences resulting in potential patient safety incidents.

Patient safety incidents have been well described and documented in the literature. There is a gap in knowledge regarding patient safety incidents in rural healthcare and the management of those incidents. This gap will persist until there is a well-established national reporting system and/or framework for which to manage events and how this manifest itself in rural areas needs to be explored.

To gain a more in-depth understanding of patient safety incidents, the decision-making processes involved in the provision of healthcare will be explored. The next section will explore the use of evidence in the decision-making process. This will cover the creation of knowledge and the implementation into practice.

Evidence-Based Decision-Making

The management of a clinical situation or condition/disease is often based on evidence. Ideally, the evidence utilized in the practice of medicine is a direct result of research in specific fields of practice. The process of taking acquired knowledge and implementing it in practice is an aspect of knowledge translation (KT). A more formal definition of KT is found in Straus, Tetroe, and Graham's book entitled *Knowledge Translation in Health Care*:

> Knowledge translation is the synthesis, dissemination, exchange, and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the health care system (Straus, Tetroe, & Graham, 2013, p. 3).

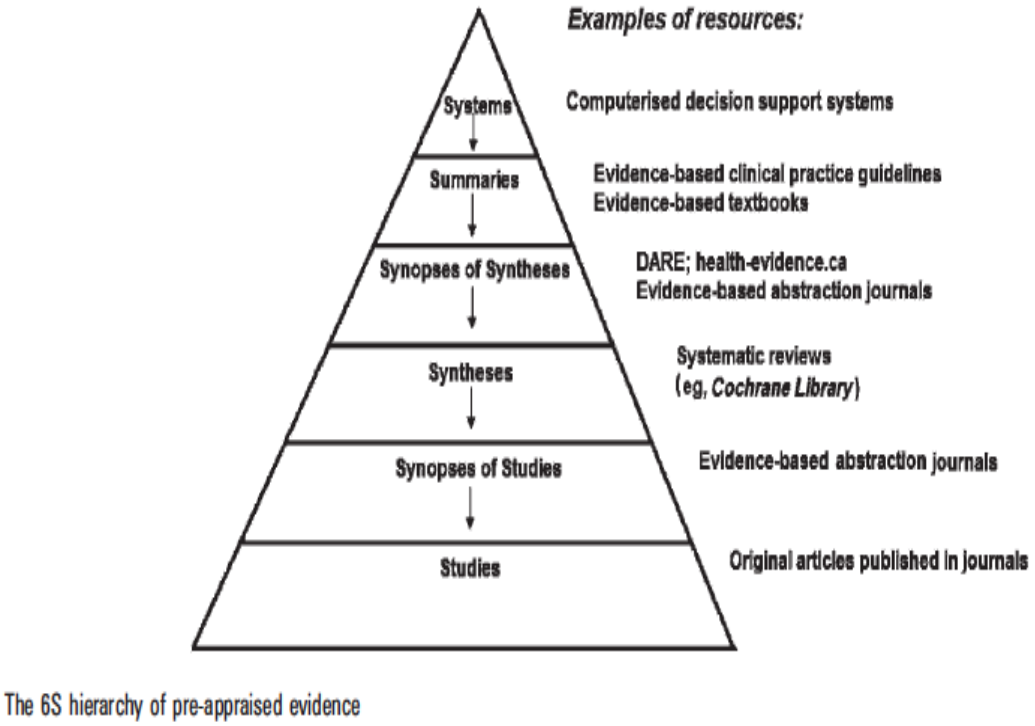
This definition of KT is endorsed by the Canadian Institutes for Health Research (CIHR) (2014). Emphasis is placed on the strengthening of the healthcare system as the key and the ultimate outcome is the improvement of quality care by putting knowledge into action. Evidence-based medicine (EBM) is the act of research uptake.

Evidence comes in many layers, often referred to as the knowledge funnel or the hierarchy of evidence. Graham et al.'s (2006) model of KT, a widely adopted model of KT in Canada, explores evidence as generational knowledge illustrated by using a knowledge funnel. First-generation knowledge refers to the research phase, the original primary studies. Second-generation knowledge is the synthesis of information, often resulting in systematic reviews. Third-generation knowledge is the tailoring of information into knowledge tools or products. These products may include, CPGs, care pathways, synopses and decision aids.

With the continued growth of research and knowledge products, it is easy to become overwhelmed with information. Approaches to strategizing how one finds and uses information assists in the overall use of evidence in practice. The intent of DiCenso, Bayley,

and Haynes' (2009) hierarchy of evidence is to encourage the use of filtered information resources in practice and is one model of approaching the research literature. The hierarchy of evidence has evolved from a 4S model to a 6S model (see Figure 1 – The 6S hierarchy of pre-appraised evidence). The 4S model included original single studies, synthesis, synopses, and summaries. The 6S model progressed to include systems and synopses of single studies. The hierarchy is a pyramid shaped where primary research occupies the lower lever scaffolding to pre-appraised literature in the middle and computerized-design holding the top position on the pyramid. The pre-appraised literature is much like second-generation knowledge, in that it involves the synthesis of information using systematic review methodology. Above that is the summary level that constitutes the same knowledge products defined in the knowledge funnel. Both models of evidence creation are intended to assist in evidence-based practice and uptake of research.

Figure 1. The 6S hierarchy of pre-appraised evidence (DiCenso et al., 2009, p. 100)



The 6S hierarchy of pre-appraised evidence

EBM has received criticism over the years. It has been called "cookbook medicine" and referred to as practice that only those in "ivory towers and armchairs" can actually achieve (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996), meaning those on the frontlines delivering healthcare are not always able to turn policy into practice due to the realities of the frontline, such as workload, and/or the applicability of research. The KT movement acknowledges that there is a problem with research being translated to practice, manifesting a problem of unnecessary research funding and unused research findings (Graham et al., 2006). The concept of implementation and adaptation of guidelines will be discussed further in this section. Epstein & Gramling (2013) argue that evidence "can improve quality of care, reduce unwarranted variations in practice, and highlight concerns for which the patient's voice is sought" (p. 97S). The authors note that evidence is often

population based consequently making it difficult for a physician, and their patient/family member, to apply the evidence directly to an individual's specific care need. In addition, a patient/family members' inability to understand the information and/or the information being too broad to apply to the specific clinical situation is also a factor that hinders EBM (this will be discussed further in the next section). The authors also highlight that CPGs can be confusing: 'do this' versus 'if you do X, there is a chance that Y might happen'. Recognition of this issue is critical in that guidelines, by their very nature, are both prescriptive and descriptive, requiring the physician, and patient to make a decision based, again, on conjecture (Epstein & Gramling, 2013). Building on this, recent critics state that EBM is "meaningless unless societal, cultural and political perspectives are taken into account" and is not understood by those developing policy (Kelly, Heath, Howick, & Greenhalgh, 2015, p. 3). Another recent paper argues that EBM does not take into account real and practical situations for the purpose of EBM and suggests that knowledge translation needs to begin with the patient (Wieringa, Engebretsen, Heggen, & Greenhalgh, 2017).

Other critiques of EBM describe the practice as over prescribed and not open to interpretation or judgment (van Baalen & Boon, 2014). van Baalen and Boon's (2014) review article discusses the criticisms of EBM. They state that EBM does not allow for personal judgment and the use of information beyond CPGs. The authors' coin the term 'epistemological responsibility'. This term makes physicians accountable for their decisions by requiring physicians to integrate various sources of information claiming that EBM focuses solely on CPGs. This review paper draws on works from narrative and case-based reasoning that challenge the EBM approach. We must continue to acknowledge the importance of EBM in the decision-making process with both contextual and personal aspects. The subsequent section will focus on CPGs.

Clinical Practice Guideline Development, Implementation and Adherence

The common definition of CPGs is "systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances" (DiCenso et al., 2009, p. 100; Field & Lohr, 1990, p. 8; Guyatt et al., 2002, p. 185; KT Clearinghouse, 2013). Wieringa and Greenhalgh challenge the use of CPGs with the notion that CPGs are the focus of one medical situation, condition and/or event with the intent of ensuring "consistency of care" (2015, p. 9). These authors argue that the strict parameters of CPGs can lead to misdiagnosis and mistreatment because healthcare providers lean on CPGs too heavily, missing opportunities to look elsewhere.

As mentioned previously, CPGs are created by a team of experts who read, synthesize and evaluate existing evidence, and write a statement to be utilized by healthcare providers in patient care to inform their decision-making processes. In the late 1990s, Graham, one of the leading researchers in the field of Integrated Knowledge Translation (IKT), and a team of researchers surveyed CPG developers about the development process used to create CPGs (Graham, Beardall, Carter, Tetroe, & Davies, 2003). The authors found that guideline development involved the following process: the development of a committee, searching of evidence with or without a stated search strategy, critical appraisal of evidence, and consensus based on discussion, a structured process, or other. This was a launch pad for improved CPG development processes and research, including the creation of CPG development, critical appraisal and adaptation tools.

Searching the literature is a critical step in the process of developing a CPG. Essentially, CPGs are based on systematic reviews of the literature. This is fairly standard amongst guideline development frameworks yet there is controversy on whether a systematic review should be conducted on the main question of the CPG or of each question that lies

within (Turner, Misso, Harris, & Green, 2008). Therefore, a brief description of the systematic review searching process is described based on the *Cochrane Handbook for Systematic Reviews of Interventions* (*Cochrane Handbook for Systematic Reviews of Interventions*, 2011). Evaluation of the literature for CPGs ideally involves identifying a topic. Topics can be focused using clinical scenario tools such as PICO (Population/Patient/Problem, Intervention/Issue, Comparison, and Outcome(s)). An early study that looked at the development, dissemination and implementation of guidelines found that most CPGs reviewed scientific literature but only 87.5% actually conducted database searching; shockingly only 33.5% of CPGs included the search methodology (Graham et al., 2003).

Based on inclusion and exclusion criteria, research will be considered by the CPG development committee. Graham et al.'s (2003) early work found that guidelines did not consistently critically appraise the included research and used a variety of consensus-based techniques to make recommendations. These findings generated the creation of tools used to critically appraise research in the development of CPGs.

In 2008, the British Medical Journal (BMJ) published a series of articles outlining and describing a CPG development tool; the *Grading of Recommendations Assessment, Development and Evaluation (GRADE)* tool was created to help guide and streamline the critical appraisal process of developing CGPs with a focus on critical appraisal and making recommendations (Guyatt, Oxman, Schunemann, Tugwell, & Knottnerus, 2011; Guyatt et al., 2008). The *GRADE* tool provides criteria to critically evaluate the research considered in the development of the CPG from high quality to very low-quality research. The quality of the evidence is then taken into consideration when developing recommendations. The recommendations using the *GRADE* tool are given either a strong or weak suggestion. The

following are domains that are considered when making a strong or weak practice-based recommendation:

- Balance between desirable and undesirable outcomes (estimated effects), with consideration of values and preferences (estimated typical) (trade-offs).
- Confidence in the magnitude of estimates of effect of the interventions on important outcomes (overall quality of evidence for outcomes).
- Confidence in values and preferences and variability. (Guyatt et al., 2011; Guyatt et al., 2008)

As a knowledge tool, the attachment of strong or weak recommendations is helpful to the stakeholders making individual patient-care decisions. Once the CPG is fully developed and recommendations given the implementation process can begin. A recent review of prostate cancer guidelines spanning 15 years, found that there still remains variability in the methods used to develop CPGs and the quality of the CPGs found (Gupta et al., 2014). This challenges the notion that CPGs development is improving.

The implementation of knowledge has been a major focus in CPG research. The implementation research stresses the need for CPGs to be adaptable to local contexts and remain flexible enough for shared decision-making processes to take place. This approach to local implementation involves the process of adopting CPGs as is or adapting the CPG to local setting, patient, and/or practice (Andrews et al., 2013).

Implementation and Adherence of Clinical Practice Guideline

Although CPGs are the focus of this section, evidence is often challenging to implement into practice, particularly at an organizational level. Implementation science research has studied many ways of disseminating and ensuring uptake of research. This research has ranged from push and pull strategies (Tetroe et al., 2008), the development of knowledge tools, such as CPGs, and stakeholder engagement (Straus et al., 2013). Push strategies are those that involve the researcher(s) pushing the knowledge out to stakeholders;

whereas, pull strategies involve stakeholders commissioning research, engaging research findings amongst stakeholders and decision-makers, and engaging in the research process (Tetroe et al., 2008). In addition, organizational change theories have been explored, such as Diffusion of Innovation (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). Theories such as this provide some insight into the ways in which change is implemented across complex organizations, such as healthcare. However, the focus of this particular section will be on the implementation of CPGs in practice within various contexts because this remains an issue within implementation research.

The creation of CPG development tools led to the creation of adaptation tools. An international tool called the Appraisal of Guidelines Research and Evaluation (ADAPTE) was designed to assist regional/local teams in adapting guidelines to local environments with the intent of increased adherence (Fervers et al., 2011; Harrison, Legare, Graham, & Fervers, 2010). ADAPTE is a rigorous process that involves three phases: set up phase, adaptation phase and the finalization phase. The set-up phase involves the creation of a committee with all available stakeholders, including patients. The adaptation phase involves defining the local question, searching the literature, critically appraising available guidelines, selecting the guidelines to include, and developing local recommendations.

In the final phase a CPG is peer reviewed and disseminated. This process has been evaluated based on stakeholder perspectives on use of the tool (Fervers et al., 2011; Harrison et al., 2010). Recently, another tool, Guideline Implementability Tool (GUIDE-IT), has been developed specifically for family physicians (Kastner et al., 2014).This tool has been evaluated based on feedback from 20 family physicians in Toronto, Ontario, which will lead to the further development of this tool.

Missing from the adaptation and implementation research are outcome measures. In one of the first KT articles published, Graham et al. (2003) argued that medical record audits conducted in various settings found that evidence was not consistently applied: missing from the literature is why and how. Measuring the adherence of locally adapted and implemented guidelines is imperative to quality of care and the continued improvement of CPG development. A recent scoping review of the provision of anti-D immunoglobulin in RhD negative pregnant women found that adherence to CPGs regarding the delivery of anti-D was inconsistently applied, despite guidelines being available for many years (Fyfe et al., 2014). The continued suboptimal delivery of care in this example leads to potential cases of hemolytic disease of the fetus/newborn or fetal/newborn demise. In addition to this, measuring the adherence of rurally adapted and implemented CPGs is imperative.

Rural utilization of CPGs

There is limited research on healthcare providers' use of EBM in rural environments. The literature that does exist is predominantly based in Australia. The barriers faced by healthcare providers in rural areas in Australia are professional and geographic isolation, inability to find and appraise evidence, inability to always meet patient care needs based on CPG recommendations and patient preferences, and lack of resources (human resources, time, technology, and so on) (Taylor, Wilkinson, & Blue, 2001; Taylor, Wilkinson, Blue, & Dollard, 2002). One of the major complaints about CPGs is that they are not applicable to all patient situations, which was discussed earlier. The Australian review paper found that rural Family Physicians perceived that,

> randomized trials provide important evidence but the study subjects may not be representative of those managed in the primary care setting. For example, trials may exclude patients with multiple illnesses and those of particular clinical significance such as rural population (Taylor et al., 2001, p. 3).

This continues to be a challenge for healthcare providers because they are unable to relate CPG recommendations to patient care decision-making, particularly when the patient/family member is involved in the decision-making process.

Solutions suggested by participants in the Australian studies, discussed in the previous paragraph, encouraged the following: flexibility in the delivery of continuing medical education, opportunities for instruction during work time, an increase in patient education activities particularly geared towards rural areas, improvement in the development and dissemination of CPGs, and the recruitment and retention of healthcare providers in rural areas (Taylor et al., 2002). In addition, the use of evidence in an ideal rural health situation would involve both rural context, clinical experiences, and shared decision-making (Taylor et al., 2001). These suggestions are similar to the challenges by researchers and stakeholders and are being addressed through KT and continuing medical education, but rural environments have their own unique difficulties in the uptake of evidence that need to be addressed at the outset.

In Canada, only one study has explored rural physicians' perceptions of guidelines and shared decision-making. Boivin, Légaré, and Gagnon (2008) conducted a qualitative study in a remote town in Quebec[3]. The authors found that rural family physicians appreciated the purpose of CPGs and agreed that they aid in decision-making, or at least orientating the clinical situation. The participants expressed a need for CPGs to include more information due to the generalization of CPGs to clinical events. Hesitation to utilize CPGs

[3] The term remote is the authors' terminology.

was expressed in regards to competing interests between making a decision and involving the patient/family members in the decision-making process. Several physicians commented that incorporating patient decision aids with CPGs would be helpful in engaging in shared decision-making. The authors suggest that this is an area for future research, the incorporation of patient decision aids with CPGs, something Canada has yet to implement at a national level.

The lack of research in the area of rural physician (or other healthcare providers) use of evidence is detrimental to the further development of CPGs. Research studies need to be conducted within other parts of Canada, and Australia, to further explore the uptake of evidence in different rural contexts, amongst various populations and differing levels of resource availability. The barriers and challenges described by rural physicians regarding uptake of evidence is similar to the challenges discussed by Campbell and Croskerry's (2003) regarding rural challenges that potentially lead to patient safety incidents. These challenges need to be studied to understand if they are perceived barriers or factual barriers that need to be overcome through intervention-based research.

Without understanding the issues faced by rural healthcare providers in applying CPGs in rural healthcare environment, particularly when faced with low occurrences, such as the pregnancy of a RhD negative woman, the current model for creating and implementing CPGs is flawed because it is not clear if the rural context for which decisions are made is the problem or if this is a rural health issue. CPGs need to incorporate decision aids for patients to assist healthcare providers in engaging in shared decision-making and need a creation and implementation framework that is conducive to rural healthcare environments. In addition, CPGs need to take into consideration the barriers and challenges faced by rural healthcare providers.

Clinical Practice Guideline Synthesis

CPGs continue to provide the standards for best practice care. In this section, CPGs that inform the prevention of RhD alloimmunization were evaluated and synthesized. A search for CPGs that address the prevention of RhD alloimmunization in pregnancy within Canada did not return a great number of results. In fact, the 2003 SOGC RhD alloimmunization prevention guideline is the only dedicated CPG in the country (Fung Kee Fung et al., 2003).

The searches did reveal Canadian CPGs that include RhD alloimmunization prevention for specific instances of sensitizing events: abortion, trauma and motor-vehicle collision (Davis, 2006; Jain et al., 2015; Van Mieghem, Whittle, Farine, Seaward, & D'Souza, 2013). These CPGs are also published by the SOGC. In order to discuss these CPGs in the context of the prevention of RhD alloimmunization, the guidelines were evaluated using the AGREE II tool (Brouwers et al., 2010). A 2013 systematic review, focusing on the utility of CPG critical appraisal tools, found that the AGREE II tool met all of the thirteen item quality dimensions used to evaluate CPG critical appraisal tools (Siering, Eikermann, Hausner, Hoffmann-Esser, & Neugebauer):

1. Information retrieval
2. Evaluation of evidence
3. Consideration of different perspectives
4. Formulation of recommendations
5. Transferability
6. Presentation of guideline content
7. Alternatives
8. Reliability
9. Scope
10. Independence
11. Clarity and presentation
12. Updating
13. Dissemination, Implementation, Evaluation

The AGREE II tool is constructed of 6 quality domains: scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability and editorial independence. Each of these domains is graded numerically, 7 being the highest value and one being the lowest value. For the purpose of this study, the abortion, trauma, motor-vehicle collision, prevention of RhD alloimmunization CPGs (Davis, 2006; Fung Kee Fung et al., 2003; Jain et al., 2015; Van Mieghem et al., 2013) were evaluated using the AGREE II tool and synthesized broadly against the larger concept of prevention.

Scope and purpose

The overall scope, purpose and objectives of all the CPGs are clearly articulated (Davis, 2006; Fung Kee Fung et al., 2003; Jain et al., 2015; Van Mieghem et al., 2013). The questions discussed in the CPG were focused and defined. The specific populations in most instances were identified. The motor-vehicle collision CPG did not specifically describe the population besides these events occurring in a pregnant population (Van Mieghem et al., 2013).

Stakeholder involvement

The abortion and trauma CPGs involved a variety of relevant experts and specialists in the development of the recommendations (Davis, 2006). The motor-vehicle collision CPG only involved three specialists to develop its recommendations, lagging behind CPGs that involve larger committees/groups and specialists (Van Mieghem et al., 2013). Patient engagement in healthcare policy is increasing (*Patient Engagement: Technical series on safer primary care*, 2016). Patient engagement is occurring at the CPG level as well and the AGREE II tool specifically looks for the engagement of patients in the CPG development process (Brouwers et al., 2010). None of the CPGs evaluated stated that patients were

engaged in the development of these guidelines. The CPGs did not state that the guidelines had been "pilot tested" among stakeholders yet the target audiences were clearly identified, except for the motor-vehicle collision CPG.

Rigour of CPG development

This section of the AGREE II tool evaluates the process by which the CPG was developed to ensure that process was clear, systematic and void of bias (Brouwers et al., 2010). Both the abortion and trauma CPGs provided narrative about the process involved in searching the literature and inclusion/exclusion criteria. These three guidelines however failed to clearly discuss the process for creating recommendations, challenging the notion of transparency and avoiding bias. The abortion and trauma CPGs drew on evidence from the literature to inform recommendations, and had the CPGs externally reviewed prior to publication. In contrast, the motor-vehicle collision CPG did quite poorly in the evaluation process. It received the lowest score possible for each category in this section.

Clarity of presentation and applicability

All three CPGs scored highly on clarity of presentation. The developers were able to create specific and unambiguous guidelines that considered multiple choices for managing the conditions discussed and the recommendations were easily identifiable.

None of the CPGs scored high for applicability. Each one struggled to identify clear support for implementation. Barriers to implementation were not identified and defined. In some instances, the cost of RhIG was not clearly indicated. In addition, the CPGs did not provide recommendations or tools for institutions or practitioners to use to assess the effectiveness, applicability and/or patient outcomes.

Overall the abortion and trauma guidelines were rated highly using the AGREE II tool. The motor-vehicle collision guideline failed in many ways, particularly in its transparency of the rigor in the development of the guideline.

These three CPGs are important in the context of RhD negative pregnancy. Of the events for which these guidelines were created are considered sensitizing events in RhD negative pregnancies. If it is not clear what the intent behind the CPG is then perhaps it is lost and underutilized. The CPGs provided consistent messaging regarding the management of RhD negative pregnant women in sensitizing events. The abortion guideline states that RhD status should be screened prior to the procedure or medication is prescribed. If she is RhD negative then, the CPG states, the women would receive RhIG. The guideline neglects to include dosage, timing and the administrative strategies for RhIG. The trauma CPG provides background information and dosage information based on the gestational age of the fetus. This guideline was thorough and clear regarding the prevention of RhD alloimmunization. Little is mentioned about RhD negative pregnancy management in the context of motor-vehicle collisions. The guideline does stress that RhD negative pregnant women need to be screened for Rh status and given RhIG after a collision but it is not clear what dosage, timing and administrative strategies for RhIG.

The 2003 SOGC prevention of RhD alloimmunization guideline (Fung Kee Fung et al., 2003) is a well written CPG that utilized good guideline development principles. It scored high in most of the domains but did not state that it engaged patients in the development and/or external review phase. The specialists and experts involved in the creation of these recommendations is impressive but the CPG did not have these externally reviewed, other than the peer review process for publication.

This exercise in CPG critical appraisal and synthesis provides context for the literature review and the research study. In the next section, decision-making, in general, will be explored within the context of healthcare. A closer examination of the factors that influence decision-making, the use of best evidence, CPGs, and the process for making patient care decisions.

Decision-Making

In the literature review thus far, concepts have been defined in order to identify the gaps and to lay out the state of the literature for the research study. The literature moved from defining concepts critical to this research, rural and low occurrences, and the impacts of patient safety incidents in healthcare to the development and use of best evidence, such as CPGs. Moving forward, the literature review will switch to some of the human and system characteristics that influence the decision-making process, starting with a general discussion about decision-making and ending with tensions in existing research.

Cognitive Biases in Decision-Making

Decision-making research has illustrated that cognitive biases have an impact on decision-making (Drach-Zahavy & Somech, 2011; Tversky & Kahneman, 1981). Many cognitive biases exist and for the purposes of this study two were deemed appropriate and will be discussed in the context of decision-making, particularly as they may influence low occurrences in rural healthcare settings.

Decision framing

One of the early cognitive biases found to impact decision-making is that of decision framing. In their early work, Tversky and Kahneman define decision problems as "the acts or

options among which one must choose, the possible outcomes or consequences of these acts, and the contingencies or conditional probabilities that relate outcomes to acts" (1981, p. 453). Framing is the act of choosing the outcomes that develop because of the decisions made (Tversky & Kahneman, 1981). The Tversky and Kahneman study examined university student decision framing through scenario-based problems. The students were divided into two groups. Each group was given a scenario describing a disease outbreak that could kill 600 people. One group was provided with two alternative solutions to select from, both had the same potential outcome (200 would be saved), but each were worded differently in regards to how the risk was presented (the total number of saved people and the proportion of people that would be saved). The students in this group were considered to be "risk averse" because they chose the scenario with the whole number and not the proportion of people saved. In the second cohort, students were provided with the same scenario with different versions of solutions to choose from. The emphasis in these scenarios was the number of people that would die. The results in this scenario suggested that when faced with considerable losses people will take more risk (Tversky & Kahneman, 1981). In each of these scenarios the same number of people would be saved and died. The way the scenarios were presented swayed the ways in which people framed their decisions.

The scenarios presented in the Tversky and Kahneman study demonstrate that the decision-making process is comparable to those made by individuals faced with decision problems in healthcare situations. When faced with numbers and percentages regarding risk, healthcare providers and/or patients/family members often misinterpret or interpret based on their current health situation, a low occurrence, health literacy skills, such as in the preeclampsia article discussed on page 67 (Brown et al., 2013), expertise and uncertainty, and/or personal experience.

Heuristics

A heuristic is a simple rule that has been learned or arrived at intuitively (Drach-Zahavy & Somech, 2011). These rules are derived from complex situations or when there is a lack of information needed to make a decision (Drach-Zahavy & Somech, 2011). Heuristics work in most situations; however, they can often lead to systematic errors (Drach-Zahavy & Somech, 2011). In two separate examples, one involving nursing and the other surgeons, heuristics were found to lead to unsafe acts as a result of the participants having never experienced adverse events as a consequence of unsafe behaviour (Drach-Zahavy & Somech, 2011; Li, Rakow, & Newell, 2009). The use of heuristics then led to complacency and ultimately provider and patient safety incidents.

Drach-Zahavy and Somech (2011) found that nurses developed their own heuristics when it came to decision-making in matters of safety. In this study, the nurses developed five heuristics. The first heuristic found that nurses would continue to work at the cost of harming themselves or their patients. The second was self-reliance. Nurses often did not ask for help and would continue to perform an act even though there is a risk of failure. The third was the notion of "it can't happen to me": experts who have worked in unsafe conditions, with no adverse consequences, may become overconfident and continue to behave in the same unsafe manner (Drach-Zahavy & Somech, 2011). Further perpetuating a heuristic is the fourth factor, which is about how recent the information/experience is to the next. For example, when a nurse is poked by a needle, everyone is hyper vigilant for the next few days, but after, they tend go back to bad habits. Drach-Zahavy and Somech (2011) state that when these incidents are not reported, the recall of the experience becomes less available. The final heuristic found in this study was that social pressure could have a positive effect on abiding

by safety measures. Therefore, a nurse would abide by the safety guideline more often if peers were present.

Li, Rakow and Newell argue, "when adverse consequences rarely occur, people become complacent and behave as if the risk of injury is trivial" (Li et al., 2009, p. 994). The authors provide an example using surgery. If surgeons never experience the risk of failure they are less likely to acknowledge that failure is a distinct possibility. Therefore, surgeons will become complacent of risk to fail and not acknowledge that harm could occur. This is a troublesome position to be in because the presence of risk provides acute awareness of the situation, without it, complacency occurs:

> As an example, if we take 0.25% as the risk of the injury, then if 100 surgeons each perform 50 operations per year with a 0.25% risk of failure (using probability theory) we would expect 88 surgeons to encounter no failures [sic]. So, on the basis of experience, most surgeons would assume zero risk. Furthermore, the experience of zero risk is not limited to individual surgeons but may also affect teams. A team of four surgeons each performing this volume of procedures is more likely than not (60% chance) to encounter no injuries. Moreover, in over 75% of the teams where an error is experienced, three of four surgeons will not encounter an adverse event. The danger is that … surgeons may gradually become less likely to maintain best practice if the possibility of error is not salient. Of course, this is not to say that the surgeons would ignore the possibility of failures. However, in the absence of exposure to failures such possibilities may receive less weight that they deserve. (Li et al., 2009, pp. 994-995)

This example of heuristics leading to systemic issues could happen in any area of healthcare (Reason, 1990). The aviation industry supports the issue of complacency. Besco states that "normalization of deviances" always results in "overconfidence and complacency" but that eventually this will lead to negative consequences, such as aviation accidents:

> When potentially lethal events seldom occur, it is only human nature to become comfortable with ignoring the potential threats from rarely occurring events. This is what makes complacency so dangerous (Besco, 2004, p. 156).

Healthcare providers, without realizing, could be perpetuating this issue through complacency, which is detrimental to the decision-making process and, ultimately, patient safety.

Reason's (1990) work on error furthers the concept of heuristics in decision-making. He argues that heuristics assist people with decision-making in complex situations. When faced with complex and uncertain situations people use available heuristics to make decisions (Reason, 1990). The more often a heuristic is used the more it becomes more easily available (Reason, 1990). It is not evident whether context influences heuristic development and use in the delivery of healthcare. Would healthcare providers in a low resource institution develop different heuristics compared to their urban counterparts? It can be argued that in the event of a low occurrence where a heuristic is not readily available a negative outcome may occur (Besco, 2004).

Research has demonstrated that cognitive biases impact decision-making. Absent from the literature is research focused on cognitive bias amongst rural healthcare providers, specifically in clinical situations where a healthcare provider is faced with a low occurrence. The next section will focus on provider-patient relationships and the decision-making process.

Shared decision-making

In the late 1990s, healthcare evolved from patient-centered care to shared decision-making (Rapley, 2008). The concept is intended to promote patient-centeredness and evidence-based practice between healthcare providers and their patients (Rapley, 2008). The most important aspect of shared decision-making is that the patient/family member and

physician relationship is moving away significantly from paternalistic practice approaches (Rapley, 2008).

A universal definition of shared decision-making in healthcare does not exist (Lown, Hanson, & Clark, 2009), yet despite this fact there are principles attached to this term that are, for the most part, widely accepted. Shared decision-making is the movement away from paternalistic decision-making, which perpetuates a power struggle that can often "create agreement and suppress open discussion" with patients and/or their family members (Epstein & Gramling, 2013, p. 106S).

There are several basic principles regarding shared decision-making that are common across authors. The first is that both the physician and the patient, or family member, acknowledge that a decision is required (Légaré & Witteman, 2013; Whitney et al., 2008). If both parties fail to recognize the need for a decision to be made, they run the risk of creating a default relationship which results in the paternalist practice approach (Roter & Hall, 1997). The second principle of shared decision-making is the need for both the physician and patient to have access to and understand available evidence (Karnieli-Miller & Eisikovits, 2009; Légaré & Witteman, 2013). Whitney et al. (2008) take this principle a bit further by outlining that all possible choices must be identified, with the exploration of potential outcomes, both positive and negative.

A Canadian study found that oncologists struggle with what information to present to patients in regards to best treatment when one of the options was either not available or not publicly funded (Chan et al., 2012). The third principle of shared decision-making requires that the patients' values, beliefs, and preferences be taken into consideration during the decision-making process (Karnieli-Miller & Eisikovits, 2009; Légaré & Witteman, 2013). Karnieli-Miller and Eisikovits (2009) further this principle by adding that the physician needs

to be recognized as the expert in the diagnosis, prevention and treatment of disease. By extending this principle Karnieli-Miller and Eisikovits have acknowledged the importance of patient-centered care, but have kept the physician's role as the medical expert at the forefront of the patient-physician relationship. Although the physician is the individual trained in the management of the disease, the Karnieli-Miller and Eisikovits study neglects to include the patients/family members' expertise in the management of their disease/condition which comes from their experience with disease/condition, personal values and beliefs, support systems, and so on. As discussed earlier, expertise is threatened in certain instances of uncertainty and context, challenging the healthcare provider-patient relationship.

Shared decision-making in healthcare is often conducted as a result of uncertainty. In clinical situations, uncertainty occurs when there is more than one option for treatment and/or management of a disease/condition, or the physician has limited experience with a clinical event and/or disease/condition. If evidence is conflicting, insufficient or lacking, and if one or both stakeholders do not understand the information presented (Légaré & Witteman, 2013), uncertainty occurs. Shared decision-making is not usually something that happens in one instance, it will reoccur over time (Lipstein, Brinkman, & Britto, 2012).

Research relating to shared decision-making models in a clinical setting continues to be explored. It must be noted that shared decision-making has been found to have positive effects on patient satisfaction and adherence to treatment (Saha & Beach, 2011; Taylor, 2009). A randomized controlled trial using vignettes of patient-centered communication by physicians, found that participants/patients preferred the vignettes with higher levels of patient-centered communication (Saha & Beach, 2011; Taylor, 2009), demonstrating that patients prefer a patient-centered approach to healthcare. Shared decision-making has shown improved patient health outcomes and adherence to medication and treatment (Taylor, 2009).

It is not evident in this literature if contexts, such as rural, have an impact on shared decision-making.

Patients expectations of their role in decision-making regarding their health have changed monumentally over the last few decades. Patients are now encouraged to be more involved in their health and the decisions that are made, despite disparate access to quality information, health literacy, numeracy and information seeking. The physician-patient relationship is one that is uniquely positioned to nurture these decision-making processes. In shared decision-making, the patient's voice is part of the decision-making process. In a similar fashion to physicians, the patient too experiences the three principles of shared decision-making and challenges that lie therein. Once both stakeholders have recognized that a decision is required evidence/information is explored and shared (Epstein & Gramling, 2013). The essence behind the second principle of shared decision-making is that information is in fact shared. In more traditional roles the patient would be passive and rely on the physician alone to make the decisions (Roter & Hall, 1997). The notion of shared information means that the patient has access to the same information used by the physician (Epstein & Gramling, 2013). The patient is then informed by the information provided by the physician, available evidence, and any information the patient solicits and/or receives external to the physician-patient relationship. This information is often retrieved through family, friends, the larger healthcare system, social networks such as discussion forums, support groups (in-person or online), the media, and information found on the internet (Epstein & Gramling, 2013; Fraenkel & McGraw, 2007; Lipstein et al., 2012; Rapley, 2008). The information obtained by the patient is sometimes shared with the physician (Rapley, 2008). Conversely, not all patients want to be informed and prefer to cope with their health situation with minimal information (Lalor, Begley, & Galavan, 2008).

Health Literacy and Information Behaviour

Ideally, in a shared decision-making approach, available information is shared between the provider and patient during the decision-making process. It is important to examine health literacy as it pertains to information behaviour amongst stakeholders making decisions related to their health. Access, availability and the ability to understand and integrate information may impact the decision-making process. In addition, a patient/family member's health literacy has a significant impact on an individual's ability to engage in health-related decision-making and needs to be explored.

Health Literacy

Accessing authoritative health information is not easy for patients. Although the Internet has afforded individuals great opportunity to access more and more information online there still remains a digital divide (Connolly & Crosby, 2014; Neter & Brainin, 2012). This digital divide differs from previous definitions that evolved around access to online information. Now the access is divided into those that can effectively retrieve what they need and understand the information versus those that do not have access nor do they have the skills to comprehend the information (Connolly & Crosby, 2014; Neter & Brainin, 2012). It is imperative that the provider share information with the patient/family members and ensures that they understand the information provided in order for shared decision-making to succeed.

In order for the patient/family member to be fully engaged in the decision-making process, it is critical for the patient/family to possess some understanding of the information being presented. The Canadian Public Health Association (CPHA) (2014) defines health literacy as "the ability to access, understand and act on information for health". In 2007, the

Canadian Council on Learning (CCL) published the results of an international survey on health literacy. The study found that 60% of Canadian adults do not possess the skills outlined in the CPHA definition of health literacy (Canadian Council on Learning, 2007, 2008). Without the ability to access, understand and act on health information patients are not able to make well-informed decisions.

Numeracy is "the ability to comprehend quantitative information" and is ultimately the "way in which people process statistical information" (Politi, Han, & Col, 2007, p. 685). The inability to understand statistical information leads to a lesser understanding of risk and screening and medication compliance (Galesic & Garcia-Retamero, 2011). For example, a study of women's perceptions of risk following preeclampsia found that the women were aware of the increased risk of preeclampsia in future pregnancies, yet were not all aware of the risks of hypertension and cardiovascular problems outside of pregnancy (Brown et al., 2013). Despite being told that the risk of developing preeclampsia in future pregnancies can be reduced, the women still expressed fear that the condition would return in future pregnancies. This study concluded that information needs to be provided to patient/family members about risk and providers need to ensure that the information is understood. Taylor (2009) adds that some physicians often have a hard time with statistical information as well; for example, they often struggle with the difference between statistical calculations of risk.

Personal experiences can influence how patients/family members perceive risk: if the experience was a negative one then likely the perception of risk will be skewed (Li et al., 2009). If a patient has had previous experience with a condition and/or a negative healthcare event they are more likely to under estimate even the smallest probability that an uncommon event might occur (Li et al., 2009). However, if a patient is told by a physician (for example) that there is a small probability an uncommon event might occur, the patient is likely to over-

emphasize the risk: for example, a patient that chooses not to take a medication because of the small chance of rare side effects (Li et al., 2009). In complex health situations, Li et al. (2009) argue that patients prefer to base their decisions on personal experience rather than information provided by others. In situations for which family members are making the decisions, such as parents of sick children, personal experiences also influence the decisions they make for their loved ones (Lipstein et al., 2012).

Information behaviour

Information theories can inform the decision-making process for patients/family members. Information theories are wide reaching yet focus on information-seeking behaviour. The monitor-blunter theory of stress coping (Miller et al., 1988) focuses on information-seeking behaviour. This theory categorizes people into two categories: monitor and blunter. A monitor is an individual that seeks information as a means of coping with a situation. A blunter is the opposite. Blunters will avoid seeking information as a coping mechanism. This has been found in health situations for which people are receiving information about a diagnosis and or prognosis. It is felt that these terms do not accurately reflect their intended characteristics. Therefore, from this point on monitors will be referred to as active seekers and blunters as avoiders.

A study exploring the information-seeking behaviours of pregnant women with the antenatal diagnosis of fetal abnormalities, found that the women would fall into these two categories upon diagnosis, active seekers or avoiders (Lalor et al., 2008). Women receiving devastating information about their unborn child put them in a high stress situation. The active seekers sought out information as a means of dealing directly with the situation. For these women having more information meant they could make informed decisions: “For

some women, their high need for additional information influenced their decision as to whether or not to opt for amniocentesis" (Lalor et al., 2008, p. 189). The women categorized as avoiders evaded information presented to them: "when amniocentesis was offered to women with low preference for information, they often refused, preferring to hope for positive outcomes" (2008, p. 190). This study found that some women prefer to have limited information until it is fully required, while others need more information in order to cope; in both instances the women's information needs were not always met (Lalor et al., 2008).

In the US and Netherlands, researchers interviewed physicians about their information behaviour (Maggio et al., 2014). This novel study identified six themes describing physicians' information needs: refreshing, confirming, logistics, teaching, idea generating and personal learning. The refreshing (updating one's knowledge), confirming (confirming one's knowledge) and idea generating (finding information to assist in the development of treatment plans or diagnosis) information relate to discussions of expertise. Identifying gaps in knowledge and uncertainty require the physician to seek out information when required. A limitation of this study, and others like it within the information behaviour research, is that they do not speak to the moments when information may not be available, or if the physician does not realize a gap in knowledge exists (Maggio, 2012).

Expertise

There is a body of research that investigates the expertise of healthcare professionals. The epidemiological aspect of this research was discussed in the section regarding low occurrences; although there is limited evidence, the research that does exist suggests that low occurrences do not impact clinical decision-making and patient outcomes (Klein et al., 2002; Society of Obstetricians and Gynaecologists of Canada, 2002). This research lacks insight

into contextual and resource factors that may influence this body of research particularly in rural healthcare settings.

The other body of research on expertise is that of knowledge use and knowledge gaps amongst healthcare providers (Klein et al., 2002; Moulton, Regehr, Lingard, Merritt, & Macrae, 2010; Mylopoulos & Regehr, 2011; Society of Obstetricians and Gynaecologists of Canada, 2002). Mylopoulos and Regehr (2011) describe experts as those that will seek information when faced with a gap in knowledge. If the information found does not provide a solution that meets the need the individual will engage in problem solving processes. The problem-solving process is dependent on the experts' knowledge of practice and flexibility to adapt to the situation. This resonates with the discussion in section two regarding healthcare practitioners use of knowledge translation products in rural settings. When faced with a CPG that is not tailored to a specific rural context the practitioner is forced to adapt the information and seek other information in order to satisfy the knowledge gap. Knowledge use and gaps remains largely unexplored in the rural literature, particularly in a physician population. Often considered generalists because of the scope of practice, rural healthcare providers are not considered experts. This seems counterintuitive to the very definition of expert, which was outlined earlier in this section. More research is required to understand the expertise that may exist amongst rural healthcare providers, particularly when it involves knowledge use and gaps.

A growing body of research on expertise focuses on self-monitoring. Self-monitoring involves 'slowing down' in planned and unplanned clinical situations. Moulton, Regehr, Lingard, Merritt, and Macrac (2010) found that surgeons slow down and become more focused when a cue is initiated at a critical or transition point during surgery. In instances for which an unplanned event occurred during a surgical procedure, causing uncertainty, the

surgeon was forced to slow down and reassess the situation or uncertainty. The interesting aspect of this research is that three factors emerged that influenced the slowing down process amongst times of uncertainty: internal, personality and situation factors. There is a lack of research examining rural healthcare providers approach to slowing down and/or ways of dealing with uncertainty and what factors influence these processes. It is hypothesized that these factors would affect decision-making.

The Royal College of Physicians and Surgeons of Canada (RCPSC) define competence as an

> array of abilities across multiple domains or aspects of physician performance. Competence is both conditional on, and constrained by, each physician's practice context, is dynamic and continually changes over time. (Royal College of Physicians and Surgeons of Canada, 2014)

In rural areas of BC, nurse practitioners play significant roles in primary care, it is important to include their competencies in this discussion (Northern Health, 2016). According to the Canadian Nurses Association's Canadian Nurse Practitioner Core Competency Framework, competency is the "specific knowledge, skills and personal attributes required for a nurse practitioner to practice [sic] safely and ethically in a designated role and setting" (Canadian Nurses Association, 2010, p. 15). These two definitions of competency place importance on the context/setting for which healthcare provider practices. A synthesis of these two definitions will form the basis of competency throughout this study.

Ireland et al.'s review paper (2007) on competencies and skills for rural maternity care found differences between rural and urban healthcare practitioners in regards to competency. The main difference between the two populations is that of acquiring information. Rural physicians face barriers when acquiring information, such as, limited availability of information resources, geographic isolation, time, lack of resources and, in

some instances, skills. Campbell et al. (2015) found that if a rural Australian healthcare provider repeated a procedure numerous times the healthcare provider felt more confident. Conversely, if a healthcare provider rarely had to conduct the procedure, the provider felt less confident; although confidence is subjective, this study is important because if a healthcare provider is not able to feel confident in their ability to conduct a procedure then perhaps that will affect competence. The next two sections attempt to mitigate tensions amongst research and policy on competency.

Resolving the Tension with Research

There is limited research on patient safety incidents in rural settings. This lack of research may be a result of centralization of healthcare systems or decentralization in others, research that does not delineate or define rural, and ethical barriers, such as the risk to provider/patient anonymity, to conducting research in rural areas. The tools used in patient safety endeavours, such as incident reporting, chart audits and root cause analysis are showing to be not as effective as once thought (Hernan et al., 2015; Lawton et al., 2012). In fact, patient safety incident reporting is still not widely accepted practice (Wu et al., 2017).

Grey literature, such as investigative reports into patient safety incidents, can provide some insight into rural patient safety. A recent investigation into medical imaging services at hospitals in British Columbia (BC), including a rural hospital, led to a change in policy regarding competency (Cochrane, 2011). The report details the investigation into medical imaging at four health authorities. One of the four involved a rural hospital, Powell River General Hospital. The investigation found that a physician had been practicing outside of the scope defined by the physician's medical license. This breech in practice led to a significant number of misinterpretations of computed tomography results. The investigator found a

number of contributing factors that led to this situation. The physician was practicing outside of scope and did not communicate his continuing medical education with the BC College of Physicians and Surgeons. The health authority did not do its due diligence in checking the credentials or license restrictions upon appointment of the physician. The staff at the hospital were aware of the physician practicing beyond the scope of practice and did not inform administration. In addition to the lack of communication of staff, there was also departure of technical staff that were then not replaced. The investigator felt that having only one medical member of the medical imaging team was a contributing factor, as well as the health authority having many different information technology systems.

An incident such as the one discussed in the previous paragraph is an example of physicians not having sufficient competencies within rural areas they serve and/or the struggle to recruit physicians to rural areas. This, however, is only true because the events took place within a rural healthcare setting. As the report indicates, urban-centred healthcare settings experienced patient safety issues in medical imaging as well (Cochrane, 2011). The take home message from the report is that in a rural setting perhaps patient safety is at an increased risk because there are limited number of healthcare staff to identify, report and/or confront the issue, particularly in centralized healthcare systems. Therefore, issues of incompetency may go undetected for some time.

As previously mentioned, rural patient safety research is limited. Grzybowski et al's research in rural maternity care in BC calls for more strategic and systematic research into rural maternity care (Grzybowski, Kornelsen, & Cooper, 2007; Kornelsen & Grzybowski, 2005; Lynch, Thommasen, Anderson, & Grzybowski, 2005). This sentiment can be translated into other health domains. In BC, Kornelsen and Gryzybowski (2005) found that healthcare providers dealing with a low volume of pregnancies in rural areas have a harder

time maintaining the skills required to offer safe (provider perception of safe) maternity care. In contrast, perinatal mortality has shown to be similar with the rest of the province and an increased risk of adverse events with the decrease in maternity care in rural areas (Lynch et al., 2005). Furthermore, a multi-provincial study, including BC, focusing on rural maternity services found that rural communities without maternity services had poorer neonatal outcomes (Grzybowski et al., 2015). The researchers recommend that the continued closure of maternity services in rural areas stop and be re-implemented. The discrepancy between perceived competency and health outcomes needs to be resolved. As mentioned, this can only be resolved through more research leading to policy frameworks. Research needs to focus on patient safety with a deeper look at competency and decision-making with low occurrence health events.

Resolving the Tension with Policy

Policy on competency has proven troublesome particularly as it relates to rural contexts. This section will focus on an example of competence policy that had ill effects on rural healthcare settings. As defined earlier, competency is often defined by a healthcare providers professional practice and performance despite varying impacting factors. In some instances, the number of patients needed to treat with a specific condition in order to remain competent, have defined competency.

In 1996, the SOGC issued a policy stating competency in the management of pregnancy by assigning it a number (Society of Obstetricians and Gynaecologists of Canada, 2002). The policy required physicians to manage 25 pregnancies per year in order to maintain competency in this area of healthcare. This policy had a significant impact in Saskatchewan (Johnston, Klein, Iglesias, & Avery, 2014) where the College of Physicians and Surgeons

implemented the SOGC policy, which had a significant negative impact on the province. As a result of the policy a vast number of physicians abandoned obstetrics resulting in a shortage of physicians offering obstetrics. As a result the SOGC overturned the policy (Society of Obstetricians and Gynaecologists of Canada, 2002).

The 2010 medical imaging patient safety issues in BC resulted in a provincial privileging strategy (Slater & Bloch-Hansen, 2014). The purpose of the strategy is to overcome potential patient safety incidents by requiring physicians to receive "permission to undertake defined activities in a specific facility" (Slater & Bloch-Hansen, 2014, p. 23). This process would involve review of credentials and define the scope of practice for that physician in a systematic manner. In doing so the system

> protects the patient from unqualified practitioners, reduces the risk of litigation, and protects the practitioner from unreasonable restrictions in practice as well as unreasonable expectations (Slater & Bloch-Hansen, 2014, p. 24).

The strategy is to have privileging directories for all disciplines, starting with medical imaging. Similar to the SOGC, BC has allotted numbers to its activities lists/procedures/tests. For example, a physician is required to do 20 fluoroscopies per year in order to ensure safe use of the equipment. The strategy uses the term currency to define this threshold: "the minimum level of current experience that will give a practitioner a reasonable chance of remaining competent" (Slater & Bloch-Hansen, 2014, p. 24).

It is expected that healthcare providers are experts in the delivery of healthcare. Competencies identify the components of expertise that healthcare providers need to achieve in order to be called experts. These competencies require providers to integrate all aspects of healthcare delivery with the use of their existing knowledge and the ability to identify gaps in knowledge. Those gaps are either self-identified or exist as part of the greater healthcare system. What makes a provider an expert is the ability to find information and adapt it to a

clinical situation or, if the information is not sufficient, the provider must adapt their existing knowledge and information to resolve uncertainty all while employing techniques of self-monitoring strategies, such as slowing down.

Summary

As described in this section, the provider-patient relationship is impacted by many factors, such as dynamics, availability and sharing of information, and the ability to understand and apply information. Since the discovery of the anti-D prophylaxis for the prevention of RhD alloimmunization, healthcare providers and RhD negative women have not been asked for their insights, knowledge and/or perceptions of this phenomenon. Exploring provider and women's knowledge and perspectives would give insight into the patient-provider relationship, the information they seek and the availability of the information on this topic.

The purpose of the literature review was to identify, discuss and inform the research questions outlined in Chapter One. The intent was to synthesize the literature in order to demonstrate that this work is relevant within the context of decision-making in a healthcare. A discussion of EBM and the adherence of CPGs is an integral piece of the decision-making process. The literature presented provided the theory and the criticism that surrounds the use of evidence in decision-making. A discussion regarding shared decision-making provides the insight into the current trend in the patient-provider relationship and the challenges and nuances that exist. A consideration at health literacy and information behaviour provides the backdrop for understanding patient and family member decision-making, particularly as it pertains to health. It was important to define rural because 7% of the province's population is spread across the north and is served by the NH (2010).

Anti-D immunoglobulin remains the gold standard in preventing RhD alloimmunization (McBain, Crowther, & Middleton, 2015). There is international evidence that suggests that RhD negative women continue to be at risk for RhD alloimmunization despite gold standard prophylaxis and guidelines (Fyfe et al., 2014). There is a paucity of research regarding women's understanding and experience with RhD negative pregnancy and the consequential development of D-antibodies. An understanding of healthcare provider decision-making and patient experience will be helpful to know the situation within the context for which it occurs. The purpose of this study is to gain a better understanding of why RhD negative women continue to be at risk for developing RhD alloimmunization by exploring experiences and care of pregnancy. This study will answer the following questions:

- Why do RhD negative women continue to be at risk for developing D antibodies in pregnancy?
    - How do healthcare providers make decisions regarding the care of RhD negative pregnancies in northern British Columbia?
    - How do RhD negative women in northern British Columbia experience pregnancy?

The next Chapter provides the approach taken to conduct this study. It will outline the rational for utilizing a qualitative approach. More specifically, the motivation and rationale for using interpretive description, an applied research method, to address the research questions will be outlined. The multiple data collection strategies will be described and the analysis will be explained.

Chapter Three: Approach to Inquiry

This chapter outlines the approach taken to explore the prevention of RhD alloimmunization in northern BC. The approach to inquiry utilized Thorne's (2008) interpretive description. The section on methods provides background and rationale for engaging with interpretive description and the processes involved in the ethical collection and analysis of the data. An IKT framework is described in detail to yield transparency of the process and to ensure applicability of the findings to the practice of healthcare.

It was anticipated that this research would contribute to a better understanding of a preventable health issue and why it continues to occur, such as RhD alloimmunization. Since the discovery of the RhD antigen, its role in HDFN, and the development of anti-D immunoglobulin researchers have not yet explored the experiences of RhD negative women or those with D-antibodies in regards to pregnancy and quality of care. Nor have researchers used qualitative methods to explore the healthcare provider experience with RhD negative and D-antibody pregnancies. Qualitative methods, such as the ones used in this project, with these two populations provided a greater understanding into the depth of quality of care for RhD negative pregnancies and insight into the decisions that inform patient safety. This study has the potential to provide information into guideline adaptation, decision-making and health literacy with low occurrence events in rural healthcare settings.

Methodology

Interpretive description provides the approach for the study. It provides the researcher the opportunity to borrow strategies from traditional methodologies, such as grounded theory and/or phenomenology, to shape data collection approaches and analysis (Thorne, Kirkham, & O'Flynn-Magee, 2004). Traditional qualitative methods were

considered, such as grounded theory, but unlike traditional qualitative methods, interpretive description acknowledges that researchers come with previous experience and knowledge about the phenomenon being studied and that this knowledge cannot be dismissed, nor should it (Thorne, Kirkham, & MacDonald-Emes, 1997). This knowledge and experience can be incorporated into the design of the study and in the findings. This was a significant factor in the decision to use interpretive description for this study based on the researcher's knowledge and experience with RhD alloimmunization.

This approach does not require the study to be bound by a theoretical framework (Thorne, Stephens, & Truant, 2015). This is important to acknowledge because this project did not utilize a theory to guide the study. Instead, it has been contextualized with a literature review that informs, discusses and embodies the research questions and the relevant and current dialogue occurring in each respective area. The method outlines the evidence for which this study is based, such as the scoping review informing this study (Fyfe et al., 2014), and provides a thoughtful discussion that guided the research design. As discussed in the literature review, there are many theories for information behaviour, health literacy, decision-making, and evidence-based practice. The research questions driving this research span these theories. Consequently, there was a struggle to find just one theory that could provide the basis for this study. In addition, often research is made to fit into a theoretical framework producing research findings that continue to prove the theory; this becomes problematic because the theory then becomes normalized (Thorne, 2008; Thorne et al., 2015). Interpretive description provides the opportunity to dismiss theory-driven research claiming that applied health research is not about proving a theory but about scaffolding a study that will develop findings applicable to practice, which is continuously changing (Koskinen & Nystrom, 2017; Thorne, 2008; Thorne et al., 2015).

Applied health research aims to conduct research that is applicable and relevant to healthcare. This approach outlines a study that attempted to answer clinically relevant questions regarding the uptake of evidence, in rural contexts, and in situations where decisions have the potential to lead to patient safety incidents. In 2001, Snadden published a commentary on qualitative methods and guideline implementation. Snadden identified that there was a need to look at non-reductionist and non-traditional constructivist approaches to guideline implementation because tension had developed and guideline adherence remained problematic (Snadden, 2001). The problem is the notion that best practice, as outlined in CPGs, is not in line with what is being practiced clinically. The results of thinking in this way have produced the KT paradigm shift. Missing from the literature are applied research approaches that study guideline implementation and adherence. Without studying applied approaches in KT research there is no way to know its validity.

Interpretive description is a non-traditional constructivist approach to knowledge creation inspired by interpretive hermeneutics (Thorne, 2008) and falls within the realm of hermeneutic application research (Koskinen & Nystrom, 2017). The premise underpinning interpretive description is to push beyond the traditional structures of qualitative methodologies and develop findings that are applicable to practice (Thorne, 2008). Interpretive description "recognizes that the clinical mind tends not to be satisfied with "pure" description, but rather seeks to discover associations, relationships and patterns within the phenomenon that has been described" (Thorne, 2008, p. 50). This research design outlines methods that were used to discover the patterns regarding the method case that will inform clinical practice and larger questions of clinical decision-making.

One of the challenges of interpretive description is in the interpretation of the findings (Hunt, 2009). Hunt's experience of using interpretive description was challenging in regards

to the depth of interpretation. The challenge is not the analysis itself but the degree to which the data must be interpreted for it to be applicable and useful in clinical practice. In this study, an IKT plan attempted to overcome this challenge. The strategy used in this study (see Integrated Knowledge Translation, below) involved key decision-makers and knowledge users in the analysis process. It aimed to ensure that the level of analysis is in-depth enough to provide insight and applicability to everyday clinical practice with a balance to understand the larger research problem.

Locating the Researcher

In the personal journey of pregnancy and child birth, the researcher faced clinical situations that caused uncertainty, a need for more information, and a decision-making process that was uninformed, resulting in RhD alloimmunization. One of the instances of uncertainty was RhD negative status and pregnancy.

As stated in the introduction, RhD negative women's experiences with pregnancy has not yet been explored. The personal experience of the researcher and the original scoping review (Fyfe et al., 2014) led to questions about the experience of RhD negative women with pregnancy. It was important to consider the experiences of healthcare providers in the delivery of maternal care. It was expected that this study would continue to create new knowledge in the area of decision-making in rural healthcare, and specifically, the management of pregnant RhD negative women. Strategies were developed and implemented throughout the process of conducting this study that acknowledged personal experiences, professional and personal knowledge on the topic, and ensured that emotional wellbeing was considered.

The approach to inquiry is embedded in a constructivist ontology (Cresswell, 2013; Thorne et al., 1997; Thorne et al., 2004). Humans construct and contextualize experience and there are moments when those experiences are shared (Thorne et al., 2004). Interpretive description acknowledges these philosophical underpinnings, but also acknowledges that individual experiences can be distinct (Thorne et al., 2004). This ontological viewpoint was kept at the forefront in the process and scaffolding of this research study.

Ethical procedures

This research received ethical approval (Appendix C, D and E) harmoniously from the Research Ethics Board of the University of Northern British Columbia (E2016.0413.032.00) and the Northern Health Authority Research Review Committee (RRC-2016-0013-H).

The anonymity of all participants was and will continue to be respected. Information that discloses participant identity will not be released without consent. Stakeholder Committee participants were encouraged not to discuss the content of the committee meetings to people outside the group; however, researchers cannot control what participants do with the information discussed. The only people that have access to this information were the researcher's supervisors, committee members, the transcriptionist and the researcher. The transcriptionist was required to sign a confidentiality agreement. All transcripts and documents are identifiable only by code number and were kept it in a locked filing cabinet in a locked office and on a password-protected computer. Subjects will not be identified by name in any reports of the completed study. The information gathered from this study will be kept for 5 years. It will then be securely destroyed [e.g. by shredding paper files, deleting digital files, etc.].

Integrated Knowledge Translation

An IKT approach guided the research process. The Canadian Institutes of Health Research (CIHR) defines IKT as:

> IKT [sic] is an approach to doing research that applies the principles of knowledge translation to the entire research process. The central premise of iKT [sic] is that involving knowledge users as equal partners alongside researchers will lead to research that is more relevant to, and more likely to be useful to, the knowledge users. Each stage in the research process is an opportunity for significant collaboration with knowledge users, including the development or refinement of the research questions, selection of the methodology, data collection and tools development, selection of outcome measures, interpretation of the findings, crafting of the message and dissemination of the results. (Canadian Institutes for Health Research, 2015)

This kind of approach to KT was critical to this project and knowledge users, such as healthcare providers and decision makers, were engaged from the onset of the research. The Stakeholder Committee provided direct guidance on the clinical elements of the research, as well as guidance relating to the research itself. This ensured that the research reflected the realities of clinical practice and that the study achieved a reasonable and applicable direction and provided an effective means of translating the knowledge the study derived.

Stakeholder committee

A group of inter-professional healthcare providers was asked to participate in this project to act as a Stakeholder Committee using a maximum variation sampling strategy to ensure that the committee was representative of frontline workers and decision-makers (Cresswell, 2013). The group consisted of healthcare providers involved in maternity and obstetrics and/or the delivery of healthcare to RhD negative pregnant women within the NH regions. It also included representation from the laboratory at NH and a patient representative that is RhD negative and has been pregnant.

The committee met four times to discuss the research process and findings. Semi-structured questioning was used to generate discussion about the findings. These meetings were audio-recorded and transcribed using transcription services. The transcripts were used for back up and recall purposes and were analyzed and included as part of the findings. Participants are not identified or tagged in the transcripts and no direct quotes will be used in order to keep the participants anonymous. The Stakeholder Committee participants were asked to sign a consent form. This IKT approach was implemented to generate awareness about the potential issues and increase adherence by engaging key stakeholders in the field of perinatal care.

Research setting and time frame

This study took place in northern BC, including Prince George. Like many rural communities (defined in Chapter Two) in northern BC, Prince George also struggles to recruit and retain healthcare providers, particularly physicians (Snadden & Bates, 2005), and does not have the critical mass of specialists (Maternal Fetal Medicine specialists) or the resources to manage high-risk pregnancies due to RhD alloimmunization. Prince George does have Obstetricians that can provide the next level of care and expertise if a local and/or northern rural healthcare provider required assistance with an RhD negative pregnancy, but if a fetus is showing signs of HDFN the pregnant mother will need specialist care from a Maternal Fetal Medicine specialist in Vancouver. Further to this, Prince George is the central hub for NH, while the entire health authority spans the vast geography of northern BC. For the most part, leadership positions and specialists with NH are in Prince George; therefore, it was important to include Prince George as a rural community. Data for this study was collected over a six-month period between June and December 2016.

Participant selection and recruitment

In keeping with interpretive description strategies, participants were recruited using a purposive sampling strategy (Thorne, 2008). Further to this, snowballing was the technique used to identify participants that met the selection criteria from a variety of sources including other patients in the study (Cresswell, 2013). Theoretical sampling was anticipated to be utilized if a deeper analysis of a particular aspect of the emerging findings was needed but this did not occur (Hunt, 2009; Thorne, 2008).

Snowball sampling only occurred with healthcare providers. This process involved healthcare provider participants and Stakeholder Committee members sending study information letters to other healthcare providers they believed to fit the inclusion and exclusion criteria. The recruitment of healthcare providers was initially attempted through associations and societies (Northern Interior Rural – Divisions of Family Practice, BC College of Physicians and Surgeons, Northern Continuing Medical Education at Northern Health, College of Midwives of BC Midwives, Northern Health and the Association of Nurse Practitioners) but did not receive cooperation from these institutions. Snowball sampling was the best strategy for recruiting providers because they were able to identify providers practicing maternal care in northern BC. This process involved meeting providers at conferences and chatting about the project (these providers were asked to email if they were interested in order to ensure that there was no pressure to participate), and through dissemination of the information letter (Appendix F) by the Stakeholder Committee members and interview participants.

The recruitment strategy for participants who were RhD negative women involved identifying women who are RhD and whom have been pregnant between the years 2004 to present, whether they had developed RhD alloimmunization or not (or do not know). These

participants were recruited using social media (Facebook Mom and baby groups in Northern BC), advertisements in laboratory waiting rooms and immunization clinics at NH, and at public libraries (Appendix G and H). Potential participants were screened based on the inclusion and exclusion criteria (see Table 1).

Table 1. Participant inclusion and exclusion criteria

Include	**Exclude**
RhD negative women that have been pregnant*	**RhD negative women that have not been pregnant**
Rh sensitized women with D-antibodies	Women with other clinically significant antibodies** Women with clinically non-significant antibodies**
Developed D-antibodies antenatal or postnatal	Developed D-antibodies due to a blood transfusion
Developed D-antibodies in the 1st or 2nd pregnancy Live births Miscarriages/spontaneous abortion Still births Ectopic pregnancies Molar pregnancies Therapeutic abortion HDF/N	RhD negative women that are currently pregnant
RhD negative women Previous pregnancies but no development of D-antibodies Received anti-D immunoglobulin	
RhD negative women that did not seek out prenatal care or refused anti-D immunoglobulin Those that did not receive anti-D immunoglobulin but did not develop D-antibodies	
Other	
Developed D-antibodies between 2004 *** and 2014	Prior to 2004***

British Columbia	Received care, at any time through pregnancy(ies) for which D-antibodies developed, outside of British Columbia
Healthcare providers that manage pregnancies	
Family physicians that manage pregnancies Midwives Nurse practitioners that manage pregnancies independently or as part of a care team Emergency physicians	Residents and medical trainees/students Ceased to practice prior to 2004***
Practicing in British Columbia	Outside of British Columbia

*Pregnancy defined as knowingly been pregnant, whether or not the pregnancy was viable, terminated, miscarried or carried to full-term with a live birth.
**As defined by BC Diagnostic Services
***Society of Obstetricians and Gynecologists of Canada (SOGC) guidelines were published in 2003

Some qualitative methods use data saturation as a data collection end point but interpretive description states that we can never know when data collection has been truly completed because each participant brings different values, knowledge and experience; instead, researchers should look for trends and patterns acknowledging that this will be a representation of a population and not a generalization (Hunt, 2009; Thorne, 2008). Thorne and Hunt's argument against data saturation ideology (Crouch & McKenzie, 2006; Guest, Bunce, & Johnson, 2006), means that there is not magic number of participants that should be included in a study. Instead, if needed, there was willingness to recruit more participants if variance remained, or if the Stakeholder Committee required further information in order for the findings to be applicable to practice.

Participant characteristics

A total of 29 participants, 16 RhD negative women and 13 healthcare providers, were interviewed. Prior to the interview, each participant was asked to compete a brief

demographic questionnaire prior to his or her interview (Appendix I and J). This section will begin by providing some aggregating information about the RhD negative women and healthcare providers collection from the questionnaires. Any identifying information was removed to protect the confidentiality of the participants.

Table 2 provides a description of the RhD negative women (RhDW) interviewed for this project. All 16 participants had some level of post-secondary education. Seven women lived in Prince George and nine lived in other rural areas of northern BC. These women varied in age and in the number of pregnancies they had.

Table 2. RhD negative women participant characteristics

ID	Blood Type	Rhesus Status	Birth Month/Year	Highest level of schooling	Number of Pregnancies
RhDW 01	O	-	09/1984	Trade/technical/ vocational training	2
RhDW02	B	-	09/1991	Other	1
RhDW03	AB	-	05/1984	Some college or university, but no degree	3
RhDW04*					
RhDW05	O	-	11/1987	Some college or university, but no degree	2
RhDW06	B	-	04/76	Bachelor's (Undergraduate) degree	2
RhDW07	A	-	08/1978	Trade/technical/vocational training	4
RhDW08	O	-	07/1986	Master's Degree	2
RhDW09	A	-	12/1984	Trade/technical/ vocational training	7
RhDW10	A	-	04/1986	Bachelor's (Undergraduate) degree	4
RhDW11	O	-	12/1984	Bachelor's (Undergraduate) degree	2

RhDW12	O	-	05/1981	Trade/technical/ vocational training	2
RhDW13	A	-	10/1981	Bachelor's (Undergraduate) degree	3
RhDW14	O	-	11/1976	Bachelor's (Undergraduate) degree	2
RhDW15	O	-	12/1979	Bachelor's (Undergraduate) degree	5
RhDW16	O	-	06/1979	Some college or university, but no degree	2
RhDW17	O	-	09/1984	Some college or university, but no degree	1

* Participant 04 was lost in follow-up.

Healthcare providers who work in the catchment area of NH were invited to participate in the study. The type of provider has not been indicated in the following table to ensure that anonymity is maintained. The healthcare providers were asked when they began practicing, the discipline of their practice, if they are part of a care team and if their practice was fee for service. These questions were asked to try to get a sense of their practice, whether they are part of NH's new care team model and when they began practice.

Table 3. Healthcare provider participant characteristics

ID	Total years of practice	Fee for service	Care team
HCP01	0-5 years	No	Yes
HCP02	Over 10 years	Yes	No
HCP03	Over 10 years	Yes	Yes
HCP04	Over 10 years	Yes	Yes
HCP05	Over 10 years	Yes	No
HCP06	Over 10 years	Yes	Yes
HCP07	0-5 years	Yes	Yes
HCP08	0-5 years	Yes	No
HCP09	6-10 years	Yes	Yes
HCP10	Over 10 years	No	Yes

HCP11	6-10 years	Yes	No
HCP12	6-10 years	Yes	No
HCP13	Over 10 years	No	No

Interviews

Participants were interviewed using semi-structured questions (See Appendix K and L). Follow-up questions were prepared and continued to evolve over the course of the study based on from the Stakeholder Committee. It must be noted that time was available to allow the participant to locate themselves within the research, meaning they themselves may have needed to provide information outside of the questions posed by the researcher in order to contextualize their story (Thorne, 2008).

The interviews were largely conducted over the phone, only three were conducted in-person. The interviews were audio-recorded and the interviewer prepared field notes simultaneously. The audio-recordings were transcribed verbatim using a third-party transcription service. The transcriber signed a confidentiality agreement.

The participants were provided with a written consent form (Appendix M and N) and verbal consent was required before the interviews began. Due to the potential sensitive nature of this study, the potential recall of harmful experiences with healthcare, the women were provided with an information sheet, if needed, with contact information for accessible counselling and crisis resources within northern BC. Healthcare providers were provided with an information sheet with contact information for resources in the event that the interviews caused any distress. Participants were offered the opportunity to review the transcripts of the interviews to ensure that the transcripts are an accurate description of their experiences.

Focus group

Focus groups enable researchers to gather data from individual participants as they interact within the group enabling the researcher to observe and document the social dynamics that emerge (Thorne, 2008). Maximum variation sampling was utilized to identify a variety of healthcare providers that would be appropriate for this study (Cresswell, 2013; Guest et al., 2006). A team of healthcare providers and decision-makers involved in perinatal guideline adaptation in Fort St John were invited to partake in a focus group. This group existed independently from this study. The group of individuals was ideal for this focus group because they all have experiential clinical knowledge (Thorne, 2008) of the research problem and were in the midst of adapting guidelines to their local rural context. The original intent was to present initial findings from the interviews with both the RhD negative women and the healthcare providers to the focus group. The findings were to be discussed generally and using guiding questions that developed from the findings. In addition, the focus group was going to be asked for their thoughts and suggestions regarding further analysis of the data. As discussed earlier, the level of interpretation of the data for its applicability to practice is challenging (Hunt, 2009). The focus group's role in providing feedback, suggestions and insight may have provided the researcher with the ability to return to the data and ensure the findings are presented in a way that is applicable to practice.

Simultaneously, as the interview process progressed, the focus group participants completed adapting a number of perinatal guidelines. The conclusion of their project meant that they were no longer meeting as a team. When the group was approached to engage in a focus group, scheduling challenges quickly became apparent. After many attempts, it was not feasible to secure a date and time with this group. This forced a change in approach to obtaining guideline adaptation data. After reflection and contemplation, it was identified that

a few of the members of the guideline adaptation team were already members of the Stakeholder Committee. In addition, the interviews with healthcare providers was exploring the use and adaptation of guidelines, as shown in my findings. In consultation with the researcher's supervisors, it was decided that the focus group strategy for this study was no longer required.

Analysis

Interpretive description encourages a reflexive and inductive approach to analysis (Thorne et al., 2004). Analysis of the interviews and Stakeholder Committee meetings was undertaken using NVIVO ("NVivo qualitative data analysis Software," 2017). Coding involved an inductive two-cycle process described by Miles, Huberman and Saldaña (2014). The first cycle involved coding chunks of data. This involved reading transcripts and reacting to chunks of data by assigning a code. If the code name did not appear at first read, it was given a generic code number, such as Code One. The coded chunks were assessed for patterns and clustered accordingly. The second cycle of analysis was descriptive. This process involved descriptive coding within the chunks. Descriptive coding within the chunks identified similarities and nuances of the data within the chunk. In some instances, this process involved re-reading the transcript and writing a narrative of the participant's story to ensure that the participant's voice remained and the descriptive coding was accurate. The codes will be presented in the next chapter as Themes and Patterns (Subthemes) (Thorne et al., 2004).

The approach to the analysis of the interview data evolved and changed after presenting the findings to the Stakeholder Committee. The information and questions from the Stakeholder Committee directed further analysis of the data. It permitted the researcher to

determine whether or not the data could answer the research questions, specific questions the committee members had of the data, or what they perceived as missing from the data based on their expertise. As a result, the level of analysis the stakeholders engaged in directed the analysis process as it is intended in interpretive description methodology.

It was anticipated that the interviews of RhD negative women and healthcare providers, would be analyzed simultaneously. As mentioned earlier, it was a struggle to recruit healthcare providers at first; consequently, the interviews with the women were analyzed first. The analysis was fluid; analyzing and interviewing often occurred at the same time. This process proved effective as it provided the researcher the opportunity to focus on the experiences of the women, present that information to the Stakeholder Committee, interview more women and conduct more analysis. This approach provided a deeper insight into the narratives of the interviews by revealing further interpretation of the data.

Implementation science research states that in order for KT to be consistently implemented it must meet the needs of the intended audience (Straus et al., 2013). Traditional qualitative methods of analysis do not necessarily provide the end user with findings that are useful in everyday practice or policy development or change (Snadden, 2001). Interpretive description encourages researchers to interact with the data in a way that allows for a level of analysis that evolves as the knowledge of the researcher grows and interacts with existing evidence. In this study, the analysis went a step further. It pushed the boundaries of interpretive description by bringing the findings to stakeholders for their perceptions, knowledge and experiences with the phenomenon. In meetings with the Stakeholder Committee, first level descriptive data was presented to the committee members. The committee members were asked semi-structured questions about their reactions to the data, what they considered to be missing from the data, if the data was accurate to existing

practice, and if the data provided applicable information. This integrated analysis process allowed the researcher to return to the data and interpret it further for information that will be of interest to those that make policy and will engage with the findings on a day to day basis.

The anonymity of the participants was protected in all aspects of this study. Specific demographic, provider and community information was stripped from the transcripts during analysis. The analyzed data from the Stakeholder Committee meetings are not shared with specifics in the next Chapter to ensure anonymity of the participants. Instead, generalized comments will be made regarding the Committee's acceptance or discrepancies with the findings from the interviews, or if general comments are helpful to the discussion of the interview findings. The analyzed data will be integrated throughout the Findings Chapter to reflect the way in which it was collected, described, interpreted and amalgamated.

Reflexivity

The researcher engaged in reflexive journaling throughout data collection and analysis. The journal entries provided the opportunity to reflect on assumptions, perceptions and generated narrative summaries of the interviews (Hunt, 2009). Dickson-Swift, James, Kippen and Liamputtong (2008) suggest that journaling can be an effective strategy for researchers in dealing with sensitive topics. For the researcher, the prevention of RhD alloimmunization is a personal topic and journaling provided a means of self-reflection and a strategy to cope with the potential emotional content. When required, the researcher debriefed with supervisors, and one of the committee members. The researcher did not need to contact the Health and Personal Wellness Services offered to students at the University of Northern BC. Reflexive journaling provided a strategy for identifying and clarifying researcher bias throughout the study (Cresswell, 2013). Furthermore, it enabled the

researcher to critically examine the emerging data with respect to these personal presuppositions and difficult data.

Rigour

In the 1980s, Guba and Lincoln (1981) developed a set of four criteria to evaluate qualitative research: credibility, transferability, dependability and conformability. These criteria provide qualitative researchers guidance in the development of trustworthiness research. Amalgamation strategies address the issue of credibility by involving the collection of multiple sources of data (Cohen & Crabtree, 2008; Guba, 1981), for this study the multiple data sources are the updated scoping review, interviews and the Stakeholder Committee.

Another means of establishing credibility is member checking, according to Creswell (2013) member checking encourages participants to review their transcripts to ensure that the narrative depicts what was said. While participants were offered the opportunity to obtain a narrative description of their interviews for verification prior to analyzing the data, not one participant requested the narrative. Despite this being a helpful process for participants, Guba and Lincoln intended for member checking to involve peers and others to verify the interpretation of the analysis (Guba, 1981; Morse, Barrett, Mayan, Olson, & Spiers, 2002). This process was met with the engagement of the Stakeholder Committee in analysis.

The Stakeholder Committee served an integral role in the study by providing clinical guidance and feedback on the level of depth that the interviews and analysis require for clinical relevance. The dependability of the findings requires that the methods and findings are consistent and transparent (Guba, 1981). Further to this, an audit trail was developed to track the various ways participants were recruited. The use of two data collection methods, interviews and Stakeholder Committee meetings, attempted to provide consistency,

particularly in the findings, that ensured the dependability of both methods and findings (Guba, 1981).

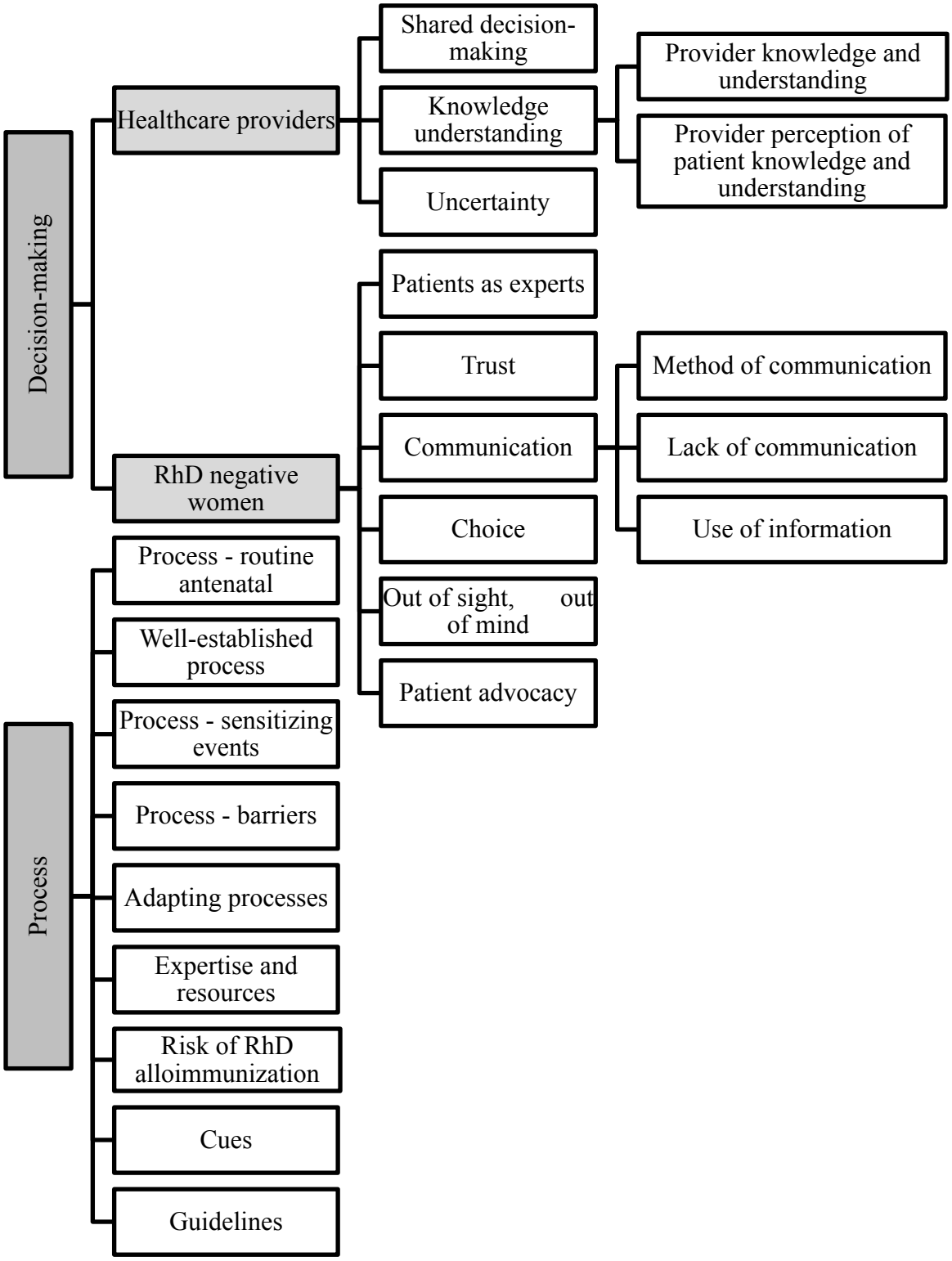
Chapter Four: Findings

A qualitative analysis of 29 interviews was undertaken. Two major themes emerged from the data: Decision-Making and Process. Subthemes provide further analysis and context within the broader major themes (Figure 2. Themes emergent from the data). In this Chapter, the themes that emerged from the data are described and interpreted. The description of the Decision-Making theme will flow from healthcare provider to RhD negative woman, with the Stakeholder Committee aligning and/or contradicting the findings throughout.

Integrating the Stakeholder Committee findings within the interview findings reflects the method of data collection, description and interpretation. The Stakeholder Committee met to discuss the themes emerging from the data while interviews were being conducted, therefore, their voices will be heard within the context of the interviews throughout this Chapter.

The second theme, Process, emerged from the findings of healthcare provider decision-making processes and experiences of RhD negative women. The factors that continue to place RhD negative pregnant women at risk for RhD alloimmunization will be described. This Chapter will conclude with an exploration of the processes and deviations of the RhD alloimmunization prevention program in northern BC, as described by the participants.

Figure 2. Themes emergent from the data



Decision-Making

This section will begin with a description of decision-making from the perspective of healthcare providers managing RhD negative pregnancies. This an in-depth assessment of providers' experiences with shared decision-making and how that is impacted in clinical situations throughout the course of caring for RhD negative women's pregnancies.

Healthcare Providers Decision-Making Regarding RhD negative Pregnancies

The healthcare provider participants were asked semi-structured questions about their experience in caring for RhD negative pregnancies. This often included the discussion of the decision-making process, understanding and contexts of practice. In addition, healthcare provider participants were asked broader questions about dealing with uncertainty in clinical practice. In both instances, questions about the information they sought and utilized to overcome uncertainty were asked.

Shared Decision-Making

Healthcare providers were asked about making decisions with patients, both specifically in regards to RhD negative pregnancies and in general. The conversations were not always about RhD alloimmunization but were helpful in exploring their decision-making process with patients. Five providers (HCP 01, 02, 06, 07 and 11) described that they did not consider themselves to be the sole decision-makers when it came to patient care, both specifically during pregnancy and in general. In these instances, the healthcare provider participants described how they sought to involve patients as much as they can and provide information to ensure patients are informed. For example, HCP 02 states that working with patients to make decisions helps them to better understand.

> Ya, I think the decision making is basically, this is similar to the case I talked about in the beginning, people may not want to do something and often times I will get referred people, not necessarily for Rh factor discussion, but because they won't accept treatment, but if you actually take the time to explain the rationale behind the treatment, then people are way more accepting of it and you can come to some sort of compromise, you know. And like it's just very, very common for people to sort of dig their heels in at certain things but if they understand it, then it's not a problem. A common example is Vitamin K after delivery. And I mean we give that for hemorrhagic disease of the newborn and a lot of people are like no, that's not natural, you know, but if you actually explain hemorrhagic disease of the newborn to somebody and the fact that it does happen and the incidence is fairly high, then people tend to view Vitamin K[4] a little bit differently. (HCP 02)

HCP 02 shared that they try to present information for patients to gain an understanding. In doing so, the patient-physician dynamic changes to one of mutual power.

> And I never try to present myself as I am right, or I have the answers, it's more like this is just the way I tend to think about it and that seems to work with the majority of people. Because lots of times it's just lack of understanding. (HCP 02)

During the interviews, HCP 07 and 09 also talked about the importance of involving the patient in the decision-making process and the need to provide an open space to enable conversations addressing treatment opportunities. HCP 07 described that a provider's role is to provide the information and "let them *[patients]* make their own decisions", a theme that was commonly identified amongst the healthcare providers.

> My approach, I think, to provide the information that I have, in an open way, and make the patient, you know, or get an idea that the patient understands what you're saying and if they choose to disagree, that's up to them, their body and health. And I, you know, we obviously provide, provide other sources, or offer them, you know, discussions with different people, or other physicians, if that's what they wanted. But, you know, ultimately, I'm not going to argue with people. Ya, that's not the point. And this happens every day, too, right, if someone doesn't agree with what you're saying, you can only, you know, convince them so much, or… Convince is not a good word, either, you know, just provide that information and let them make their own decision, I guess. (HCP 07)

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[4] Vitamin K is used as a "prophylaxis and treatment for hemorrhagic disease of the newborn" (American Society of Health System Pharmacists Inc., 2017).

While many of these conversations appeared to focus upon the more general nature, one participant (HCP 09) specifically addressed shared decision-making with RhD negative patients experiencing sensitizing events:

> Uh, well I mean you talk to this, I try to practice patient-centered care so I talk to the patient. I mean if they're really reluctant to get it done or if they don't have time or they seem like they're just not going to get it done, I factor that into the decision of how strongly I recommend it get done. You know, if they've had three miscarriages before and have never had it done before, I'm not as worried about getting it done because I think well, this is the, the risk has already happened or their problem has already happened. You know, if it's someone who's young and this is their first miscarriage and I do try to get, I think ultimately, I think it's better to err on the side of getting it rather than not getting it. I think the risk of receiving Rhogam is quite low. (HCP 09)

When talking about shared decision-making, one provider (HCP 12) highlighted that some RhD negative women have refused to receive RhIG within their practice. The provider stated that the patients were informed about being RhD negative and pregnancy, the prevention program and specifically about RhIG. The two women that refused to receive RhIG both relied on complementary and alternative therapies and beliefs to guide their decisions. When asked if these women developed D antibodies as a result and/or if their infants were healthy, the provider did not know the outcomes. HCP 12 did say that the women refused to have the infants' cord blood drawn for testing. Consequently, the women did not find out their infants' blood types. As the conversation unfolded, the provider reiterated that all the necessary information had been provided and stressed that the patient is the ultimate decision-maker. If these women chose not to receive RhIG when required then that was there choice.

During the interviews, two providers (HCP 01 and 04) described how they used information tools when communicating with women and families about RhD negative pregnancies. For example, one rural provider (HCP 01) shared how they used a handout from

BC Perinatal Services as a means of educating their patients about RhD negative pregnancies. HCP 01 encourages RhD negative women to take the handout home, read it, make notes, write down any questions they might have and bring it back to the next appointment for discussion. Despite not having anyone bring the handout back to an appointment, HCP 01 continues to "give it" and still says "how important it is". HCP 04 is a visual learner and stated that they will often draw concepts out for patients as a means of communicating knowledge. HCP 04 explained over the phone how much detail she would add to a drawing to ensure a patient understood how RhD alloimmunization might occur during a pregnancy: "So I find it easier with pictures, it's messy"; "I try to put it in Magic School Bus terms"[5]. Later, HCP 04, suggested that a cartoon that could be provided to RhD negative women would be helpful. Since the interviews, one member of the Stakeholder Committee sent me a NH pamphlet. It is interesting that not one participant discussed this pamphlet as a means of providing information.

These discussions showed a perceived sense of engaging in shared decision-making. In these instances, the power between the healthcare provider and patient are perceived as balanced. In Figure 2, the provider and the patient work together to make decisions regarding care, demonstrated by the red flag in the centre of the image. A yin and yang type image was used to denote the harmonious nature of the provider and patient relationship when both are truly engaged in shared decision-making.

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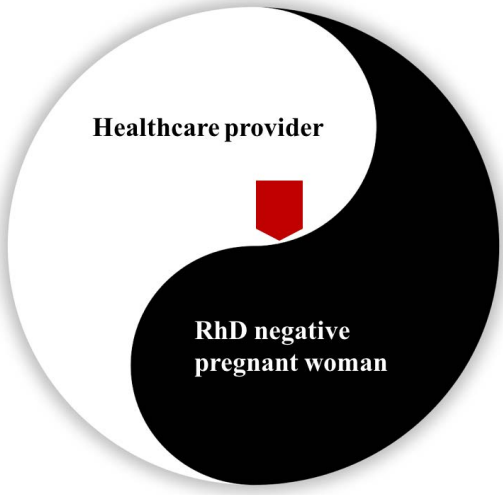
[5] Magic School Bus is a series of books and a television show for children. The premise is that an elementary school teacher takes children on adventures in science where science is easily digestable and understandable. (["The Magic School Bus," 2017])

Figure 3. Shared decision-making



This harmonious shared decision-making model was not always achieved in the prevention of RhD alloimmunization in RhD negative pregnant women. The next section will describe the themes and subthemes that emerged from interviews with healthcare providers about their knowledge and understanding of the prevention of RhD alloimmunization. The theme includes two subthemes: (1) provider knowledge and understanding, and (2) provider perception of patient knowledge and understanding.

Knowledge & Understanding

Two themes emerged in analysis regarding knowledge and understanding. The first one to be discussed is provider knowledge and understanding. Anything that provided insight into the healthcare provider's understanding and knowledge of RhD factor, the process for the management of RhD negative pregnancies and RhIG was coded as knowledge and understanding. The second theme shared in this section is that of provider perception of patient knowledge and understanding.

Provider knowledge and understanding

During their interviews, healthcare providers were asked how they explain RhD factor in pregnancy and the prevention of RhD alloimmunization. Their answers were not assessed for accuracy but were analyzed for themes that may have emerged from the data. This part of the conversations often made the participants seem uneasy and nervous. This is evident in some of the language they use, such as "freak out" (HCP 11) or "Is there something I am not picking up on" (HCP 07). There were instances of nervous behaviour such as a nervous laugh. A key element of this was the perceived infrequency of addressing this clinical issue.

> I think because the complication is rare. I think your reaction to give Rhogam is quite strong and I've heard like OB's say like that she probably didn't need Rhogam or oh she already had it 12 weeks ago so she didn't need it again and you know, the dosing, you could give a smaller dose but we really are like, we are strongly into this prevention, you know, of alloimmunization and so you just rarely see complications and it's kind of like seeded into memory. Until you see one or you get someone with antibodies, that's what always, I get really freaked out, you know, you get the blood report back and it says antibody D or whatever, all these things that you don't understand and wish you could remember from med school. Then what do you do about that and the extra observation that that woman will get. That really freaks me out. (HCP 11)

> I say oh don't make me [explain it] (laughs). No, I don't really. It's like super confusing and it is. (HCP 06)

> But, I actually don't, I've never taken a look at the evidence thoroughly, I've just kind of, that's what I've always been taught. And it really, and I, you know, if someone asks me, what are the harms of the Rhogam, you know, I could look it up but I don't know of many, like I haven't really looked at the evidence of how good this is. I think I, I quote to people, you know, risk is some one to three percent or something and with the vaccine it goes down to less than 0.1%, But I don't, ya, I don't, haven't really appraised that literature in depth, so… Is there controversy, or is it… That's what I guess… Is there something I'm not picking up on. (HCP 07)

Others told me snippets of knowledge that they recalled about RhD negative pregnancies. This knowledge was seeded in their memories from being taught the information in their

undergraduate and graduate training, while others recalled looking information up but not exactly sure where or when they found the information.

> The risk is fairly low if I understand it correctly. I looked it up many years ago, it's not that high as they perceive it and it's fairly low, right. (HCP 05)

> I remember med school, it being a confusing concept, so. (HCP 07)

> No, not specific guidelines, I just know what I was taught to do, so I do what I was taught to do. But I don't actually know where that information came from. I do follow, I do look it up, I don't know if there's specific guidelines. I do have an online resource that I use for many, it provides me with information for many clinical things, not just obstetric stuff. (HCP 09)

Overall, healthcare providers struggled with what RhIG is made of and how it works in preventing RhD alloimmunization.

HCP 09 described that she did not have a good understanding of how RhIG prevents alloimmunization. The provider mentioned that it is a blood product but that it is not really blood, it is antibodies. HCP 03 struggled with this as well, although seemed confident about understanding. The provider stated that RhIG was not a blood product and did not understand why a consent form was required.

> Uh, probably not. I'm not sure I have absolute understanding of what it is. I just know somehow it prevents that alloimmunization but I don't actually know what it does beyond that. It's a blood product, you let them know it's a blood product, that's why you have to go to the lab to get it. Or it's derived from blood, it's not blood itself but it's antibodies. (HCP 09)

Other healthcare providers were not familiar with the process of providing RhIG to pregnant women. One participant (HCP 10) reflected upon their practice within the emergency department and commented that they were unsure if consent was needed to provide RhIG to RhD negative pregnant women. HCP 11 went further to question the process for getting RhIG during pregnancy. HCP 11 went through the process and rationalized it but it was not clear if she answered all of their own questions.

> I don't completely understand, like the process that goes through, it's like prior to getting the Rhogam and so just the number of steps that the woman has to go through in order to get that I find it's cumbersome for her and it could be simplified. I'm not totally sure, is it like you want to make sure she's Rh negative? Aren't you sure the first time we do it? Like why do we have to repeat the blood test or is it to make sure there's no antibodies at that time. Like I guess that's a bit of my own confusion about it. But wouldn't it be simpler if there was someone at the lab who could be trained to then administer the Rh. I guess then it's sort of in our hands but then the negative side of that is that we don't have the same closed loop like in our office like we know it's been given, it's documented in one place, we're not trusting the fax or a patients' word to say the shot was done, so that is the advantage of the way that we do it. And there are times that, let's say the shot gets given and it doesn't get documented but because we have a small staff, they can say oh ya, I gave that shot, I'm 100% sure, you know, so then you can kind of pinpoint it as opposed to the lab you couldn't pinpoint it. (HCP 11)

Provider perception of patient knowledge and understanding

Healthcare providers were asked if women asked them questions about their RhD negative status, RhIG and/or the process of receiving RhIG. This often led to a discussion about patient understanding and, in some instances, adherence. The providers stated that women did not ask many questions about being RhD negative and pregnant. Here are some examples of provider perceptions of RhD negative women's understanding of their pregnancies.

> Very accepted practice, I guess. It's rare someone would question, even a pregnancy, or they already know that they're Rh negative and that's the process or even knew then, most don't question it too much. (HCP 05)

> They rarely do. There's the occasional patient who will. Most patients, you're like I just need to let you know, and you're trying to explain Rhogam and they just kind of glaze over a little bit. Cause often they haven't had prenatal classes at that point. If they have, usually they're like oh I get it, but it's, ya, it's one of those questions there seems to be a bit of safe, they just say okay, I'll go for my Rhogam. It'll help my baby, or help my next pregnancy. (HCP 04)

HCP 04 went on to tell me that she gets more questions about things that she deems as less controversial, such as Vitamin K injections. The participant uses the word "surprisingly" to describe that she does not get questions about RhIG.

> Never. Never. No. that's the one I can say that surprisingly, it's the one I've never, maybe a couple of times I've had to explain it a couple of times, maybe over the last 20 years, but I've delivered lots of babies, and no, it's almost, I've explained Vitamin K way more than I've explained Rhogam. (HCP 04)

HCP 09 has a similar reaction to my question. The participant stated that women are not asking questions like they "would've expected them to". This is intriguing because the provider then said that when she does explain it, the women "just accept that". She would have expected women to question their RhD negative status and getting the injection.

> Not as many as I would've expected them to. You know I explain that it has to do with antibodies, making antibodies against, like if you're negative and your baby is positive then you can make antibodies against that baby that can actually affect future pregnancies. And I say what it is and they just accept that. They don't say well what if this baby is negative? And shouldn't we just be testing my husband or my partner or whatever? So, they don't ask as many questions as I expect. (HCP 09)

When the interview with HCP 13 was ending I asked if there was anything else to add that perhaps we had not already touched on. The answer was surprising because it was not expected to see similar experiences regarding patient understanding and advocacy within the emergency department as seen within Family Physician perspectives. HCP 13 reported feeling alarmed that women are not advocating for RhIG. HCP 13 stated that they often have to argue with patients regarding other preventative measures but RhIG is not one of them. HCP 13 did not have an explanation as to why women are not advocating for RhIG but thought it important to add.

> No, the only thing that went through my head when I was thinking about it last night, but also just during our conversation today is women in pregnancy and quite rightly and very appropriately advocate for themselves, they advocate for certain things. So, they'll often ask for this to be done or that to be done because they're aware of what some of the recommendations are. Rhogam is never on that list. Women never ask for Rhogam, they never advocate for getting Rhogam. Even though as a health preventative maneuver, obviously, it's critically important and it's the only preventative maneuver for allo-immunization, so it's strange to me. It's an Emerg problem so I haven't spent any time trying to fix it, but there is absolutely no evidence for advocacy, self-advocacy around Rhogam. Women do not ask or remind us ever. Patients remind us all the time to give them tetanus shots, they remind us all

> the time to do other things. They never remind us to give Rhogam. So I don't know what it means Trina, I'm just letting you know, it's kind of one of those interesting things about Rh … And patients who often tetanus shots, they're often asking for tetanus shots, even when they don't need them. I've spent as much time telling patients they don't need tetanus because they're up to date or whatever and I've never in my career had to tell women that you don't need Rhogam cause they're asking for Rhogam and they don't need it. It just has never happened. It's just one of those weird things. (HCP 13)

Another provider (HCP 04) shared a similar outlook:

> So ya, but there's not a lot of concern about it. Like there's not, it must be it's been around enough, for long enough, that people don't, it's not one of the worrisome things, or things they stress about. I don't know why. They stress about other things, you're like really? (HCP 04)

The Stakeholder Committee confirmed the unlikeliness of RhD negative women to ask about or question RhIG. One of the members, of the committee has been practicing for many years and remembers when RhIG was introduced as the intervention for the prevention of RhD alloimmunization. The stakeholder told us that there was a collective "community" knowledge that women knew it was important to know their Rh status. The stakeholder attributed the use of RhIG to the decrease in unhealthy babies born to RhD alloimmunized women but in turn the "knowledge in the community" is now gone.

There is a risk to RhD alloimmunization with patients that do not adhere to the prevention program. HCP 11 talks about a woman who struggled with attending appointments and recommended interventions. The provider recalled the woman potentially not following up on receiving RhIG at 28 weeks putting her at risk of alloimmunization.

> I believe, unfortunately this is a patient that had trouble following up so we did not complete most of any of it. It was quite challenging for her to follow that, the recommendations. (HCP 11)

Another provider worked at a clinic for vulnerable populations and stated that it is often a struggle to get women to go to the lab to get blood work done. The adapted cumbersome process and the inability for some patients to access timely interventions, such as RhIG.

> Not in terms of Rh. No, except I mean just getting lab work done is a real challenge for these patients oftentimes … (HCP 09)

Uncertainty

Healthcare providers were asked how they overcome uncertainty in patient care within their medical practices. All of the participants stated that they face uncertainty each day in their practice. Although each had their own approach, nine of the participants (HCPs 01, 03, 04, 07, 08, 09, 10, 11 and 12) specifically stated that they used their colleagues and specialists as a source of information. For some, this meant asking a senior colleague (07 and 08) or contacting the specialist available on back-up and/or via the telephone (04, 06, 07, 08, 09 and 10). When asked what information they used, 5 of them (HCP 06, 07, 08 and 09) talked about using information from online resources, such as UpToDate[6], and integrating that information with information provided from colleagues and specialists. This was the same for healthcare providers in all geographic locations.

> …but we often run into weird stuff and it's a lot of phone calls and looking stuff up and you know usually you have your, you start local, so if it's not too weird, we start with our local specialists and we just make phone calls. So whoever's on-call, you call and if it's something that seems bigger than that, you might go further afield to Vancouver or somewhere else to try and. Cause we don't have a hematologist in Prince George so if it was something that was, there was more specific hematology thing or baby thing, I would call down to Vancouver and find the hematology, the Perinatologist or whoever on that thing. And then we use Up-to-Date a lot. (HCP 04)

> Well I think, like I said, I think that happens most days, that there's something you don't know. It doesn't have to be a big thing, it could be very small, but, I guess the way I overcome it is, you know, if I have a colleague around, that would probably be the best, more experienced colleague, talk to somebody. Of course, using resources to look things up, if it's something straightforward, would probably be the number one thing. (HCP 07)

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[6] UpToDate is a commercial electronic resource designed to be used as a point-of-care decision-making tool. For more information please see the UpToDate website: http://ww.uptodate.com/home.

HCP 01 is a provider in a smaller rural community in Northern BC. The provider described their approach to becoming familiar with caring for an RhD negative pregnancy upon arrival to the rural community. The approach involved contacting the supports they would utilize to learn about out the process for obtaining and administering RhIG. HCP 01 had to ask very specific questions to obtain the proper process of obtaining and administering RhIG:

> I know the way things have to go with an injection before and an injection after especially with an Rh positive father, but do I give that injection, do you give that injection? Does she get the injection from the nurse? How does it work in this general area? … And then I had to find out how to get the injection. So, in our hospital, the injection is done by the head nurse and what you do is actually write it on a lab req cause it's kept in the lab which is something I've never seen before but that's the system they're finding works. So I called the head nurse and asked how do we get Rhogam, do we keep it here and he said yes, we do, it's in the Lab, it's not in the Pharmacy because it needs to be under certain conditions. So when you are ready at the time and date, you can send it on the lab req for the third trimester blood screening. (HCP 01)

Even in the emergency department, HCPs 04, 10 and 13 use online resources and colleagues to overcome uncertainty.

> Well, I go to my resource, so I got to UpToDate. So for example, yesterday I had a guy who was potentially a TB exposure and he actually had a pneumonia on the x-ray so he actually had a positive x-ray but it didn't look like a TB pattern but he came from the Health Unit with a suspected contact to an active TB member. So I hadn't treated that in the past. I haven't done any TB work since medical school which was an awfully long time ago. So, I went to Up to Date and I looked at what the Standards of Care were and then when I still wasn't sure, I actually phoned the specialist for internal medicine on call and asked for them to give me some guidance. (HCP 10)

HCP 09 looks up dosage information when requesting RhIG for a RhD negative pregnant woman because RhD negative women having sensitizing events are not often seen in practice.

> I always have to look up the doses but I think I do 300 micrograms if it's at 28 weeks, like if it's a regular pregnancy and then if it's an early end to the pregnancy, so either it be termination or a miscarriage, I think it's a 150. It might be only 50, I always have to look it up cause it doesn't actually happen that often. (HCP 09)

A few providers discussed that they "just know" that RhD negative women require RhIG to prevent RhD alloimmunization.

> No, not specific guidelines, I just know what I was taught to do, so I do what I was taught to do. But I don't actually know where that information came from. I do follow, I do look it up, I don't know if there's specific guidelines. I do have an online resource that I use for many, it provides me with information for many clinical things, not just obstetric stuff. (HCP 09)

> Ya, it's true, because you're not necessarily seeing people who deliver prenatal care. And not that it's not taught, but it's not the thing you come to first. (HCP 04)

> So, we would go from sort of what we were taught in school and that first trimester bleeding in an Rh negative woman, concerns for alloimmunization, give them Rhogam. (Rural, 10)

These providers relied on their education, but recognized that this is not always helpful in the decision-making process because they are unable to recall the information that they were provided and learned.

Summary of Findings from Healthcare Providers

When the healthcare provider has a limited understanding of the process or cannot recall the specifics of Rh status and pregnancy this can lead to a diminishing of the balance between provider and patient shared decision-making. The red lines in Figure 3 demonstrate a breakdown of the line between healthcare providers and patient in decision-making when a provider does not have the information needed to make a sound clinical decision. This has the potential to lead to a patient safety incident.

Figure 4. Breakdown in decision-making

The next section will look at decision-making from the perspective of RhD negative women, identifying the factors found to be involved in the decision-making process during pregnancy. Information needs and behaviours will follow in the context of decision-making; ending with how women talked about being experts and needing to advocate for themselves in various situations.

Experiences with the Prevention of RhD alloimmunization

The RhD negative women participants interviews for this study told a different story of decision-making, one that was not always shared between the provider and the patient. Women stated that the communication regarding RhD alloimmunization prevention program was lacking and some needed more information to feel informed. This lack of shared decision-making let some of the women advocating for themselves out of necessity, being uninformed and finding information on their own. This kind of experience demonstrates a shift in the shared decision-making model, one to where the provider has more power.

Figure 5. Unbalanced decision-making

This section begins by sharing the experiences of RhD negative women with pregnancy. This will be done by examining emerging themes: communication, patients as experts, trust, choice, out of sight, out of mind and patient advocacy. Women described the communication they received about Rh status and the prevention program. Aspects of decision-making heard by the RhD negative women and communicated during interviews will be explored.

Communication

Twelve of the 15 women that participated in this study discussed healthcare provider's communication during interviews. Anything a participant discussed regarding the provision of, or lack of, information, whether it was verbal or written (or other), were coded as communication. This term was used to code communication between healthcare providers and RhD negative women. This included the method used to communicate information, how it was perceived, the role of the patient in the communication, lack of communication and the type of information that was or was not communicated.

Method of communication

The method and delivery used to communicate information to RhD negative women varied. RhDW 05 described the interactions she had with a resident that provided some of her prenatal care and the way the resident communicated to her, specifically about being RhD negative. She perceived that the resident lacked confidence in communicating information about her pregnancy. This perceived lack of confidence in the way the resident communicated made the participant feel that being RhD negative was "scary". This left her to look up information on her own and decided that being RhD negative during pregnancy was not as "scary" as the resident had made it out to be. This same woman stated that the information about being RhD negative is often skimmed over by healthcare providers. As a result communication issue, she expressed that women may potentially become fearful about being RhD negative and the interventions they will need during pregnancy. This participant identified that some people may have varying needs and understanding of information, requiring healthcare providers to consider the ways in which they communicate information to their patients.

> I think for me, like it doesn't really matter in the long run, it was a resident doctor explaining all this to me and she didn't seem to be confident in the way she was telling me stuff so it made it scarier than it needed to be. Ya, so looking it up myself, oh this is not a big deal but the way it was explained to me, she just wasn't confident how she was explaining it, which happened with a couple things she had told me when I was pregnant. (laughs). (RhDW 05)

Conversely, when a participant experienced the confident delivery of information they trusted the information that was given and did not have any questions. RhDW 02 experienced a sense of confidence in the way her healthcare provider communicated information to her about being RhD negative. The confidence in the delivery of information

permitted the participant to trust the information that was provided, leaving her without questions.

> My doctor seemed so confident in what they were telling me, and like you know, very nonchalant about it, so I don't think, like it didn't really arise any questions for me. (RhDW 02)

RhDW 05 expressed her preferred method of communication by sharing interactions she had with her physician. This experience was quite different from the communication she received from her previous physician in a larger centre, in northern BC. The difference was marked by a willingness to listen to questions the participant had about her pregnancy. The provider did this by asking the participant if she had any further questions even after she had "already berated him with so many questions" (RhDW 05). She said that "he realized like I don't know why you're making these decisions", almost acknowledging that, yes, the provider has done this so many times that it is routine but to her this was new and uncharted territory. The use of the word "you're" puts the decision-making on the provider and not on the woman. She appreciated the provider's approach to communicating information and ultimately stated that she preferred this healthcare provider to her previous healthcare provider.

Lack of communication

For 11 participants, information about being RhD negative and pregnancy was first provided by the healthcare provider during prenatal care. For another four participants, their first encounter with this information was following a sensitizing event, such as a miscarriage or a termination. In each situation, there is potential for the provision or lack of information, and how it is communicated would influence a women's experience of her care during pregnancy.

Two women expressed that time and the perceived workload of the healthcare provider were contributing factors for not receiving or asking for information:

> Or you could ask your doctor to explain it. I know with my doctor he's really crazy busy and I feel like he doesn't really give you the time of day for stuff like that. (RhDW 09)

As shown in the above quote, RhDW 09 describes her doctor as being really busy and, based on her tone, resents this because he does not take a lot of time with her to listen and to answer her questions. RhDW 07 said that she did not ask questions because she did not "want to give them more work" to do.

Receiving information during difficult clinical situations, such as miscarriages, often meant a lack of communication regarding the patient's Rh factor and RhIG. RhDW 07 had two miscarriages. Her first miscarriage required an emergency dilation and curettage (D&C). She described her physical and mental state after the procedure as tired and emotional. She tried to recall the conversation with the nurse about RhIG, but did not really understand this until she did her own research. She said that having the information delivered to her in that state made them seem "quite flippant about it", almost like it was not important. The participant thought that perhaps having some sort of information available for patients in these types of clinical situations would be helpful. It would provide patients with information they can look at when they are perhaps in a better physical and mental state, instead of trying to recall information from a conversation when you are tired and emotional.

In regards to the lack of information they received, 6 of the women suggested that, a "little one-pager" (RhDW 13) and "education" (RhDW 10) about what it means to be RhD negative during pregnancy, the potential complications, and what RhIG is and why it is provided would be helpful.

Use of information

For some women not having enough information made them seek further information in order to satisfy their information needs. They used the Internet, their healthcare providers, books, and family and friends. Women (RhDW 07, 09, 12 and 13) that stated they searched the Internet, searched for broad overviews of being RhD negative and pregnant, some specifically looked at the history of hemolytic disease of the newborn and the discovery of RhIG. There was discussion about the dissatisfaction with pregnancy books stating that they "put worry and doubt into your head" (RhDW 08). One woman commented that she felt one of the popular pregnancy books "was kind of archaic and it was very regimented in what you should be having at this moment, which I don't think is really accurate" (RhDW 06). In both these interviews, the women used the Internet to obtain information instead of pregnancy books. Some women (RhDW 07, 09, 12 and 13) described critically appraising the information they found online. All participants self-identified that they had some education beyond high school in the questionnaire. It is assumed that this education provided them with some critical appraisal skills that were utilized in the process of finding information.

> The Internet fortunately. I mean I do ask my doctor and I do have a [health] background so I do know about who to stay away from and the ones that are kind of, the better sites to use but basically that's kind of where I look for that information. Ya, and then I just kind of pass it to my doctor to make sure I wasn't, that it wasn't going to be an issue for me. And he said, no, you're good. (RhDW 12)

> You know I try to go for like websites I feel like I can trust rather than kind of a random forum or people with random thoughts on the subjects. (RhDW 07)

> If it's somebody just spouting their opinion or if it's a peer reviewed article or from a reputable like medical based website. (RhDW 13)

Two women described learning that they were RhD negative from their mothers/parents. The women that discussed being RhD negative with family and friends expressed that they learned about the process of RhIG, particularly if these people had gone

through the process themselves. Family and friends also played a supportive role by reassuring women about their RhD negative pregnancies:

> Ya, well, she knew my blood type and her boss, his wife is O negative, so she knew through them and she had lots of kids, I think she had six kids, it was crazy, and she had to get the Rhogam shot with all her children so she knew to tell me that. And she just tried to reassure me because they're like health nuts, her boss and his wife and she said it's all good, you know, so and so did tons of research on it and don't stress about it or anything. (RhDW 08)

> I knew that it involved some things later on in the pregnancy cause my sister is also a negative blood type and she had been pregnant before me and mentioned having to get this Rhogam stuff that prevents issues with crossover. (RhDW13)

In contrast, one woman told me that RhD status was not something that she and her friends discussed:

> I feel like it's not even something that, even when I talk to girlfriends who've had babies and stuff, it's not something that you always talk about like, you know, whether you had to get IV if you had an epidural and all that stuff but the shot thing doesn't. (RhDW 06)

It is curious that this is not something shared amongst RhD negative women but it might be because it is not common.

Appearing in the women's stories were discussions of information seeking behaviour based on each individuals' specific coping styles. Four women wanted more information to satisfy the gap in information:

> Um, well, I'm a very detail oriented person so more information for me is the best …I would've loved more information about it. Definitely. To have it explained a little bit more, for sure. (RhDW 02)

> No, thinking back that would've been handy if they had some literature to give you to read through rather than, you know, going on Google trying to decipher which is actually good information and not good information. (RhDW 07)

> …like I guess it would be interesting to know what it is and like what that shot is made up of and actually it would be interesting to know whether the first shot is different than the second shot, or if it's just the same medication or ya. Like I don't know any of that. (RhDW 09)

> Um, if the doctor actually came and told you about it, what is it, like some nurse or whatever, you know, just her opinion about it, a doctor would actually know more about it. Sit there and explain what it actually means. The nurse, you know, she said she wasn't, sure she was supposed to tell me about my blood type but she says well that's what you are so that's why you need a shot. So, I'm like okay, well, news to me, okay. So, it would be nice to have a little more information, you know, from the doctor on the day I think. (RhDW 16)

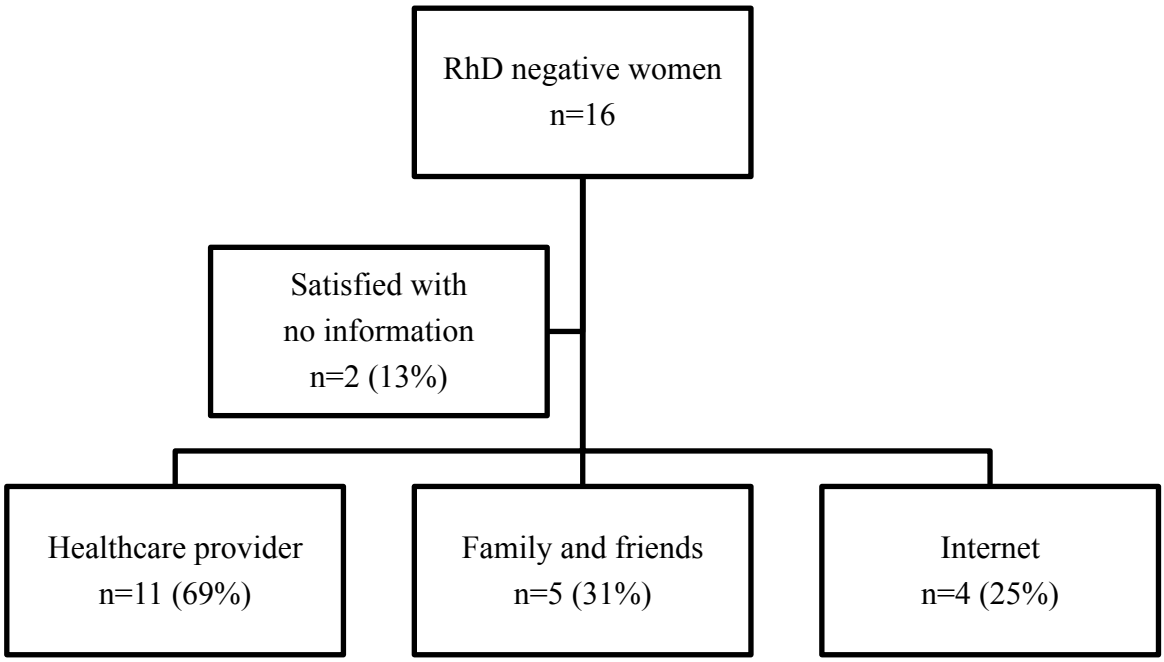
While another woman said that having information may make her worry unnecessarily about being RhD negative during pregnancy:

> Because I immediately go to the worst-case scenario so I'm getting an epidural, I'm going to be paralyzed forever. I'm going to have a C-section, I'm going to die of flesh eating disease. Cause they don't seem natural. So, I think if I had known that what exactly, or it had been more of an issue in terms of more of a discussion even about like okay, you're Rh negative so if your children are positive, the risks are these, this is what can happen and so we have to do these things so that these things don't happen, then I would've maybe dwelled on it more probably. Like knowing me, and researched it and looked up on the Internet, read about people's experience. Like done all those things, but because it wasn't something that was brought up, I wouldn't even have seen it as a big risk. It's just like, it's just common, it's you know, it's routine. (RhDW 06)

These contradictory statements exemplify the difference in information needs women have regarding their pregnancies and Rh status.

Figure 5 provides an algorithm of information needs and seeking based on participant experiences. It must be noted that some women could be considered experts in their knowledge and, therefore, less information was needed and had different experiences regarding information.

Figure 6. RhD negative women's sources of information



Patients as experts

Patients as experts came up in two different circumstances. The first circumstance involved women with healthcare training: working in healthcare as a provider and/or had some health education background. Women that have health education and/or currently work in healthcare were able to discuss, with more depth, RhD status and pregnancy. The other patients as expert circumstance are the women, despite their background and work experience, that have had more than one pregnancy.

Here are two examples of women (RhDW 01 and 10) that have health education backgrounds and currently work in healthcare. They both have prior knowledge about the significance of Rh status in pregnancy. In fact, one states that she is more of an expert than the providers that she saw during her pregnancy.

> I know more than care providers about the ins and outs of the implications (laughs). (RhDW 01)

> Um, well I mean I had my daughter when I was in nursing school so this was all very fresh and exciting for me so as soon as I found out I was pregnant I already knew my blood type and thought well we have to be checked because there's treatment for this if you end up being positive and the baby is positive and ya, and I know that they test once baby is born anyways but I thought knowledge is power and it would be good to know. (RhDW 10)

RhDW 10 later described a potential patient safety incident regarding a miscarriage and receiving RhIG. Without her healthcare knowledge, she may not have been able to advocate for herself during this medical event. More will be discussed about this under *Patient Advocacy*, but it is important to bring it up here because her knowledge eventually led to RhD alloimmunization prevention.

> Um, the second pregnancy resulted in a miscarriage and I was about 16 weeks and they had to, you know, you have to go through ultrasounds and everything else and unfortunately there was a failure to communicate between my family doctor in [community A] and the OB/G in [community B] so I went two weeks before I had received a Rhogam injection and it was only because I demanded it, because there was an actual delivery following the miscarriage. And I said you know, this could have been a positive blood type, maybe not, and you're setting me up for further risk to continue to miscarry future children because of their blood type and I was quite concerned actually following that, that I would continue to have miscarriages as a result because it was so far gone. (RhDW 10)

This is a powerful quote because the concern in her voice was evident in the interview, and is evident in the words she uses, "failure to communicate", "demanded", "further risk" and "so far gone". She was fearful and frustrated that her reproductive opportunities were potentially jeopardized.

Women that have had more than one pregnancy often stated that they felt more informed in their subsequent pregnancies than their first. They knew what to expect in their subsequent pregnancies that led to less questions and, sometimes, satisfied with the level of information provided.

> So, I think, not that I had to remind him that like the 28 weeks was coming around, but he, like when I was like a week before 28 weeks, I'm like oh ya, and I also need to get that shot and he was like oh ya. Ya, it's not that he didn't remember, I think he just wasn't paying attention that we were already at 27 weeks. So, this time I was more forthcoming about okay let's get this done, I'm totally ready to do this. (RhDW 05)

> And I think I felt maybe like I knew a bit more about what was going on this time and could be a little more pushy about what I wanted to happen. (RhDW 13)

One participant (RhDW 03) said she felt she knew a bit about being RhD negative and pregnancies but did not fully understand the entirety of the issue until her third pregnancy. She stated that she thought the consent form for obtaining RhIG had changed by her third pregnancy. She recalls the earlier consent form not explaining that RhIG was a blood product and that the newer form did explicitly state this and it was "an eye-opener". Although this is contradictory in nature to the sub-theme of expertise, it is an instance of a patient feeling confident in their understanding and the way that information is provided can change that confidence. Perhaps knowing this earlier on would have influenced her decision-making and the way she communicated with her provider(s).

Trust

There were instances during the interviews when women expressed that they trusted their healthcare providers. They trusted the healthcare system and that healthcare providers would make good decisions in care of their pregnancies. They said statements like:

> I think for the most part it's just believe in the healthcare system, I guess, like I know your general practitioners and midwives aren't going to recommend something unless you know it's absolutely necessary, right. (RhDW 05)

> Like I just trust that that's, that they know what they're doing and that's what I need and okay like I just get it. (RhDW 09)

> Um, I just kind of felt it was, I mean I felt that my midwife was on top of it. I trusted my midwife. I felt that it was a pretty standard thing. Like it wasn't oh look at this, you're one in a million people, right, so and ya, I never felt that it was life threatening

> or anything like that. With anything medical there's always some sort of worry that something can happen but I just kind of had trust in health providers and I felt informed so ya, I wasn't really concerned. (RhDW 11)

In each of these statements, the women expressed that they believed healthcare providers were providing adequate care. They used strong words like "believe" and trust" to describe their dependence on the system that cared for their pregnancies.

Choice

One woman expressed that healthcare providers' approach to caring for her pregnancy felt like a choice, or at least a perceived choice in receiving RhIG. RhDW 11 said that she had discussions with her provider, resulting in being part of the decision-making process.

> Um, I think just making sure people are informed and that people feel like they have a choice, like I said, I didn't ever really feel, I felt like I needed to have the shot but I always felt that I wasn't being told that I had to have the shot, you know, if that makes sense. And I feel like there's a bit of a difference there…Um, no, like I said my midwives were always very, I mean it's partially why I went with a midwife, (interruption). Choice, no, I always felt with my midwives that everything was kind of, that I was part of the decision, you know, like even if things had to be done, it was always a discussion with my midwife, you know, it was never like this has to happen so we're going to do it now. And that kind of goes with everything from my pregnancies. Ya. (RhDW 11)

Other participants (RhDW 02 and 05) portrayed their experiences differently regarding the decision-making process. They expressed that they felt there was no choice and they required the prophylaxis. Perhaps there is a misunderstanding about what RhIG is and why it is important. One woman, RhDW 05, said that she would have opted out if she could have, knowing that the baby would be unaffected. She seemed frustrated by the prevention program because it functioned under the assumption of worst-case scenario. She used the phrase "just for kicks" to emphasis that this program of prevention seems a bit unnecessary, particularly if some of the risk factors could be ruled out.

> Well, it's like I'm negative so we didn't really know for sure if my husband was positive or negative, right, it was like test him when I get pregnant. So, with that they just like well cause we don't know, we're not going to test him, we're just going to assume that your baby is going to be positive and we're going to give you the, I can't remember what it's called. Whatever that shot is, midway through your pregnancy just for kicks, really, is how I felt about it. (RhDW 05)

The Stakeholder Committee confirmed that women are always given RhIG if they are RhD negative, regardless if the father is known to be RhD positive. It provides reassurance that the prevention program is being delivered despite any uncertainty that may exist, including paternity. RhDW 02 did not know if there was a choice to receive RhIG but did understand that without it future pregnancies may have poor outcomes. She stated that more information and explanation about RhIG and the potential consequences of not having RhIG would be beneficial.

Out of sight, out of mind

Not all women had their RhD negative status at the forefront of their minds during pregnancy. For some women, there were other concerns that needed attention and left them not thinking about being RhD negative.

RhDW 02 had an underlying condition that needed attention during her pregnancy. In recalling the management of her Rh status, she mentioned that she did not really have any questions.

> Um, ya, but that could also be because I asked a lot more questions around the protein, like the protein S deficiency definitely. The pain in my rib cage which lead to the diagnosis of the fluid backup in my kidney, um, I was definitely asking a lot of questions about that. Whereas with the Rh negative part, I wasn't asking very many questions. So definitely I was more informed for the everything else. (RhDW 02)

As seen earlier, RhDW 07 was tired and emotional after having an emergency D&C for a miscarriage. This participant expressed that after her procedure she was "foggy" because she was dealing with the death of her baby and it was early in the morning. She also

expressed the added stress of putting on a "brave face" for her mother-in-law that was visiting from out of town. For her this meant that being RhD negative was not really her priority at that moment in time.

Some of the participants (RhDW 05, 09, 12) made a choice not to stress about their RhD negative status during pregnancy. RhDW 09 had 07 pregnancies and did not "stress" about being RhD negative because it really only involved a "shot". This was a conscious decision not to worry because "nothing was really different compared to anyone else who would've been pregnant. It's just a shot …". RhDW 12 also made a choice not to worry about being RhD negative. She stated that she was in an "oblivious bubble". This appeared to be a coping strategy because she went on to express that the less she knew could go wrong was best: "I feel like through my first pregnancy I was kind of in this oblivious bubble, the less things that I knew that could go wrong in some ways".

Patient advocacy

There were instances in the conversations that, in certain circumstances, women advocated for themselves after their first pregnancy. There were statements that described that they did not know what to expect in their first pregnancy. In subsequent pregnancies, women knew what to expect and, in some instances, could advocate for their own care when they felt it was required. RhDW 05, 07 and 10 described having to remind and/or question their providers as to whether they should receive RhIG.

> So, this one was I was bleeding and so it was then confirmed in my blood work and I passed quite a big clot so I knew it happened. So then when I went back to the doctor I said ooh, do I need a shot? And his response at the time was um, not really because it's early days, your pregnancy was very early. But I remember sort of saying oh, really? And I think then he changed his mind. I seemed quite concerned, so then he decided to err on the side of the caution and sent me off to get the Rhogam. So, then I did, I think I got it that day or the next day and got a shot… It was my family doctor, ya, so I kind of, I think I'd seen him three times that week with the bleedings.

> Because at first my cervix was closed so we were hoping, you know, I wasn't going to completely miscarry, so we, then I had a few days of taking my blood to see where my blood levels were. So, then it was confirmed that they were definitely coming down and then I had passed a blood clot that night, so I was pretty sure I had. So, then it was probably the next day when I went in. I sort of was like do I need to have the shot? Or I need the shot. So, I got the shot. (RhDW 07)

> I just always knew mine so I was kind of, I don't know, and this may be because of my experience with my doctor but I kind of feel I have to be on top of things with him. (RhDW 09)

RhDW 13's first miscarriage was incomplete. She was given misoprostol[7] to ensure the miscarriage was completed. She recalled not having a lot of follow-up. Two months later she had an ultrasound that showed she still had fetal tissue in her uterus. This ended in an emergency D & C and received RhIG afterwards. She went on to conceive again; unfortunately, this pregnancy resulted in another miscarriage. The second time she told me she knew what to expect and was more "proactive" in her care.

> It was a little more efficient the second time and wasn't as drawn out so I was as little more proactive about following up with myself so it was not as hard on as the first one. (RhDW 13)

The statement "proactive about following up with myself" demonstrates a sense of responsibility in her own health.

RhDW 10 has the added advantage of being a healthcare provider. After experiencing a miscarriage and having to demand that she receive RhIG she told me that she was concerned for women that do not have her knowledge and experience.

> And if I wasn't a healthcare professional, would I have known to ask for it? Right, and that was concerning to me and it was only because I know that I'm Rh negative and that was the treatment that you received after having a positive offspring that you would get this and you know, some other mom who's just a regular mom, you know, with brand new baby and a whole flood of emotion and everything else, and you get the placenta brain, is she going to know to even ask that? (RhDW 10)

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[7] Misoprostol is used to induce labour in early pregnancy. It is often combined with methotrexate or mifepristone. (American Society of Health System Pharmacists Inc., 2017)

Summary of findings from RhD negative women

RhD negative women were consistent in their desire for information regarding their RhD negative status in pregnancy, the process of getting RhIG and what RhIG is made of and why it works. Some women were satisfied with the information they received because they either did not want to know more or felt they received adequate amount of information from their providers.

All women included in the study had some post-secondary education and still did not believe they fully understood what the significance of RhD negative status means in pregnancy. This has implications for more patient education and health information development on this topic for women that require more information based on their information needs.

RhDW 01 and 10 self-identified during the interview that they have healthcare backgrounds and experience. They credited this knowledge and experience to being able to advocate for themselves when required. Some women, participants 05, 09 and 13, whose interviews discussed their first pregnancy were less able to advocate for themselves because they lack experience and knowledge. They did not know their blood types unless they have had to type themselves in their schooling and/or if their parents told them about their blood type. Regardless, women that did know their blood types did not always understand the significance of RhD negative status in pregnancy, such as participant 03 and 08.

For most of the women interviewed, the relationship they had with their healthcare providers during pregnancy was significant to the decision whether to receive RhIG. Some women trusted that their providers would only do what is best for them and their unborn children. Others felt informed and were able to make good decisions throughout their pregnancies.

Process

The program for preventing RhD alloimmunization in Northern BC

The prevention of RhD alloimmunization was discussed in each interview with both healthcare provider and RhD negative women participants. Therefore, the data from these two data sets have been merged to provide an examination of the process for the prevention of RhD alloimmunization in northern BC. During analysis, excerpts from the interviews with RhD negative women and healthcare providers were coded as process if there was discussion about the process for obtaining RhIG during pregnancy(ies). The excerpts were organized according to when they received RhIG, including sensitizing events. These processes were confirmed and/or questioned by the Stakeholder Committee.

The sub-questions asked by this study provided insight into the larger question of why RhD negative women continue to be at risk for RhD alloimmunization. The inclusion of a wide variety of participants in this study, healthcare providers, RhD negative women, decision-makers and frontline workers, provided a 360-degree review of process in place for the prevention of RhD alloimmunization. These processes have been mapped within the context of northern BC.

Process - routine antenatal

RhD negative women described the process for obtaining RhIG at 28 weeks. The common theme was that providers had to write a requisition for women to obtain RhIG. The place the women take the requisition is dependent on the geographic context. In Prince George, women take the requisition to the hospital laboratory where they have their Rh status checked and then are given the RhIG to take back to their provider to be administered. In other communities in northern BC, women take the requisitions to the local clinic or the

emergency department. For example, one participant (RhDW 05) described her experience with pregnancy in two communities in northern BC.

> Well, that was the one thing that definitely is a huge difference between Prince George and Terrace. In Prince George, the doctor gives you a prescription and you go to the hospital pharmacy lab area to get it but you have an appointment with your doctor within the hour of picking it up and you go to your doctor and your doctor injects it for you. In Terrace, the doctor gives you a prescription for it and then you're sent to the ER to go pick it up and they administer it. (RhDW 05)

RhDW 05 told me about her experience waiting for her RhIG in the Terrace emergency department. She stated that having to go to the emergency department could have been problematic for her had she taken her older children. This process has the potential to be a deterrent to women not understanding the significance of RhIG in sensitizing situations.

> Ya, and that's what happened to me cause I was like you're sending me to the ER just to get this shot and it was like, I went to the ER and went through all the back and forth of getting admitted to the ER and then it's like okay this is all you need, once it's all put together, we'll come get you. And then an hour goes by and I was like really, it's an hour, what's going on here? And someone finally comes, okay, we're almost done getting it ready and we'll get back to you. And hours and hours and hours ago by, I'm like seriously, did you forget about me? I'm pregnant and now I'm starving. It's taking this long to do it. Ya, so for the whole ordeal, cause once they finally do give you the shot, you have to wait around for like 15 minutes, like the whole ordeal took me five hours and I was so glad that my husband was home that day and he could watch our oldest. What would I have done with a two-year-old. (RhDW 05)

The Stakeholder Committee confirmed that this is the process in some rural areas due to the inability for some healthcare providers to follow-up with their RhD negative pregnant patients.

Well-established process

Five healthcare providers stated that the process for delivering RhIG in routine clinical situations, at 28 weeks and post-partum, is well established. HCP 02 and HCP 04 both discussed that everything was routine.

> No, I think it was kind of around before we starting thinking that way. Everybody's just kind of accepted it as ya, it's just part of the deal. (HCP 02)

> I mean the system is reasonably well set up for that, for routine stuff now, I find it's missed rarely. Um, it's between, routine pre-natal stuff is so, it's so well established so when you get a person who's Rh negative, you get their blood work after the first 10 weeks. You know at 28 weeks they need to get their anti-bodies and their Rhogam. And so the system flows really well. We just sign the req and go across to the lab. And then they come back, and then they get their Rhogam. So to be honest I've had, I can't remember if I had, I don't think I've had any misses since I've been practicing. (HCP 04)

Two providers, HCP 08 and 11, expressed that the documentation for 28 week RhIG simplifies the process. HCP 08 made comments that trivialize the process, "It's very pregnancy by numbers. Like painting by numbers except with babies" and "It's fairly idiot proof". The interpretation here is not that this provider was being flippant but expressing how well established the process is and that patients are not at risk for RhD alloimmunization.

> … so like when you get the bloodwork back, if they're Rh negative, sometimes they ask you to do another set of things to see if there's any other antibodies present and then you give them another form and you get that bloodwork done, or like if they've never had a baby before and have never had a transfusion then they'd say this is when you should give them the Rhogam and to talk to them about bleeding and that they should come in if they have bleeding and that sort of thing. It's fairly idiot proof (laughs). (HCP 08)

HCP 11 described how well established the process is because it is within the scope of nursing practice.

> So that's also algorithmic and that's the nurse in our hospital. So they have amongst their bazillion pages of paperwork, they document on all their charting, like there's spaces in their charting for she's O positive or O negative so they will have documented before the delivery. And then there's post-partum pre-printed orders for the mom. The doctor signs after the delivery and there's four or five things listed there and one of them is if mom is Rh negative, give Rhogam after delivery if baby is Rh positive. And so during the delivery, like if she's Rh negative, they'll put an extra syringe on the delivery cart and they'll remind you, you know, draw some blood from the cord and that blood gets sent down to the lab and then you sign the forms. You don't even think about finding the forms if she's Rh positive or not and then the nurses will look up the result and if baby is Rh positive, then they'll give Rhogam. That all happens, like as long as we sign those orders, it just sort of, it happens on the nursing side. (HCP 11)

Table 4. Prevention of RhD alloimmunization in northern BC founded in the interviews

Prevention Program	**Prince George**	**Rural**
1st trimester (first prenatal appointment)	Patient is sent for RhD status and antibody screening blood work.	Patient is sent for RhD status and antibody screening blood work.
28-week	Healthcare Provider gives patient a requisition for blood typing confirmation and to obtain RhIG. Patient takes requisition to the hospital lab. Patient has RhD status confirmed via a blood work. Patient receives RhIG blood work confirmed RhD negative status and not antibodies are detected. Patient takes RhIG back to the healthcare providers office for administration.	Healthcare Provider gives patient a requisition for blood typing confirmation and to obtain RhIG. Patient takes requisition to the emergency department or available clinic. Patient has RhD status confirmed via a blood work. Patient receives RhIG blood work confirmed RhD negative status and not antibodies are detected. The emergency department or clinic administers the RhIG.
Post-delivery	Infants cord blood is typed and if RhD positive the mother receives RhIG. **Home births:** Midwife takes mother and babies blood to the hospital lab for testing	Infants cord blood is typed and if RhD positive the mother receives RhIG. **Home births:** Midwife takes mother and babies blood to the hospital lab for testing. If it is after lab hours the midwife takes the blood to the Emergency department and puts it in the fridge with requisition for it to be tested the next day.
Potentially sensitizing event	**Antenatal bleeding:** Emergency physician (or GP) request RhIG **Surgical early terminations:**	**Antenatal bleeding:** Emergency physician (or GP) request RhIG. If this occurs after lab hours the patient is asked to come

	RhIG is administered in the operating room **Early medical terminations:** Healthcare Provider gives patient a requisition for blood typing confirmation and to obtain RhIG. Patient has RhD status confirmed via a blood work. Patient receives RhIG blood work confirmed RhD negative status and not antibodies are detected. Patient takes RhIG back to the healthcare providers office for administration.	back the next day or the lab staff is called in. **Early surgical terminations:** RhIG is administered in the operating room **Early medical terminations:** The process for obtaining and administering RhIG has been customized in rural areas to avoid discrimination and confusion.

At first glance the process, founded in the interviews and laid out in the above table, looks simple and straightforward. This was not always the case for some providers and RhD negative women that expressed the challenges and barriers they faced when attempting to access the required services for the prevention of RhD alloimmunization. Feedback from the Stakeholder Committee verified this table, and some were concerned about the aspects of the processes, particularly that these processes were not documented anywhere within the larger regional health authority (NH).

Process – sensitizing events

Eight of the 15 women who had sensitizing events (7 miscarriages, three with multiple miscarriages, two terminations, two D&Cs and one had bleeding or spotting) during their pregnancies discussed their experiences getting RhIG. These sensitizing events are not to be considered results of RhD alloimmunization; however, they are events that could lead

to RhD alloimmunization if not treated appropriately with RhIG. Communication is one factor that can influence the risk of developing RhD alloimmunization during sensitizing events. RhDW 01 and 08 stated that everything went well when they experienced a potential sensitizing event in early pregnancy.

> My first pregnancy I got the first dose a week or two earlier than normal because I had a bit of spotting, cause I had a low-lying placenta, so then anytime there's bleeding in a pregnancy, there can be risk that you're exposed to the baby's blood at that time so just to cover all our bases, I just got it a little bit early. But other than that, it was the same as any other pregnancy I would guess. (RhDW 01)

> No, I had a miscarriage pretty early, it was only about, oh goodness, I think I was only a month along, like four weeks and then I had the Rhogam shot after that happened too … Ya, it was different because I had to go to the ER, it was on the weekend when it happened, so I had to go to the Emergency room and I knew that I was O negative and everything but they had to confirm that, so they did bloodwork and I was there for quite some time and then they realized that I was O negative, so they knew, the nurses knew they needed to give me that shot before I left. (RhDW 08)

These two statements exemplify what happens when the process works well. Unfortunately, it does not always work well. The next few sections will look at the aspects of care that create opportunities for RhD alloimmunization to occur.

Process - barriers

Two healthcare providers, HCP 03 and 05, who provide medical and surgical terminations (both being potentially sensitizing events) for pregnant women expressed frustration over the process for these women in receiving RhIG. The following quote from my interview with HCP 03 demonstrates the frustration that RhD negative pregnant women face when attempting to obtain RhIG for early medical terminations.

> … so now I look after my own. I go to the lab, I get it myself, I sign for it and I give it, because it is too awkward. They [the Laboratory] just don't get it, right, kind of thing, around the early pregnancy option service. It's no problem when it's a D & C in the OR. I write standing orders, Rhogam if Rh negative. That's it. I don't see anything. I don't sign a consent. It's all looked after by the daycare process. But the outpatient medication termination that's a Rh negative girl, we have been unable

> locally to set up something … we've been unable to develop something that is patient centered for the medical terminations. (HCP 03)

In one rural community, pregnant women that are RhD negative and seeking terminations have been denied preventative care leaving these women at risk of developing RhD alloimmunization. HCP 05 has experienced barriers in providing RhD negative women RhIG in early medical termination situations in a rural area. In HCP 05's experience women are stigmatized and face discrimination when they are trying to obtain RhIG to prevent RhD alloimmunization as a result of a termination. The provider described women being turned away at the laboratory by the person providing the screening and giving the RhIG. These barriers are not process-based, but behavioural. HCP 05 worked directly with head of the laboratory at the hospital to ensure that this type of incident did not occur again. This will be discussed further in the section called *Adapting Process*.

> I think we looked it up with the lab because there was some delay in some women who had the medicated abortion and Rhogam was not given because the lab personnel refused it. (HCP 05)

An emergency physician in another rural area described the barriers faced when RhD negative pregnant women require RhIG after laboratory hours. HCP 04 described the struggle to make a decision to call the laboratory staff in after hours to prepare RhIG for a woman experiencing a potential sensitizing event or to ask the RhD negative pregnant woman to come back the following day. This is a tricky decision because calling the laboratory staff back in would be costly, yet leaving the woman to follow-up runs the risk of the woman not adhering.

> Cause we only have lab until 4:30 so if they come in at 7:00 at night, do you call the lab back in or do you ask them to come back the next day to find out what blood type they are? It's complex, so ya. (HCP 04)

Adapting processes

Healthcare providers working and living in northern BC made conscious efforts to reduce the risk of RhD alloimmunization by adapting processes within their healthcare systems. HCP 09 said that some women have difficulty getting blood work done during their pregnancies. In order to try to encourage patients to complete the blood work, the provider works with the office nurse to support women to obtain their blood work.

> Not in terms of Rh. No, except I mean just getting lab work done is a real challenge for these patients oftentimes, like there is also a lab at the clinic, the nurses at the clinic know how to do lab work so we're often doing it during their appointments. So, it would be probably a significant effort for many of them to go to the lab to get Rhogam done. I mean we would organize that if it needed doing. Again, it doesn't happen very often but like the prenatal nurse would just accompany them to the lab to get it done. (HCP 09)

One emergency physician described that emergency departments often see pregnant women that are unattached to a family physician because of the shortage of physicians in that community. The physician expressed that the emergency department tries to take care of RhIG when they see patients to try to mitigate the risk of RhD alloimmunization, particularly when the woman does not have a physician to follow-up with in the community. The physicians in emergency take this one step further by referring these women to physicians in the community that may be willing to take them on during their pregnancies.

> I mean I think most of them do okay, they don't fall through the cracks but there is a certain risk with each patient and I think because of that we try and treat them when we see them. I mean our community has tried to address the fact that women show up in our community, they don't have a GP, they're pregnant, they don't know what to do, so we do have a referral system for that. So, they move into the community, they find out they're pregnant, they come, they confirm the pregnancy test in Emergency and then we can refer them to somebody. So that's a good thing. You know I don't know if there's anybody who falls through the cracks there but I think that at least at the hospital we have a way of hopefully getting them connected with somebody. (HCP 10)

HCP 03 works as a physician in a rural area in northern BC. The HCP has seen changes to the administration of RhIG to RhD negative pregnant women since the beginning of practice. During our interview, HCP 03 talked about early medical terminations that are provided and the frustrations the provider, and the women, face regarding the administration of RhIG in these medical situations.

In a rural community, HCP 03 described the challenges and history of obtaining and administering RhIG to RhD negative pregnant women. HCP 03 stated that RhIG is requested for RhD negative women having D & Cs and surgical terminations and it is given to them prior to discharge. According to this provider there are a number of barriers RhD negative pregnant women experience when attempting to obtain RhIG, particularly in outpatient early medical terminations. In the participant's community, RhD negative pregnant women were historically sent to the chemotherapy department during set hours to receive RhIG. Then the process was taken over by Maternity. HCP 03 recalled having to write in the book that patients would be there to get RhIG and often they would be faced by a nurse that would turn them away for one reason or another. In HCP 03's terms, the other issue is that Maternity does not have the RhIG on the floor. In order to obtain RhIG, HCP 03 would have to request that a porter go and get it from the lab. HCP 03 expressed frustration with this mediated process for obtaining RhIG because often patients need care after porters' regular working hours. In order to overcome these perceived barriers, HCP 03 orders and obtains the RhIG for women getting early outpatient terminations to ensure they receive efficient and patient-centred care.

HCP 03's experience provides an example of the way providers can change or adapt processes to reduce the risk of RhD alloimmunization. HCP 03's actions in changing the process removed barriers to accessing the care that these women need in situations where

sensitivity, confidentiality and empathy are of the upmost importance, such as being flexible to meet these women after their work hours and making arrangements for RhIG outside of the regular porters' working hours. HCP 03 stated that women receiving early medical termination may get missed, resulting in not receiving RhIG, because HCP 03 and colleagues do not see many RhD negative pregnant women: "And so I just set it up, I mean it isn't that many girls and that's probably part of the problem, it's not a consistent enough flow …". HCP 03 also stated that the constant change in nursing staff impacted care because it creates inconsistency in the sharing of knowledge amongst staff.

HCP 05 worked with the head of the laboratory at the hospital to create a process that reduced the barriers women were facing when attempting to receive RhIG when going through a medical termination.

> They should've done what I ordered and they refused to do what I ordered and I thought is it discrimination against the women, right, and I was kind of upset and then she went and did the problem solving, talked to her staff and then she developed this extra code for me so that they would not be asked questions or discriminated against. It still happens, right, and behaviour and stuff… and she was the lead of the lab so I got lucky, right, and she was pretty open-minded and she said let's go about it this way and then there's no questions asked and they have to follow protocol. (HCP 05)

It is interesting that HCP 05 felt "lucky" to find someone in the lab that was "pretty open-minded" to try to find a process that would not identify the reason these women needed RhIG. This phrase and wording is significant because HCP 05 described a lot of the barriers that providers and pregnant women face with terminations. HCP 05 has dealt with a great deal of behavioural issues, in the operating room and from other healthcare providers, in the provision of medical and surgical terminations, and specifically in the prevention of RhD alloimmunization. The Stakeholder Committee was surprised by this story and wanted more answers that the data was not able to provide because it became outside the scope of this

project. Barriers such as these create an opportunity for increased risk of RhD alloimmunization.

Expertise and resources

Access to specialists and resources, such as technology, was discussed by some of the women. RhDW 12 was very aware of the barriers and challenges of living rurally. She explained that she had not really thought of the worst-case scenario and what that would mean in a rural location until she watched a friend go through a pregnancy with complications. Her friend had to be transferred to the referring city for care of pregnancy. She went on to describe what that would look like in her rural community:

> I mean [in X community] you have to wait for the air ambulance to get plus, you know, then now they try to send people to Prince George and then if things don't go well there, then they can do a Vancouver kind of thing and if it's not what your picture, you keep going right? (RhDW 12)

RhDW 12 did experience the challenges of rurality in regards to her and her husband's fertility. She stated, although her Family Physician was great, the physicians did not have a great deal of knowledge about fertility and pregnancy. In addition, the resources and expertise to obtain fertility assistance did not exist in her community and they had to travel to larger community centers and Vancouver to receive specialist care.

> Ya, you know, like I mean to be honest [X community] is a great place but if you have any problems, like for example, for our fertility stuff, any information that, like I have to get, I do use our clinic as a resource a lot more, just because, our GP is great but he doesn't know a lot about a fertility classes or even just like pregnancy, they don't spend time. Like even when I asked him should I take prenatal classes. He said well, women have been giving birth for years and they never always have prenatal lessons so he didn't really think that like to push that. It was my first pregnancy but I just kind of like went through it and everything was good so I didn't really worry and so looking back I think I was in an oblivious bubble (laughs). I do feel though that I was a little bit isolated in a sense that like I mean we didn't get a lot of help here so I spent a lot money traveling to Vancouver to get pregnant and even like when we first initially searched, we had to go into Terrace just to get a little of extra help. (RhDW 12)

Women described that anything beyond regular antenatal care required trips to referring centres to obtain more specialized care and/or to have certain screening tests or procedures done.

> Ya, it started more or less the same, I had an ultrasound probably at nine weeks just to confirm that I was pregnant and then another one at 20 weeks. It was still good. I had, we went to Prince Rupert to get a neural tube translucency something ultrasound just cause I'm so old. And that was fine. And that was for the testing for different genetic anomalies, I guess. (RhDW 13)

> I had a different physician delivering, ya, like my medical doctor here didn't deliver any of my babies. I had to go to Dawson Creek. I had to go to the hospital there. So I mean I had my prenatal care here but then I had to travel to Dawson Creek to have a baby. (RhDW14)

Patient Safety Incidents – risk of RhD alloimmunization

Patients identified that there were times during their pregnancies that, based on guideline sensitizing event definitions described in the first two chapters, patient safety incidents could have occurred. It is understood that none of the women interviewed had poor baby outcomes due to RhD negative status or the development of antibodies from the potential sensitizing incidents they discussed. Some of them did realize the significance of Rh status in pregnancy and the complexity of it all:

> I remember watching that video thinking how crazy that is and stuff. Because it is so treatable and preventable but at the same time it's not exactly easy either. (RhDW 11)

She is referring to a video of a man in Australia with the "golden arm" (Bresnahan, 2015). The man is considered to have a "golden arm" because he had D antibodies and donates his blood for the production of RhIG. In 2015, the man with the "golden arm" was featured in the news across the world.

> Well, I think you have to be aware. I knew my blood type before I got pregnant. My mom told me I was O negative and she's heard when you're O negative, you need these shots. So, I knew ahead of time before I even had my first prenatal appointment, I did the research and I knew exactly when I would need to get that Rhogam shot

> throughout all of it. And I find it's not, most people don't know their blood type, not everyone knows it, right. It's not really common knowledge unless for some reason you need to do it. So, I think it's something that could even sometimes get missed, right. (RhDW 08)

> Well, it was scary because I mean, not only had we, you know, we were really excited about that pregnancy and then it was gone, um, we got pregnant within the month and I was not in any mental space to be having a baby because I'm still grieving the loss of the last one, but then of course I was worried that if we do have a termination is that going to it, am I not going to be able to have anymore because of potential antibody development from the last one? (RhDW 10)

One woman did not remember receiving RhIG after a potentially sensitizing event:

> No, not after the miscarriages I didn't. Definitely not Rhogam. I had bloodwork, just like I said, to see if my body had built up those antibodies. (RhDW 09)

Participant 07 had to ask her provider if she required RhIG after an early trimester bleed. After some back and forth conversation the provider did give her the prophylaxis despite not believing it was necessary. Her reaction to this was the following: "Just how scary it could've been if they hadn't given me the shot" (RhDW 07). Participant 06 did not remember getting RhIG at any point during her pregnancy.

> Oh. I didn't know that. No, for sure, never got any shots, for sure. And ya, no, peeing, remember, the peeing, the weighing and like the ultrasound and doing the diabetes thing or whatever, but no, no shots. For sure. (RhDW 06)

The accounts of the participants' pregnancies demonstrate that the prevention of RhD alloimmunization is not standardized and routine, resulting in a risk of developing D antibodies and increased risks to future pregnancies.

The prevention approaches to RhD alloimmunization among healthcare providers in northern BC is inconsistent. The inconsistency is due to adaptive processes and uncertainty about these processes. For the most part, the prevention program is working, but there still remains instances that put RhD negative women at risk for RhD alloimmunization.

Cues

Healthcare providers (01, 4 and 11) spoke about the need for cues regarding the care of RhD negative pregnancies. In some instances, the providers (04, 10 and 13) stated that they lack cues to alert them to check for Rh status and/or to provide RhIG. In other instances, healthcare providers described how they developed cues to ensure that they did not miss opportunities to provide RhIG when required. In each situation, the providers talked about cues being helpful in the provision of providing care.

In Family Physician offices, the physicians that participated stated that they are responsible for writing the requisition for RhD negative pregnant women to get RhIG at 28 weeks. In one instance, HCP 11, the office had streamlined the process. HCP 11 described that the enhanced system simplifies the existing process and ensures that RhIG is not missed during pregnancy. In the quote below, HCP 11 describes the system they have in place:

> … the staff at our office, at the most part, fill out the prenatal form, the lab part when that comes in and so there's the top corner, there's a place for blood type and their Rh status and so the women that are Rh negative, that gets highlighted yellow and then which is sort of like an internal side and whereas there's usually no highlighting on that form at all and then they also highlight the place where it's put when they get their Rhogam. There's sort of a date box and they highlight that and then that usually reminds us that the next visit to mention it to the woman if she wasn't already aware that come later in her pregnancy she's going to need a shot. And then when around their 24-week visit, the staff again are as part of their duty, when they see a woman who has the yellow signifying the Rh negative and they're around the 24 week, then they will pull out the sheet that's for the repeat blood test and for the Rhogam requisition. (HCP 11)

The office staff are depended upon to highlight the need to do blood typing and to give RhIG when necessary. HCP 11 said that it "reminds me if I haven't clued in that I should be giving this to the woman and talking to her about it". This enhanced process creates cues for the provider to inform the patient of their blood type and to communicate to the patient that they

will require RhIG at 28 weeks. In addition, the cue reminds the provider to order RhIG at 28 weeks.

HCP 01 self-identified as still fairly new to prenatal care. To address gaps in knowledge, based on an identified learning style, the provider created personal cues. The provider took existing guidelines, such as the *Prevention of RhD alloimmunization* guidelines from SOGC, and turned them into checklists. These checklists became a tool that provided cues for caring for pregnant women. In the following quote, HCP 01 described how the provider turned the RhD alloimmunization guidelines into a point-of-need tool.

> I use the SOGC guidelines all the time. They are an easy printout, I have them laminated as a little booklet in my work bag cause for my pregnant people, most of them are very straight forward so I keep my checklist laminated, my blood laminated and the SOGC guidelines laminated cause I don't want to have to fish through my bag and have it ripped or have coffee on it and I can just tick, tick, tick and make sure that everything is done so you're not missing something and that way you can spend more time with the patient instead of dealing with the paperwork. (HCP 01)

The three emergency room physicians interviewed discussed the use, or lack of, cues. The physicians shared that there are no cues to prompt them to check a pregnant woman's Rh status or to provide RhIG (and the dosage) when they present to the emergency room with a potential sensitizing event. These providers rely on what they have been taught to guide them in caring for RhD negative pregnancies at risk for RhD alloimmunization.

> Well, because we know that first trimester bleeding in an Rh negative woman requires them to be immunized with the Rhogam. So, we know that that's standard of care from just our education and my understanding is I think it is SOGC that's the protocol. (HCP 10)

> Um, for physicians, it's easy, we just write down "Give Rhogam" as an order and then it generates the process. (HCP 13)

Rural HCP 04 is both a family physician that does obstetrics and an emergency physician. The provider said that there are no "triggers" for emergency physicians to look at the Rh status of these women. HCP 04 knows to do so because of the his/her obstetrics practice.

> So, it depends where they present. So, for people who presently acutely bleeding where it's heavier, they'll often go to Emerg and unless people have it in their head, oh I wonder what blood type they are, you don't have anything in front of you because often it's their first, they haven't had their prenatal bloodwork. And you don't have any cues to remind you to think about Rh status, at that point … because you're not necessarily seeing people who deliver prenatal care. And not that it's not taught, but it's not the thing you come to first. And there's no triggers, whereas on your prenatal form, your Rh status is right there. And there's a little pail thing that says Rhogam and Rh at 28 weeks. So there's lots of cues. (HCP 04)

As a result of the interview, HCP 10 asked a colleague to locate the SOGC guideline and to add relevant information to the departmental library.

> So in fact, I've asked one of my colleagues who's just graduated from the Emergency Care program to actually find the flow chart so we can actually put it in our information package. Cause right now we're just doing it because that's what we know is supposed to be done but there's nothing that says we have to. (HCP 10)

Guidelines

HCP 13 described that the use of guidelines for the provision of RhIG in sensitizing events is contentious. The tension lies in the interpretation of the SOGC guidelines regarding the amount of RhIG to give in early trimester bleeding. HCP 13 described that the laboratory would ignore the doses the emergency physicians write. The staff in the lab would ignore the dosage and provide what they believe, based on the lab guidelines, for the emergency nurses to give to the patient. HCP 13 alluded to arguments between the physicians and lab regarding dosage that has led to changes in the process. The physicians in the emergency room write the requisitions for RhIG and the lab decides on the dosage, despite that it might be more than is required based on SOGC guidelines.

> Um, for physicians, it's easy, we just write down "Give Rhogam" as an order and then it generates the process. So what we used to do is the physicians would order the dose but the lab would ignore that, they have basically their dosing criteria downstairs and they would override any dose order we gave and they give the dose they feel meets their chart which is fine, for sometimes it's probably a little more Rhogam than the patient actually needs, if you got back to the SOCG guidelines and then you compare them. So probably there are times our pathology department asks us to give

> slightly more Rhogam than SOGC would ask us to give in the early pregnancies. But it's not worth arguing over so as long as they're getting enough, whether they get a little bit more is inconsequential. So essentially for the physicians, the process is confirm that blood type, if you either have to find it or you have to order it and get a grouping screen done and then you just basically order Rhogam. The lab sends to the nurses, Blood Bank sends to the nurses the appropriate dose, the vial, and the nurses give it. (HCP 13)

When this information was presented to the Stakeholder Committee it generated an animated discussion between those that worked in the lab and the ER. There was tension between what the physicians would ask for and the laboratory staffs' perceived responsibility in ensuring the dosage amounts requested were correct. It was identified that perhaps the guidelines being used are different. This conversation demonstrated the conflict discussed in HCP 13's interview. The outcome of the conversation at the stakeholder meeting was to table a future project to look at current best practices regarding dosage and process for RhIG in various clinically relevant situations, sensitizing events. With this endeavor, there needs to be a look at consistency and discrepancies amongst the guideline each department utilizes.

Healthcare providers sometimes have to work with guidelines that provide low levels of evidence, as discussed in Chapter Two, such as the SOGC guidelines for the prevention of RhD alloimmunization (Fung Kee Fung et al., 2003). CPG recommendations are based on evidence that is often graded (Andrews et al., 2013). The grading system used by CPG developers provides readers with transparency in the criteria used to critically appraise the evidence that informs the recommendations. In instances where the evidence is deemed low it means that the recommendations are based on minimal evidence and/or the research that was used to make the recommendation is of lower quality. HCP 03 talked about the struggle to work with guidelines that have low levels of evidence and how they have to present that information to the patients in order to make a decision about care.

> But when you look at UpToDate, so when you look at MORE^{OB} [defined on pages 32], they actually make the statement that the level of evidence on which the guidelines have been made is of the lowest order. But it's dogmatic, right. And you go to UpToDate, which summarizes the best studies, you take 1000 VBAC's and a 1000 of them get the balloon catheter, so 6-7 out of a thousand are going to have a rupture. You look at the oxytocin infusions, 10 our 1000 are going to have a rupture. And you look at the progestogen gels and it's 13-14 out of 1000, right. So none of that is statistically significant. But it's heresy if you, so sometimes there's discussion around and you know at the end of the day it's the physician that assumes the risk ultimately and the nurses, you can document the discussion and you have the discussion around what is the evidence? The evidence is poor and this is what we want to do here, kind of thing. (HCP 03)

Two providers describe their struggles in applying guidelines to individual patients in these excerpts.

> I don't know, there's two schools of thought on that one. That was a hard one, because it's a miserable test [referring to gestational diabetes screening]. People don't want to get their test done and you've got two obstetrician groups who say it's relevant and no it's not. And some people are super strict and some people are totally relaxed. So, it's really challenging to try and counsel people on that one. (HCP 04)

HCP 06 finds the Diabetes guidelines problematic because they are not realistic in most instances.

> Partly because you know one of the guidelines is we should check the Hemoglobin A1C, for example, every three months. Well, okay, so we do that for a lot of people and of course we have a lot of diabetic patients. I'm not really sure what difference that makes …You know, so someone will have a Hemoglobin A1C of 5 or 6. Great. And then someone comes in with one that's 10 and you're like that's pretty high. And three months later it's still 10 (laughs). You know, so I don't know how much difference we're really making. Doing so many frequent tests, like people kind of know, I would think, right. No one's really shocked by the fact that their Hemoglobin A1C is super high or super low. They kind of know, without doing the test probably. And for the most part, someone who is 10 is eating not well for a diabetic. And you can tell them that, but they already know that. And whether or not, they're actually going to change and then the other thing is, does changing really change an outcome? (HCP 06)

As was found in the adaptation of guidelines, they are often the most helpful when they have been interpreted and turned into a process:

> Ya, those are for Canada and then the maternity care pathway for the Perinatal Services of BC and that's the guideline I use that's so easy. And it says, it breaks it

> down by weeks, what's important to do in those timelines cause there's some things that are really time sensitive including the Rhogam. And then we look, I wonder if I can find it, there, blood groups and rhesus recommended for every pregnancy within the first trimester and again at 28 weeks in Rh negative women with only previous typing screen done by Canadian Blood Services. So they detect it, they do, oh this is the guidelines from SOGC that they're pulling from which is great, but it's old, it's 2003. (HCP 01)

HCP 01 makes an interesting observation about the SOGC prevention guidelines. These guidelines are roughly 14 years old. In this statement, the provider acknowledged the struggle with the use of guidelines in clinical practice.

HCP 13 told me that using guidelines is not that easy. HCP 13 said that one of the first issues with using guidelines is that you have to know that they exist and "there's no easy way to know if there's a guideline for the particular question you're asking". The provider then said the second issue is that there may be multiple guidelines on the same topic and they are often lengthy documents. This makes it difficult to do in emergency situations, "you just don't have time in Emerg in the middle of a shift to read through a large document trying to find the answer to one question. So they're unwieldy for point of care use". Further to this, HCP 13 stated that the guidelines are often out of date, or at least it is unclear if some are out of date. These are just the external guidelines. HCP 13 then described to me the complexity of using internal, NH, guidelines. NH only recently began to continuously review internal guidelines. They now provide an expiry date and state the review cycle. In addition, described how difficult it is to find internal guidelines because they are not indexed.

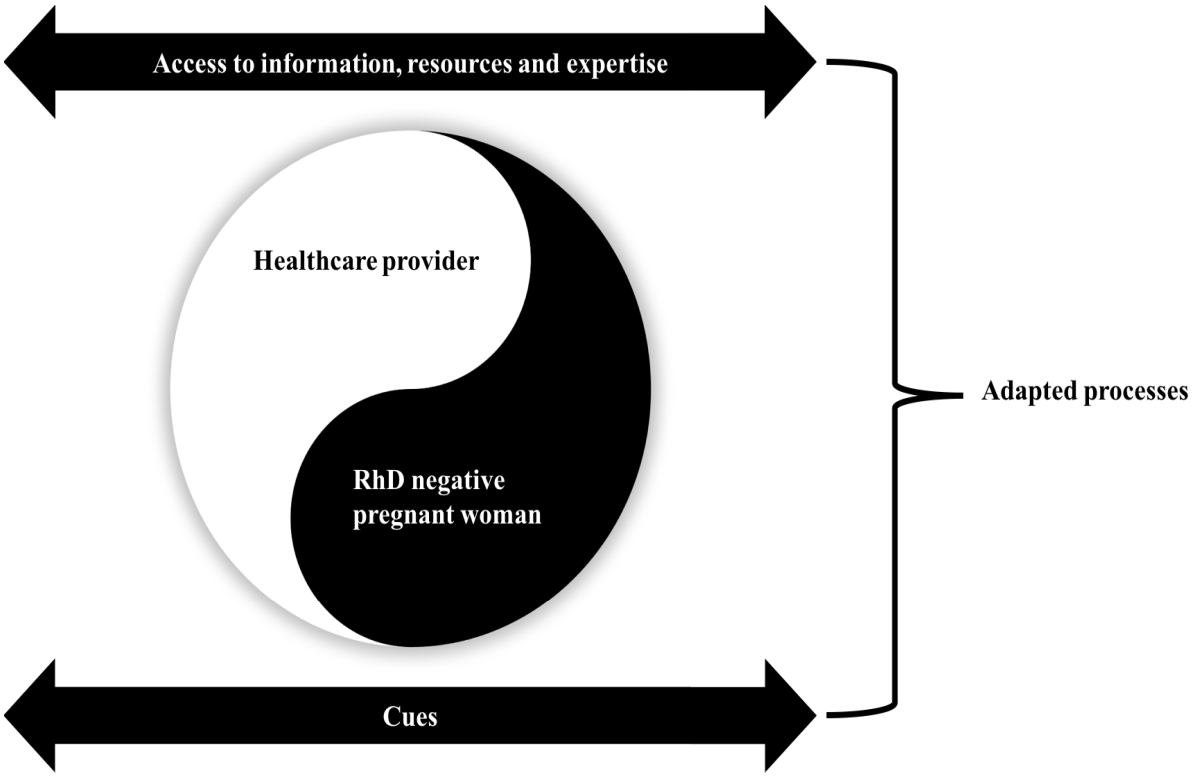
> So, they're on our NH server but they're not classified or sorted in any way that's particularly useful you're with the group that the guideline was generated by. So, let's say Pediatrics generates a guideline for something. So generally, because they're part of the process, they know two things, one they know the guideline exists, and two, they know where to find it. But if you're outside of that group, let's say you're a primary care provider, you would have no idea that the guideline exists and you wouldn't know where on the server, necessarily on the server to find it and because there's no mandatory kind of key wording, it's very difficult to find the right key

> word to find a guideline, even if you know it's there. It can be difficult to find, ya. (HCP 13)

The use of guidelines was discussed with all HCPs. They all expressed utilizing guidelines is a cautionary tale. They are helpful to overcome uncertainty but do not always fit individual situations, nor do they always work well in the context for which they are needed, such a rural healthcare.

The factors that impact the decision-making process in the prevention of RhD alloimmunization (access to information, resources and expertise) go forward and backward again the shared decision-making process. Healthcare providers have had to rely on cues and/or make cues to trigger the prevention process into action, to ensure patient safety. Processes are adapted by healthcare providers when all else fails. They make revisions to processes in order to ensure RhD negative pregnant woman receive RhIG on time in both routine and sensitizing clinical situations. The diagram of decision-making for low occurrence events evolves to include a top bi-directional arrow that illustrates the constraints put on the provider-patient relationship when access to information, resources and expertise is not readily available. Another bi-directional arrow is added to demonstrate that cues are developed and implemented, both at a systems and individual level, to ensure that the prevention program is adhered to despite challenges to decision-making both at the individual and systems level. Finally, the bracket that points to adapted processes exists because providers have had to adapt existing processes within a system that does not allow for shared decision-making and/or creates too many challenges to a successful prevention program.

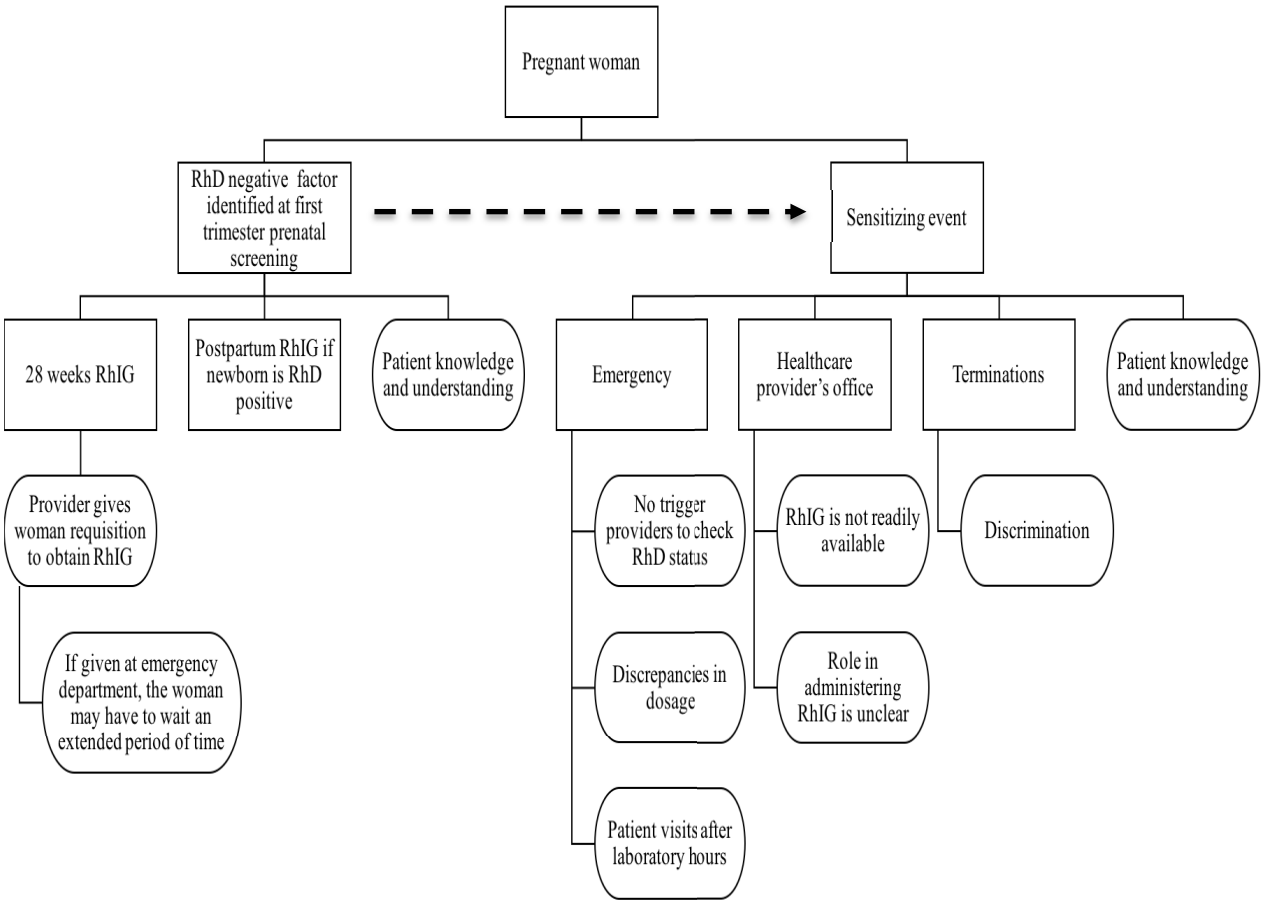
Figure 7. Factors influencing decision-making



Documenting the process for the prevention of RhD alloimmunization in northern BC has its challenges. Based on the interviews and Stakeholder Committee feedback, the instances for error happens more in times of crisis than it does during routine situations. As discussed in this Chapter, there are roadblocks in the way for the prevention program to be successful. Some of these roadblocks are at the systems level, while others are individual characteristics. The roadblocks appear in both routine and crisis situations, and are increased when there is a sensitizing event (crisis). The following figure demonstrates the instances where the prevention program is road blocked within northern BC. The rectangular boxes are the prevention program and the rounded boxes are the potential road blocked. There is a

dotted link leading from the RhD factor screening box to the sensitizing event box because sometimes the women have been identified as RhD negative prior to a sensitizing event.

Figure 8. Breakdown in RhD alloimmunization prevention program



Summary of findings

There are a multitude of factors that influence the decision-making that occur when patients and healthcare providers experience a low occurrence clinical event. When an RhD negative pregnant woman experiences a sensitizing event, there are individual factors

involved in decision-making that are set in motion. A woman's existing knowledge and understanding of being RhD negative and pregnant determines what information is needed and when, information needs and behaviours. This motion is often in conflict with the direction of the decision-making process by the healthcare provider. The healthcare provider's decision-making process regarding RhD negative pregnancies is dependent on existing knowledge and understanding, and experience with, RhD negative pregnancies and sensitizing events. If uncertain, the healthcare provider seeks information. The information sought by providers is sometimes fraught with confusion due to conflicting information found and the larger system(s) at play. This then interferes with what is communicated to the RhD negative woman about process and the issues of being RhD negative and pregnant.

Access to resources, information and expertise is depicted as going against the decision-making flow of both HCPs and patients (Figure 7). The decisions that are made at the individual and provider level are met with challenges at the systems level. If a provider attempts to order RhIG for a RhD negative pregnant woman that is experiencing a miscarriage, and does not have access to RhIG in that moment, it provides an opportunity for the patient to miss receiving RhIG. If the provider is faced with a sensitizing event that they are uncertain about and attempts to find information to overcome the uncertainty they may be faced with a lack of, incorrect or incomplete information, such as an outdated CPG, stalling the process. If the healthcare provider and patient agree to receiving RhIG but it is not available, the patient will need to follow-up when the prophylaxis arrives or is required to go and get it herself.

RhD negative women in rural areas described many differences in process for receiving RhIG than did women from the larger centre of Prince George. Women had to take requisitions to clinics and emergency departments, often waiting hours to receive RhIG.

Women that experienced sensitizing events did not receive a great deal of information, or at least not at the right time for them to retain, for getting RhIG.

Cues are something that healthcare providers are given or develop as reminders for themselves. These cues activate systems and assist individual levels of decision-making by overcoming barriers to availability of information and expertise. Although cues do not necessarily overcome a lack of resources they can provide a direction to accessing what is needed.

In some instances, healthcare providers adapt processes to ensure that their patients have access to the best care, particularly in smaller rural communities. These providers have adapted processes to ensure that their RhD negative pregnant women are able to receive RhIG when needed and to ensure comfort and ease in obtaining RhIG in sensitive situations, such as medical terminations. These adaptations are often done in silo. The adaptations are site and circumstance specific, and not often shared with the regional health authority.

The next chapter will provide a comprehensive discussion of these findings within the context of existing literature. The strengths and weaknesses of the research study will be examined and recommendations for practice, policy, research and education will be made. Completed knowledge dissemination strategies and developing KT products will be described.

Chapter Five: Discussion

This chapter will present the findings by interpreting what was learned from the participants in this study and incorporating new evidence within the literature. The discussion will include reasons why RhD negative pregnant women continue to be at risk and provide some of the practicalities of the RhD alloimmunization prevention program within the context of rural healthcare delivery in northern BC.

Interpretive description challenges the researcher to look at the data and interpret it within the literature that generates the rationale for the research study (Thorne, 2008). Thorne (2008) pushes the researcher to further interpret the data by telling a story of what is new and unfounded within the existing literature and then to identify where and how the new findings fit into the larger body of evidence. In order to do this, it was important to continually reflect on the overarching research question: Why do RhD negative women continue to be at risk for developing D antibodies in pregnancy?

In exploring risk, this study examined healthcare provider decision-making regarding the care of RhD negative pregnancies and the experiences of RhD negative women with pregnancy in northern BC. A Stakeholder Committee provided guidance across the research process to provide clinical and health services insights and to support the analysis and credibility of the findings.

This is the first study to explore the experiences of care for RhD negative pregnancies that has involved women as participants. Since the inception of RhIG, RhD negative women have not been asked about their experiences with care. This is the first study to qualitatively explore healthcare providers decision-making regarding the care for RhD negative pregnancies, particularly in rural and northern communities. This is important to distinguish within the larger body of evidence that addresses RhD negative pregnancies focusing on the

frequency of RhD alloimmunization and the efficacy of RhIG. In this section, the decision-making processes healthcare providers engage in when caring for low occurrences, such as RhD negative pregnancies, will be discussed. A level of interpretation that is set against the literature was introduced at the beginning of this dissertation and will now share further interpretation within new literature.

The themes that will be discussed in this Chapter emerged from the data and are further contextualized within the existing body of literature. The prevention program strengths and weakness that were identified in the findings will be discussed. The influence of the provider-patient relationship will be presented against the backdrop of the prevention program as it relates to decision-making. The controversial topic of competency will be explored by looking at the healthcare provider findings and the existing conversations in the literature.

The Chapter will conclude with a description the implications of this research in practice, policy, and research. Thorne (2008) argues that it is not enough to suggest similar studies be conducted to validate what was found in this study. Instead, interpretive description moves beyond this into practical and applied recommendations. A commentary on proposed steps or actions to move this new evidence forward into practice, policy, and research, is imperative to ensuring the applicability of the findings. This insight stems from the interpretations of the meetings held with the Stakeholder Committee and how this study fits meaningfully into the broader research community.

Prevention of RhD Alloimmunization

The findings indicate that it is not that healthcare providers do not always remember that RhD Alloimmunization is important to prevent, it is that they struggle with knowing how

to apply the prevention program. This struggle leads to frustration and adaptive processes that create many work arounds at the systems level. Sometimes this leads to leaving RhD negative women at risk of developing anti-D antibodies. Before the perceived problematic aspects of the prevention program is presented, a presentation of the perceived strengths of the prevention program within northern BC is critical.

Strengths in routine prevention

There are strengths in healthcare provider practice in the routine provision of RhIG within northern BC. Although healthcare providers may not always know the exact process for obtaining RhIG at 28 weeks, each RhD negative woman or healthcare provider, could describe something, even if it was not much, about routine RhIG at 28 weeks (or there about) and after delivery. Despite issues with the delivery of the routine RhIG, it was carried out in most instances. This is reflective in the existing literature found in the scoping review published in 2014 (Fyfe et al., 2014). For example, the three studies included in the updated scoping review (Chapter Two) examined the use of RhIG and concluded that in the majority of instances, RhIG is provided (Badami et al., 2014; Hassan et al., 2015; McCauley et al., 2017).

One of the limitations of the study presented in this dissertation, is that it did not interview RhD negative women that had become RhD alloimmunized. This may have occurred because of a limitation within the recruitment strategy. The recruitment material did not specifically state RhD negative women with D antibodies were eligible to participate (Appendix G and H). It was not the intent to exclude them but perhaps it was not clear. In addition, as seen in the introductory chapter, RhD alloimmunization is not common and there are no descriptive statistics to know how many RhD negative women have developed D-

antibodies in northern BC. This lack of information made predicting the population sample size and recruitment strategies challenging.

Areas for improvement

Healthcare providers are aware that RhD negative women require special attention during pregnancy. For some, the prevention program is straightforward and, for others, it is confusing and unclear. Each of these is problematic because one insinuates healthcare provider complacency and the other is an issue with the existing system.

Systems issues in the prevention of RhD alloimmunization

There is still no account for the prevalence of RhD alloimmunization and HDFN within northern BC. The existing data from Canadian Blood Services (2014) does not provide us with descriptive statistics that would provide a better picture of what this looks like across the province and the country. Healthcare providers in rural areas in northern BC struggle with providing consistent care for RhD negative pregnant women. The challenges are within the process for obtaining RhIG. In most instances, the provision of RhIG at 28 weeks and after deliver is not an issue. It remains, as the original scoping review found (Fyfe et al., 2014), that near misses occur around sensitizing events because the systems fail healthcare providers and, consequently, RhD negative women.

When faced with a low occurrence, the system is not always prepared. In rural areas, RhIG is not always readily available or access may not be well defined or understood. This creates a process that has a cascading effect in attempts to try to find the means to manage low occurrence clinical situation. For example, in this study of healthcare providers and RhD negative women, the healthcare providers explained that they had developed processes to protect patient privacy, such as the rural provider developing processes to obtain RhIG for

medical terminations. In other instances, healthcare providers have had to develop processes in the moment, such as the provider that told the Stakeholder Committee about a patient she struggled to get RhIG for during the patient's miscarriage. It is concerning that these processes have not been evaluated and resolved, considering the RhD alloimmunization prevention program has been around since 1968 (Bowman, 2003) and national guidelines since 2003 (Fung Kee Fung et al., 2003).

Looking back at Reason's (1990) work, systems errors that continue to be unidentified, evaluated and unresolved create a chasm for failure and harm. These latent errors in process are compounded over time. Continuing to patch the process with adaptive measures never gets at the underlying issues. Not surprisingly, the Stakeholder Committee members were unaware of the adaptive measures found in the interview data. This meant that these adaptive processes had not been communicated and/or documented in a way that is transferable and transparent to others. This finding resonates with Greenhalgh et al's (2004) early work on the diffusion of innovation. In this seminal work, the authors systematically synthesized research addressing the dissemination and uptake of innovation in healthcare. The synthesis found many individual and organizational factors that influence the success of an innovation across an organization. One of the factors described in the synthesis was that the size of an organization and its availability of resources and functional differences, decentralized decision-making occurs. An example of this is screening women with gestational diabetes after birth for diabetes mellitus (Clark, Graham, Karovitch, & Keely, 2009). The Canadian CPGs recommends that women with gestational diabetes are screened for diabetes mellitus 6 weeks to 6 months after birth, yet studies have shown that adherence to screening is low.

In other organizational behavioural research, the decoupling of policy and practice can explain the reason the Stakeholder Committee was not always aware of local adaptions in other regions of the health authority (Austen & Kapias, 2016). The concept, as described by the Austen and Kapias, is complex but can involve the individual within an organization making decisions to adopt a process that may or may not fit within the larger organization's goals and/or policy. This decision is based on many facets, such as personal values and/or accessibility of resources to ensure the policy is put into practice. The adaption of medical termination processes in rural areas described by participants in this study is a salient example. The adaptations described by the participants of this study need to be identified and discussed regionally within NH. Discussing the adaptations regionally could potentially resolve other local and regional systems issues.

Competency versus complacency

The term competency has been used to declare healthcare providers unfit to carry out certain skills and procedures (Ireland et al., 2007; Slater & Bloch-Hansen, 2014; Society of Obstetricians and Gynaecologists of Canada, 2002). As discussed in the literature in Chapter Two, rural areas have seen a decreased model of maternal care services (Hearns et al., 2010; Johnston et al., 2014; Society of Obstetricians and Gynaecologists of Canada, 2002). The current research demonstrates that rural areas have higher incidence of poor maternal and neonatal outcomes (Lisonkova et al., 2016), yet, there continues to be a decrease in the number of providers that offer perinatal care in rural areas. This study has been critiqued by experts in rural maternal services research stating that it did not take into account travel distance to referral centres, an important risk factor in maternal care (Grzybowski &

Kornelsen, 2016). This contradictory phenomenon neither benefits rural provider competence, nor does it increase well baby outcomes in rural areas.

Competency was defined broadly in Chapter Two to include skills, knowledge and individual characteristics that a healthcare provider possesses regarding performance (Canadian Nurses Association, 2010; Royal College of Physicians and Surgeons of Canada, 2014). It was acknowledged that context, such as access to resources, information and expertise, are factors that can restrict competence. There were instances in the findings that demonstrate that a lack of access to resources, information and expertise did not impact competency of the healthcare provider, but perhaps suggested complacency. Competency issues are the result of a deficient system in rural and remote northern BC, a system that lacks access to sufficient resources and services to provide consistent care to RhD negative pregnant women.

The term complacency has a negative connotation. The Oxford English Dictionary defines complacency as "the fact or state of being pleased with a thing or person; tranquil pleasure or satisfaction in something or someone" (Oxford English Dictionary, 2017). According to the Merriam-Webster Dictionary, the word complacency means

1. Self-satisfaction especially when accompanied by unawareness of actual dangers or deficiencies. When it comes to safety, complacency can be dangerous.
2. An instance of usually unaware or uninformed self-satisfaction. (Meriam-Webster, 2017)

A lack of awareness due to a sense of self-satisfaction is relatable to the management of low occurrences in healthcare.

In 2015, Ruscio, Ciceri and Biassoni published a paper on automotive collision warning signals and brake response time in drivers. This study's findings are intriguing and applicable to issues of complacency in the provision of healthcare. The automotive industry

has developed advanced technology that implements vehicles with collision warning systems. Vehicles are becoming increasingly equipped with this technology as a means of ensuring driver and passenger safety by alerting drivers to obstacles. The Ruscio et al. (2015) study found that when drivers are faced with an unanticipated obstacle, in a controlled environment, participant reaction times were reliant on collision warning signals. When the warning signals were made to give false notifications, or did not work at all, the participants failed to react and avoid unexpected collisions.

This resonates with what was heard from providers in northern BC. Providers described not having triggers or cues to alert them to an unexpected clinical event that occurs infrequently, such as a sensitizing event in RhD negative pregnancies. Some providers created their own trigger systems that delivers an alert to ensure they do not miss the routine 28 week RhIG and/or generated a cheat sheet to refer to when faced with a sensitizing event. These strategies gave those providers a sense of confidence that they would not miss part of the prevention program, just like a collision warning system in the event of an unanticipated collision.

Surprisingly, when speaking with providers it was revealed that some were complacent about the provision of care for RhD negative pregnancies. The sense of confidence heard from some providers suggested that they were relying on the systems in place to ensure that women were receiving consistent and optimal care. In interpretation of this phenomenon, these providers had not experienced a systems glitch or a poor infant/fetal outcome due to RhD alloimmunization. This has been discussed in the heuristics literature (Besco, 2004; Li et al., 2009) but not in regards to low occurrence clinical events. This resulted in almost ambivalent attitudes towards the threat of the development of anti-D antibodies. Perhaps, if providers experience the negative outcomes of complacency, such as a

glitch in the trigger system, or faced with a sensitizing event, just as the drivers did in the collision warning systems study, then complacency would diminish.

Guidelines and systems

The interviews involved thought provoking conversations with healthcare providers about the use of guidelines in practice. Based on the results of the 2014 (Fyfe et al.) scoping review, it was hypothesized that there was trouble in interpreting the guidelines, but that is not the case. Providers, in most instances, acknowledged the RhD alloimmunization guidelines and were familiar with the recommendations. The use of these guidelines was contentious in three ways: the dosage of RhIG in sensitizing events, the adaptation of guidelines in the delivery of the program in rural areas and the lack of knowledge regarding low occurrence events.

The adaptation of the guidelines in the delivery of the program in rural areas was identified early on in the interviews. RhD negative women described the process of obtaining RhIG through emergency departments and clinics, instead of hospital laboratories and healthcare providers. These adaptations to process were tied to limited resources in communities, such as not having access to laboratories. In some instances, rural communities do not stock RhIG because there is rarely an encounter with a RhD negative pregnancy. If RhIG is to be stocked, it would likely expire before it could be used. This is an example of a deficiency in the healthcare system leading to a competency issue in the rural maternal health.

The dosage ordered for RhIG for a RhD negative woman with a sensitizing event was controversial. It was identified as controversial because the interview data brought back to the Stakeholder Committee initiated a heated discussion. The committee was told that there

were discrepancies between what physicians ordered and what the lab sent up to be administered to the patient(s). It was apparent that different guidelines with different dosages were being used.

CPG use is challenged by isolation, lack of continuing education opportunities, lack of resources, and unrealistic patient recommendations in rural contexts. Instead, this research project comments on the adaptation of guidelines for low occurrence events, something not specifically discussed in existing literature. Adaptation of guidelines for low occurrence events require triggers or cues to alert healthcare providers to situations where guidelines should be enacted, remembering that in some cases becoming too reliant on triggers/cues can lead to complacency.

Knowledge of low occurrence events

One of the healthcare providers talked about the community of practice around RhD negative pregnancies and the prevention of RhD alloimmunization has gone because of healthcare provider retirements. The providers that practiced during the implementation of the prevention program in the 1970s had likely retired by 2016, when data collection occurred. The provider commented that retired healthcare providers took with them first-hand knowledge of RhIG implementation. The providers remembered learning about Rh status, RhD negative pregnancy and prevention of RhD alloimmunization but it was not something they had experienced and witnessed implementation into practice. In instances like this, it was interpreted that the providers are reliant on their learned knowledge, the ability to identify a knowledge gap, available information, and the ability to apply available information both cognitively and with available resources in respective contexts.

Healthcare providers relied on their knowledge from education and experience to care for RhD negative pregnancies. The level of recall varied amongst the providers interviewed. They described their limited understanding of the mechanisms of Rh status and pregnancy, the process of the prevention program and there was limited knowledge about RhIG and its use in the prevention of developing antibodies. This limited recall is consistent in the medical education literature. A 2011 cross-sectional study conducted in the Netherlands, explored basic science retention of medical students and practicing physicians (Custers & Ten Cate, 2011). This study found that retention of basic science knowledge was negatively impacted by the length of time out of medical school. Therefore, it is important that the healthcare system implement cues that trigger a healthcare provider's recall of knowledge and to ensure that clinical process are enacted to prevent patient safety incidents.

According to the participants, it was not often that rural providers cared for RhD negative pregnancies. When they came across a RhD negative pregnancy the providers struggled, in some cases, to have RhIG administered. The providers recalled an awareness of giving timely RhIG but the process for actual delivery of the RhIG was sometimes not readily available. The lack of clear and readily available protocols, and associated support such as clearly established protocol for ordering RhIG, for rural providers to rely on made a somewhat simple "paint by numbers" process complex. This lack of a clear process can lead to latent errors, identified in Reasons' Swiss Cheese Model (1990, 2000).

The Swiss Cheese Model is an analogy that evolved from Reason's early work on the dynamics of accident causation (Reason, 1990, 2000). In this model, Reason acknowledges many layers of protection that are put in place in complex systems, such as healthcare, to prevent accidents and/or harm. Like swiss cheese, these layers of protection can have holes within each layer (latent errors); individually, these will not necessarily lead to harm, but if

the holes within the layers align at any point in time, an error can occur. In this study, both RhD negative women and healthcare providers identified holes within the complex systems that can lead to RhD alloimmunization or foster increased risk.

Healthcare providers gave insight into the prevention of Rh alloimmunization when sensitizing events occur. They talked about the lack of cues to trigger the prevention process. This means that the providers are relying on their knowledge and experience. They are required to recall that information in order to initiate the prevention program. When providers face an unknown or uncertain clinical situation they rely on heuristics (Reason, 1990). Once this becomes their new experiential knowledge it remains easily accessible information (Reason, 1990).

Conversely, developing heuristics was a known area for potential risk in complex systems. This falls into the literature about trials and tribulations of relying on heuristics, particularly the notion that if a negative outcome has not occurred it is less likely to occur and heuristics that are built upon poor practice behaviours (Besco, 2004; Drach-Zahavy & Somech, 2011; Li et al., 2009; Reason, 1990). Consequently, it was an area that was questioned but never actually resolved. This means that providers are relying on practices that may or may not be safe for the patient. A subset of providers did create their own triggers for identifying RhD negative pregnancies and in the management of their care.

Healthcare provider and patient relationships

One of the main themes that emerged from the data was that of the relationship between healthcare provider and patient. The relationships described by both populations were impacted by communication, sharing of information, health literacy, information behaviour and the engaged process of decision-making. The relationship between a provider

and patient, in this situation RhD negative pregnant women, can impact the potential for risk, the way decisions are made and how they are experienced. Both populations described the model relationship is one that is shared and equal.

RhD negative women's experiences with healthcare providers told a story about the strain a poor relationship can have on the patient and, in contrast, how a relationship can also lead to empowerment. Some women stated that they did not want to ask their providers questions. In one interview, the participant explained that she did not want to bother the provider because he/she was busy. Another said that she did not want to challenge the provider's course of action. One simply said she did not know what questions to ask and because of this did not ask any questions. Each of these situations changes the power dynamic within a relationship. Roter and Hall (1997) provide a model of physician-patient dynamics that attempt to make sense of these situations. These relationship typologies can strain the relationship if one or neither of the parties involved are not satisfied. This is an issue of share decision-making and patient-centred care not working.

Communication of information was another theme that emerged from the interviews. RhD negative women often said that they were not given enough information about Rh factor, being RhD negative and pregnant, what RhIG is and what the process for receiving RhIG during and after pregnancy. RhD negative women wanted information but did not ask for it and/or were not sure what questions to ask. Conversely, providers said that women often did not understand the information they were conveying to the pregnant RhD negative patient. In some instances, the provider would then not be motivated to offer information if they believed the patient could not comprehend the information provided. These findings are characteristic of the difficulties in bringing both parties together to communicate in a means that satisfies everyone's needs (Roter & Hall, 1997).

Some of the RhD negative women participants expressed a knowledge gap and information seeking process when they shared that they would seek out information from family/friends and from online sources of information. This information seeking pattern is founded in an expanding literature on the use of online information during pregnancy (Munro et al., 2017; Prescott & Mackie, 2017). In some instances, RhD negative women could be categorized as active seekers and avoiders (monitors and blunters) (Miller et al., 1988). A few women stated that they wanted more information about being RhD negative and pregnant. Although not all were deemed stressful situations, those that did have sensitizing events were dissatisfied with the amount of information received. A few avoiders said that they were satisfied with the little information they received. There was even a smaller number of women that said they chose not to think about all the things that could go wrong in pregnancy, including that of RhD alloimmunization.

Some of the active seekers utilized the Internet as a means of finding information. Some of these women took it a step further and discussed critically appraising the information they found online. In hindsight, it would have been beneficial to probe the women about the sources they chose, but at the time the focus was on seeking and not necessarily on the use of information, future opportunity for research. These findings fit with the emerging literature on the use of the Internet as a source of information during pregnancy. A recent systematic review found that women use the Internet to find information to boost confidence and knowledge during pregnancy (Sayakhot & Carolan-Olah, 2016). The review found that although women are using the internet they are not always sharing that information and knowledge with their providers, particularly physicians. This study found that women are not asking questions, perhaps the information they find is enough or is it the provider-patient relationship that shapes this sharing of information. Interestingly, the

Sayakhot and Carolan-Olah (2016) study found that women early in their pregnancy sought information more frequently, concluding that perhaps women require more information earlier on than they actually receive. The review found that women with higher levels of education were more likely to utilize the internet and find the information they sought as authoritative. Wiley et al.'s (2015) study focusing on women's internet use in situations of public health crises relates to the findings of this study because all the women interviewed had post-secondary education, at various levels of completion, and most sought information online. It is important not to draw firm ties with this because information use was only one aspect of this study. However, what was heard from women is that they wanted more information about being RhD negative and pregnant. This demonstrates that women are not receiving the information they need, when they need it, and how they need it to be confident and informed.

In a recent qualitative study exploring the use of the internet in pregnancy supports the findings in this study and that of the Sayakhot and Carolan-Olah (Prescott & Mackie, 2017; Sayakhot & Carolan-Olah, 2016). Prescott and Mackie (2017) interviewed women about their use of the internet during pregnancy. They found that women had an increased use of the internet during pregnancy and the use was a source of reassurance and a sense of feeling informed. The need for information outside of the provider office continues to grow within pregnancy and internet use research, and is a concept that needs to be embraced by healthcare providers (Ellingson & Chamberlain, 2018; Fredriksen, Moland, & Harris, 2018; Sinclair, Lagan, Dolk, & McCullough, 2018). They need to be taught to be comfortable with patients seeking information on their own and how they incorporate that information within their navigation of their health. The provider is now just one means of healthcare decision-making for patients. This needs to be viewed as a reality and embraced.

Healthcare providers struggled to recall knowledge about the mechanisms involved in Rh factor and pregnancy, and the use of RhIG in the prevention of RhD alloimmunization. This explains why providers struggled with communicating to RhD negative women about the risk of RhD alloimmunization, the mechanisms and the prevention program. It may also be why women stated that they did not always receive information and/or the lack of confidence in the way that information is provided, when it is provider.

RhD negative women were asked about their understanding of being RhD negative in the context of being pregnant. Some women struggled to answer this question confidently. Those that stated they had healthcare and/or science backgrounds were more able to describe what they know. Their knowledge and understanding were not assessed because the focus was on the participants' knowledge and understanding, and less about if they were correct. RhD negative women did not have a good understanding of RhIG. They did not, for the most part, know that it is a blood product and how the prophylaxis prevents the development of antibodies in pregnancy.

The knowledge and understanding of RhD factor, its importance in pregnancy and the prevention program was not well understood by the RhD negative women interviewed. Those that self-identified as having healthcare backgrounds had a slight increase in their knowledge and understanding, from their perspective, but not all were as fortunate. This is lack of knowledge and understanding is problematic. The complacency in healthcare providers and within the system has developed an ambivalence amongst an entire population, RhD negative women. This complacent situation hinders the decision-making process, health literacy of patients and the relationship between provider and patient, for which communication is the cornerstone. Essentially, RhD negative women have been accepting, for the most part, a prevention program without being fully informed.

Surprisingly women did not ask about RhIG that often. As discussed with information behaviour theories people do not always seek information but in the current climate of increasing anti-vaccination. It is puzzling that women were not asking more about what RhIG is and how it works to prevent the development of anti-D antibodies. Perhaps there is something more here than information behaviour, perhaps it is a need to protect one's baby from harm. This notion is founded in recent literature of pregnant women's views and attitudes toward influenza and pertussis vaccines (Wiley et al., 2015). In Wiley et al's (2015) study, women perceived pertussis to be a riskier disease than influenza because of its impact on the fetus. Influenza was perceived as a mild illness only affecting the mother. This is reflective of Tversky and Kahneman's (1981) decision-framing phenomenon. Perhaps if women knew more about RhIG there may be an increase in questions regarding the rationale for getting the prophylaxis, or would there be apprehension, or would there be better understanding and informed decision-making occurring that does not currently exist?

Recommendations for Practice

Rural communities in northern BC have seen their maternal care programs closed and centralized within a larger centre, such as Prince George (Grzybowski, Kornelsen, & Barclay, 2016; Grzybowski et al., 2007; Grzybowski, Stoll, & Kornelsen, 2011; Hearns et al., 2010). These closures are based on research about provider competency and maternal and fetal/neonatal outcomes, yet there is contradictory evidence in the literature that should be explored before these drastic changes continue to be implemented.

As discussed in Chapter Two, there is contradictory research on competency in rural healthcare. A recent retrospective study conducted in BC found that there are higher risks of harmful morbidity than urban pregnancies (Lisonkova et al., 2016). Instead of focusing on

the competency of providers, these researchers suggest that perhaps policy makers need to consider observing these incidents of morbidity and consider the reasons for this increase. As mentioned earlier in the discussion, this paper received criticism (Grzybowski & Kornelsen, 2016) because it did not take into account important risk factors, such as travel distance to referral centres, but the fact remains that it highlights that something is occurring beyond healthcare provider competency. This is a distinct contrast to patient safety incident literature discussed in Chapter Two.

In light of this, policy makers need to look at complacency and systems inequities that lead to system incompetence. They need to identify what is working well and why. They also need to identify what is not working well and why. In each instance, low occurrence events should not be ignored. As seen in this study, healthcare providers in northern BC struggle to understand the process for providing RhIG in sensitizing event situations. All of the providers interviewed understood the importance of the prevention program demonstrating that this is not a competency issue. What is problematic is when a healthcare provider identifies the opportune time to provide RhIG and the system fails in the process (system incompetence), consequently putting a RhD negative woman at risk. Complacency is an issue for providers that are too comfortable with the process. The process and systems that support these providers need to be interrogated. Instead of shutting down maternal health services in rural areas, policy makers need to identify, find solutions and assess strategies to overcome systems inequities that inherently cause competency issues within rural and remote healthcare.

Those that develop policy and CPGs should seek out and commission research and evidence that incorporates healthcare provider/stakeholder/frontline worker and patient experience/perceptions. Although CPGs are designed to provide clinical guidance, without

engaging patients and/or healthcare providers and frontline workers in the process fails to comprehensively approach the clinical scenario.

Recommendations for education

When providers are faced with patients experiencing a knowledge gap, an active seeker or avoider, they need to be able to respond to these varying information needs and behaviours. These information needs and behaviours are interwoven within the provider-patient relationship. If this is not satisfied by either person in the relationship the dynamics will change and there will be relationship dissatisfaction and a potential for lack of communication of information that can lead to harm. It is also a missed opportunity to generate informed decision-making for the patient.

Healthcare providers were unable to recall from their early training the details of RhD alloimmunization. Although healthcare systems should incorporate cues that trigger the recall of knowledge and process, there is an opportunity for medical educators to provide medical students with the knowledge they require with strategies that encourage knowledge retention. It is recommended that continuing education programs focused on perinatal care should include low occurrence clinical scenarios. In the development and implementation of these education programs, the content should not only include diagnosis and clinical management but opportunities for healthcare providers to ask questions about the content and to learn strategies for communicating the complex clinical information to patients.

Recommendations for Policy

Much more work needs to be done to understand the state of current RhD alloimmunization prevention programs, provincially, nationally and internationally. Retrospective and prospective studies continue to be done to identify that women continue to

be at risk for RhD alloimmunization (McCauley et al., 2017; Serious Hazards Of Transfusion, 2017). The current Serious Hazards of Transfusion (SHOT) study being conducted in the United Kingdom is a rigorous quantitative approach to learning more about the reasons behind near misses and the continued development of D-antibodies (Serious Hazards Of Transfusion, 2017). This large mixed methods study will identify the prevalence and reasons behind the RhD alloimmunization. The surveys are targeted at providers that report RhD alloimmunization. The survey questions are designed to capture more information about "previous pregnancies, recorded sensitising events, anti-D prophylaxis, and outcome" (Serious Hazards Of Transfusion, 2017). This study will aid in future policy development regarding the prevention of RhD alloimmunization in the United Kingdom. It would be helpful to adapt a program of quality improvement and research similar to SHOT in the province of BC, and perhaps nationally.

In 2017, the SOGC published new recommendations for the screening of RhD negative pregnancies (Johnson et al., 2017). These recommendations are preliminary, but if implemented in Canada the recommendation would have an impact in rural areas. The SOCG has recommended that at the first prenatal visit, 10 weeks, pregnant women would receive fetal molecular RHD genotyping. The RHD genotyping would be done simultaneously with the other first visit serology and routine RhD factor typing would be conducted. If the maternal genotyping comes back as RhD positive the pregnant women would no longer require RhIG. If the sample comes back as RhD negative, then the sample, if no antibodies are found, is sent away for further testing. This process involves separating out DNA of the fetus from the mother's plasma. If the fetus is identified as RhD positive, the pregnant woman would receive RhIG. If the fetus is found to be RhD negative, the women would not need RhIG.

The rationale for these recommendations are to decrease the number of women receiving RhIG unnecessarily. The SOGC states that the

> Implementation of non-invasive fetal RHD genotyping with targeted routine antenatal anti-D [RhIG] would enable up to 40% of D-negative women to avoid use of Rh immune globulin. (Johnson et al., 2017, p. 367)

A variety of studies were cited to demonstrate the sensitivity and specificity of RHD genotyping. The current model proposed by SOGC is to have the sample use for RHD genotyping to be sent to Bristol, England where it will be tested and a reactive system would trigger to ensure RhD negative women receive RhIG if needed.

The recommendations make sense in principle. The document attempts to provide a system that would alleviate the burden of over delivery of a prophylaxis that may not always be indicated. The recommendations go as far as to say that this could be implemented in BC because there is a system in place to send blood samples to Bristol for testing. Based on the findings in this study, there are process implications that would need to be considered in rural areas, such as:

- access to resources that would ship blood samples in a timely manner in order for RHD genotyping to occur;
- training and role clarification for healthcare providers in rural areas;
- protocols in place for sensitizing events that occur outside of the routine RHD genotyping and RhIG procedures; and
- education of pregnant women regarding RHD genotyping and the RhD alloimmunization prevention program.

It is recommended that RhD negative women that have been pregnant be involved in further development, implementation and adaptation of these recommendations in Canada.

In Nova Scotia, an RhD prevention program has existed has existed since 1964 (Reproductive Care Program of Nova Scotia, 2017a). The Rh Program of Nova Scotia has been educating healthcare providers and collecting data in the province since its inception

(Reproductive Care Program of Nova Scotia, 2017b). This is a unique program in Canada. It is the only province that has a specific program dealing with RhD negative pregnancies. Although the program is part of the larger Reproductive Care Program of Nova Scotia, it has been around longer and continues to collect data regarding the provision of RhIG in the province. BC does not have a specific RhD program. Perhaps if BC developed a RhD program that worked with Perinatal Services BC and Canadian Blood Services, there would be targeted education material for both providers and RhD negative women, targeted data collection and communication about the prevention of RhD alloimmunization. This would be crucial if the SOGC's 2017 recommendations were to ever see fruition because it would be a new approach to care for RhD negative pregnancies. There would need to be in-depth consultation with rural communities to ensure that the resources are available to implement the new recommendations in practice.

Internationally, developing countries face challenges in preventing RhD alloimmunization (Bhutani et al., 2013; Zipursky & Bhutani, 2015a, 2015b; Zipursky & Paul, 2011). In a Clinical Campaign, Dr. Zipursky, called for scientists and researchers to overcome the burden of RhD alloimmunization globally. The Canadian physician/researcher, and colleague Dr. Bhutani, stated that "more than 100 000 newborn babies die of the disease and more than 25 000 have permanent brain damage as a result of the disease annually" (Zipursky & Bhutani, 2015b, p. 651). The campaign described the creation of a global consortium focusing on the eradication of Rh disease[8]. It is not clear if this consortium is in collaboration with researchers, scientists and decision-makers in higher and lower income

[8] CURhE (Consortium for Universal Rh disease Elimination): http://curhe.org

countries. If not, perhaps a world-wide network that pulls together stakeholders from both higher and lower income countries can unite to globally deal with RhD alloimmunization.

Recommendations for Research

This section will describe the strengths and limitations of this research study. It will provide recommendations for future research regarding RhD alloimmunization and access to maternal health services within northern BC.

Strengths

This study has created a new discussion about the prevention of RhD alloimmunization and, more broadly, low occurrence clinical events in rural healthcare settings. Thorne (2008) stresses the importance of remaining hesitant to generalizing the findings of qualitative research. Interpretive description (Thorne, 2008) suggests that the individual nature of each data source, such as interviews, be treated independently as one perspective and analysis should look for broad patterns and trends. The IKT strategy employed in the interpretive description approach in this study allowed for the amalgamation of data and patterns emerging from the data were confirmed and/or generated awareness amongst the Stakeholder Committee members. The benefit of engaging the Stakeholder Committee throughout the research process meant rapid cycles of knowledge exchange and ability to include a range of insights from practice to the broader healthcare system. It must be noted that although the method case of RhD alloimmunization prevention was the focus of this study, researchers should consider interpretive description with an embedded IKT approach when researching low occurrence clinical events. There is opportunity to further explore this methodology in this content and to explore other low occurrence events to understand if the findings of this study are generalizable.

Much is known about the mechanisms for HDFN, the role of RhD factors in pregnancy, and the prevention of RhD alloimmunization. This issue has been called one of the greatest discoveries and successful prevention programs of the twentieth century (Bowman, 2003), yet, RhD negative women's experiences and/or perceptions have never been explored. This is the first study to explore the experiences of RhD negative women and pregnancy. A qualitative approach to this study provided an in-depth examination of the decision-making processes healthcare providers engage in when caring for RhD negative pregnancies, and the experiences of RhD negative women's experiences of care during pregnancy.

Interpretive description was an excellent method for studying low occurrences and decision-making in a rural area. The approach allowed for a complex topic with small incidence to be studied within the context for which is may/or may not occur. It permitted the inclusion of an IKT strategy that clinically guided the project and engaged in the analysis of the findings to ensure applicability. These opportunities provide flexible design required for research in rural and northern areas.

Limitations

This study utilized Thorne's (2008) first iteration of interpretive description. While this study was being conducted a new edition of Thorne's work was published (Thorne, 2016). It was too late to integrate some of the newer insights and approaches into this study, but it is important to note in this dissertation that interpretive description has evolved. The evolution of interpretive description has grown to broadly integrate knowledge translation, much like this study did with its IKT approach.

This study was conducted across a vast geographic landscape, northern BC. Although the recruitment material was sent out across NH, there were definitely areas that were likely overlooked because follow-up was not always attainable due to the wide distribution sent out by NH staff on behalf of the researcher. One of the advantages of conducting research in rural communities is that you often are able to obtain support directly from the stakeholders involved because of the relationships that already exist and/or are easily made based on reputations and confidence of colleagues within the field. This was essentially the case for this study. From the very beginning stakeholders were willing to engage in this study because there was a connection already made within the community.

Surprisingly, there were drawbacks to working within a small community. As stated in the methods section, the original proposal included a set of focus groups. The group would have been made of providers involved in adapting process for perinatal guidelines in northern BC. This group was made up of healthcare providers and researchers form NH and UNBC. Once there was enough data to share with the focus group an attempt to arrange a date and time to meet to hold the focus group. After a few failed attempts, it was decided to abandon the use of focus groups for this study. This decision involved looking at the interview data and comparing/contrasting that with the Stakeholder Committee members. During this process, it was identified that some of the members on the Stakeholder Committee were also part of the proposed focus group. Based on the duplication of membership, it did not make sense to include both participants in two different data collection strategies. It was also evident that guideline adherence and process adaptation was something that was being shared within the interviews. It is imperative to adapt data collection strategies in environments that involve rural and northern contexts.

Recommendations

Studies that garner a broader perspective, through qualitative and/or mixed methods approaches will be able to further explore the experiences of RhD negative women and pregnancy, especially for those who may have limited access to care and those that do not have post-secondary education, knowledge and understanding of RhD factors, pregnancy, and RhIG. RhD negative women that have become RhD alloimmunized should be involved in research in that examines their experiences with healthcare, the reasons for sensitization and the decisions they have had to make because of RhD alloimmunization. This study scratched the surface of decision-making in low occurrence clinical situations. More studies using different case studies of low occurrence medical events would help to broaden the research in this area and should further be explored in rural contexts. More studies that use applied qualitative methods will further our understanding of the development of risk in complex systems.

There are aspects of this study's findings that need further research. A deeper examination into process adaption, particularly in clinical situations that are sensitive, such as medical/surgical terminations, would provide a better understanding of the issues, concerns and successes in adapting processes within a large regional health authority. It is troubling that women, and providers, experience discrimination, barriers and stigma regarding medical/surgical terminations in northern BC. A qualitative approach to obtain an in-depth understanding of this phenomenon would allow for improved access and care for women, and provide healthcare providers the opportunity to shape the system.

A large descriptive study in BC, or nationally, on the prevalence of RhD alloimmunization would be helpful to understand the true impact of the prevention program. A national study on the experiences of those impacted by RhD alloimmunization would

provide an insight into the disease that has yet to be explored. This kind of study could be replicated internationally with women in both developing and developed countries. The impact of a disease that has been forgotten would demonstrate both the successes and challenges faced by those that it impacts. There is potential for an international network of researchers to be put together with the goal to explore and interrogate RhD alloimmunization. Bringing together content and methods experts could support the development of methodologies that will open the doors for access to the unresolved tensions of RhD alloimmunization prevention.

Knowledge Translation

Interpretive description provided the methodology for this study and an IKT approach guided the research process. These two components of the research design and process encouraged the development of KT. Based on the findings of this study, several KT outcomes have been completed and initiated.

Early findings from the interviews with RhD negative women were presented in a poster format at the national Qualitative Health Research Conference (QHRC) in 2016. This was an opportunity to network and obtain feedback from leaders in qualitative research, such as Sally Thorne, the developer of interpretive description. Based on feedback from the QHRC participants, the advancement of this work was presented at a local conference, Northern Research Days in 2016. This conference presentation was an opportunity to generate awareness amongst stakeholders at NH about the experiences of RhD negative women with pregnancy within the health region. One of the Stakeholder Committee members suggested that this research be presented at the BC Nurse Practitioner Association conference

in 2017. By this time, the full analysis was complete and presented to nurse practitioners working within the province.

It is clear from the findings of this study that RhD negative women perceived that they would benefit from more information about being RhD negative and pregnant. Furthermore, healthcare providers suggested that they would benefit from an information resource that they can share with patients and begin a conversation about RhD negative pregnancies. The researcher is currently working with a second year medical student, Samuel Marleau, at the Northern Medical Program (NMP), University of British Columbia (UBC) on the development of an information resource for RhD negative women that provides information at a level that meets health literacy guidelines ("How to write easy-to-read health materials," 2017).

The process for the provision of RhIG across the various regions examined within NH demonstrated that variations in process exist. The Stakeholder Committee suggested that a process chart would be helpful to develop, but that was outside of the scope of this research study. The researcher is working with the same second year medical student to develop, with input from various healthcare providers at NH, a flowchart for the steps and considerations in the provision of RhIG in RhD negative pregnancies.

The researcher is a tutor of Case-Based Learning (CBL) with the NMP. One of the weekly cases that the tutored engaged with incorporated student learning about RhD alloimmunization. Without revealing too much of the case, a RhD negative woman gives birth to an RhD negative infant. The researcher noted that the students struggled with the concept of RhD alloimmunization, the pathophysiology and clinical management. At the end of the week, the tutor provided feedback to the case developers and suggested that the infant involved in the case should be RhD positive. The researcher provided evidence from this

study regarding the knowledge and understanding of healthcare providers and the uncertainty they have regarding this clinical scenario. The case developers were receptive to the feedback and felt that small change would support greater discussion about the prevention of RhD alloimmunization within future cohorts of students.

Although this study was conducted in northern BC, there is an opportunity to engage in national and international discussions about the prevention of RhD alloimmunization. Throughout the duration of this study, the researcher has made connections with researchers working in this area of research globally. It is anticipated that further networking with these researchers will develop an international exploration of RhD negative women's experiences with pregnancy and RhD alloimmunization.

Chapter Six: Conclusion

Research in the prevention of RhD alloimmunization has declared that it has been deemed eradicated in developing countries. Yet, while it is a completely preventable clinical outcome, RhD negative women continue to be at risk. The risk continues to be problematic in already complex healthcare systems that are geographically dispersed and where resources may be limited. In northern BC, RhD alloimmunization is a known risk to RhD negative pregnant women amongst healthcare providers, but healthcare provider complacency and failures to support providers in the healthcare system continue to put these women at risk. RhD negative women that are pregnant are not informed and at risk of RhD alloimmunization in times of sensitizing events.

This research study utilized a qualitative approach to conduct an in-depth examination the risk of RhD alloimmunization in northern BC. Interviews were conducted with16 RhD negative women about their experiences with pregnancy, and 13 healthcare providers were interviewed focusing on the care of RhD negative pregnancies. An IKT strategy was implemented throughout the research process. This strategy involved a Stakeholder Committee with healthcare provider, decision-maker and patient representation. This committee provided rapid cycles of knowledge exchange leading to in-depth analysis and practice applicable findings.

This study discovered that RhD negative women continue to be at risk of RhD alloimmunization during pregnancy in northern BC. Routine provision of RhIG is deemed to be done well in northern BC, but the process has become complacent. Healthcare providers and RhD negative pregnant women go through the motions of receiving prophylaxis for RhD alloimmunization, but when a non-routine event occurs, sensitizing event, the system in place may fail. Healthcare systems must not assume that everything is working smoothly when

everything seems to be going well. There needs to be ongoing quality improvement on things deemed “working well”. If continued “out of sight, out of mind” or “all is well” attitudes and perceptions prevail, there is potential for continued near misses and patient safety incidents to occur. The healthcare system in northern BC needs to be proactive and check-in with situations of low occurrence to ensure that systems are running smoothly, everyone is informed, and near misses are not occurring.

RhD negative women shared their experiences of pregnancy. RhD negative women are not informed about pregnancy as an RhD negative, RhIG, and/or the potential consequences of sensitizing events. When faced with a low occurrence, women require information to feel supported and informed in the decisions that they make throughout pregnancy. RhD negative women need this information at various intervals throughout their pregnancy. The contexts for the dissemination of information to patients is critical. In some situations, RhD negative women receive information, and in others, like crisis situations, RhD negative women may not. Information should be aimed at educating patients and opening a dialogue between patients and healthcare providers.

Low occurrence clinical events, such as RhD negative pregnancies, require the same attention as regularly occurring clinical events in the healthcare system. Assuming the processes in place are working leads to a culture of complacency, disconnect and adaptive processes. Checking-in with healthcare providers and patients that engage in the healthcare system needs to be done in order to ensure that safe practices are being conducted and barriers to offering safe care are overcome in routine and non-routine clinical situations.

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Appendix A

Fyfe, T. M., Ritchey, M. J., Taruc, C., Crompton, D., Galliford, B., & Perrin, R. (2014). Appropriate provision of anti-D prophylaxis to RhD negative pregnant women: A scoping review. *BMC Pregnancy Childbirth, 14*, 411. doi:10.1186/s12884-014-0411-1

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RESEARCH ARTICLE Open Access

Appropriate provision of anti-D prophylaxis to RhD negative pregnant women: a scoping review

Trina M Fyfe[1*], M Jane Ritchey[2], Christorina Taruc[2], Daniel Crompton[2], Brian Galliford[2] and Rose Perrin[2]

Abstract

Background: The purpose of this scoping review was to review the literature on healthcare provider provision of anti-D prophylaxis to RhD negative pregnant women in appropriate clinical situations in various healthcare settings.

Methods: A scoping review framework was used to structure the process. The following databases were searched: CINAHL (EBSCO), EBM Reviews (OvidSP), Embase (OvidSP), Medline (OvidSP), and Web of Science (ISI). In addition, hand searching of article references was conducted. The search yielded 301 articles. Thirty-five articles remained for review after screening. Two team members reviewed each article using a detailed data collection sheet. A third reviewer was utilized if discrepancies occurred amongst reviewers.

Results: The review process yielded 18 included articles. The majority of the studies were conducted in the United Kingdom. Of the 18 studies, 15 were retrospective studies. The articles were largely conducted in one institution. The articles with a focus on routine antenatal provision of anti-D immunoglobulin found that it was given 80 to 90% of the time. Postpartum provision of anti-D immunoglobulin had significantly higher results of 95-100%. The review found that the delivery of anti-D immunoglobulin to RhD negative pregnant women during situations of potential sensitizing events was suboptimal.

Conclusions: The included articles examine the management of RhD negative pregnancies in various countries with existing national guidelines. The existing evidence indicates an opportunity for quality improvement in situations where potential sensitizing events are not at routine times in pregnancy, such as miscarriage or fetal demise early in pregnancy. Routine care for the prevention of RhD alloimmunization in pregnancy and postpartum appears to be fairly consistent. The paucity of recent literature in this area leads to a recommendation for further research.

Keywords: RhD isoimmunization, practice guidelines, Rho(D) Immune Globulin, guideline adherence, anti-D immunoglobulin

Background

RhD alloimmunization can lead to Hemolytic Disease of the Fetus and Newborn (HDFN) or in severe cases fetal demise [1]. This can occur if an RhD negative pregnant woman has a sensitizing event during her pregnancy that causes the development of anti-D antibodies [2]. These antibodies work to destroy fetal red blood cells [1].

The prophylaxis for the prevention of RhD alloimmunization was developed in the 1960s [1]. Since its discovery, anti-D immunoglobulin has remained the gold standard in the prevention of RhD alloimmunization and consequently HDFN [3]. However, this is under debate in the current literature [4]. Anti-D immunoglobulin is a blood product given to RhD negative pregnant women during pregnancy and after delivery. According to various guidelines, RhD negative women receive the prophylaxis at 28 weeks (and again at 34 weeks if the guideline indicates a two dose regime) and again after the delivery of an RhD positive fetus [5-10]. Outside of routine provision, RhD negative pregnant women can receive anti-D immunoglobulin during pregnancy when potential sensitizing events occur. A list of potential sensitizing events can be found in an additional file (see Additional file 1). Since the development of anti-D immunoglobulin, the rate of RhD alloimmunization and its consequences has been significantly reduced but the cited RhD alloimmunization

* Correspondence: trina.fyfe@unbc.ca
[1]Northern Medical Program, University of Northern British Columbia, 3333 University Way, Prince George, BC V2N 4Z9, Canada
Full list of author information is available at the end of the article

rate remains at 6.7/1000 live births, which leaves room for improvement [11].

In 2012, two retrospective studies were published that examined the delivery of anti-D immunoglobulin to RhD negative pregnant women in appropriate clinical situations within emergency departments [12,13]. These two studies found that in certain clinical situations the delivery of anti-D immunoglobulin to RhD negative pregnant women was suboptimal. The recent emergence of these two studies led the authors of this review to question whether more research exists on the provision of prophylaxis to RhD negative pregnant women and if there are settings besides emergency departments that contribute to the RhD alloimmunization rate of 6.7/1000 births [11].

The purpose of this scoping review is to explore the literature on the provision of anti-D prophylaxis to RhD negative pregnant women in appropriate clinical situations in various healthcare settings. The hypothesis is that RhD negative pregnant women receive anti-D immunoglobulin in routine situations, such as within 72 hours after birth, but in situations of potential sensitizing events, such as miscarriage or fetal demise, anti-D immunoglobulin may not always be provided correctly or at all. To date, a knowledge synthesis has not been conducted on this topic.

Methods

A scoping review framework was chosen because it is an exploratory process, enabling the team to determine the depth, range, and nature of the research that exists, thereby not limiting to specific types of research methodology and critical analysis. This review followed Levac et al's [14] scoping review framework: identify the research question, identify relevant studies, select the studies, chart the data, summarize and report the results, and consult with knowledge users. Ethics was not required because this review methodology was not experimental research nor did it involve human participants.

Data sources

The following databases were searched by a librarian: CINAHL (EBSCO), EBM Reviews (OvidSP), Embase (OvidSP), Medline (OvidSP), and Web of Science (ISI). In addition to database searching the librarian hand searched reference lists of potential articles to include. To ensure rigor, the librarian had the database search strategy peer reviewed by another librarian. This process reduced the likelihood of human based search error [15].

The following search terms were used: Rho(D) Immune Globulin, immunoglobulins, anti-idiotypic antibodies, anti-D immunoglobulin, anti-D immune globulin, anti-D prophylaxis, anti-D immunoprophylaxis, Rhogam, Winrho, pregnancy, pregnant women, Rh alloimmunization, Rh sensitization, Rh isoimmunization, Rh incompatibility, rhesus disease, blood group incompatibility, hospitalists, family physicians, emergency physicians, obstetricians, nurse practitioners, midwifery, nurse midwives, hospital emergency service, emergency department, acute care, obstetrics and gynecology department, primary care, outposts, ambulatory care facilities, hospital units, or birthing centres. Medical subject headings were used when available and deemed appropriate. Keyword searching utilized truncation and alternative spelling.

Study selection

In order to explore the nature and size of the literature in this area the selection criteria for this synthesis were broad. After the search was complete, the results were combined and duplicates removed, the articles were screened for relevancy. After the screening process, two team members reviewed the full text of each article. A data extraction sheet was used to compile data on each article with the option of inclusion or exclusion. Reviewers were asked to solve discrepancies amongst themselves but in the event that they were unable to do this a third reviewer was brought in to resolve the discrepancy. A reviewer included an article if it addressed the provision of prophylaxis in routine and/or sensitizing situations within healthcare settings. Articles that explored dosage and/or the administration of anti-D immunoglobulin practices were excluded.

Potential sensitizing events

The authors define a sensitizing event in RhD negative pregnant women as an event that leads to the development of anti-D antibodies due to maternal-fetal blood exchange. The following list of potential sensitizing events was adapted from Urbaniak & Greiss' [2] and incorporated events listed in existing guidelines. The guidelines consulted in this process were from the World Health Organization, American Congress of Obstetricians and Gynecologists in the United States (US), the National Institute for Clinical Excellence in the United Kingdom (UK), Australia's National Blood Institute, the Society of Obstetricians and Gynecologists of Canada, and the British Committee for Standards in Haematology [5-9,16]. An additional file provides a list that summarizes all clinical events considered at risk for sensitization in RhD negative pregnant women because of the potential for fetal-maternal hemorrhage as outlined in the aforementioned guidelines (see Additional file 1) [1].

Summarizing and reporting results

Each reviewer completed a data extraction form for each article reviewed. The form included four predefined themes: policy, practice, education, and research. The reviewers were asked to provide comments regarding the articles' contribution, challenges, or opportunities for each of the themes. A narrative discussion was used to synthesize the studies

according to the four predefined themes. The articles were categorized and summarized into a matrix: methodology, geographic location, healthcare setting, number of participants, and if the study looked at the provision of anti-D immunoglobulin for routine antenatal, routine postnatal, and/or sensitizing events. An additional file provides the matrix of included articles (See Additional file 2).

Results

The searches yielded 323 articles. After duplicates were removed 301 articles remained. The screening process weeded out 266 abstracts, leaving 35 articles for review. Hand searching references of the 35 articles identified another 13 articles for potential inclusion in the review. The final reviewing process included a total number of 18 articles. The review process is illustrated in an additional file using a flow chart (see Additional file 3).

Of the 18 articles included in the review, 13 were conducted in the UK, two in Canada, one in Australia, one in the US, and one review article. The settings included maternity units, nurse led clinics, emergency departments, and general practice clinics.

The majority, 15 articles, of the included studies are retrospective cohort studies. There was only one prospective cohort study available. Of the retrospective studies 5 involved more than one institution, 7 articles were at one institution, and two articles were not clear on the setting. Of the 15 retrospective studies one utilized data from a national reporting system.

Routine antenatal

According to the guidelines in the UK, Australia, Canada, and the US, anti-D immunoglobulin should be given routinely to RhD negative pregnant women [5,7-10]. The guidelines state that the prophylaxis may be given in two injections at 28 and 34 weeks or in one injection at 28 weeks. Of the 18 articles, 8 explored adherence to the delivery of routine antenatal anti-D immunoglobulin [12,17-23]. Each article varied in the approach but the overall findings are that the delivery of anti-D immunoglobulin in these routine situations is consistently delivered. The figures ranged from 80 to 90% adherence. MacKenzie et al's [20] study found the timing of the delivery of anti-D prophylaxis was an issue: "There was limited success at providing prophylaxis at the correct gestation for eligible women. Eighty-nine percent received one injection and 74% received both, but only 29% at the correct gestation." In a 2012 Canadian study, Koby et al. [12] found that the routine postnatal delivery of anti-D immunoglobulin occurred 98.5% of the time, whereas the antenatal delivery of the prophylaxis was suboptimal at 85.7%. The authors suggest that hospital-based protocol systems lead to increased adherence in postnatal administration [12]. The hospital-based protocol described involves various checkpoints throughout labour and delivery. These checkpoints alert physicians and nurses to note and deliver anti-D immunoglobulin (if needed) at admission, post-delivery, transfer to postpartum unit, and at discharge [12]. The authors hypothesize that the administration rate of antenatal anti-D immunoglobulin is lower due to errors that may occur in physician-dependent situations, such as failure to identify and treat RhD negative women and lack of protocols and/or team based approaches [12].

Routine postnatal

The provision of anti-D immunoglobulin to RhD negative women upon the delivery of an RhD positive infant should occur within 72 hours [1]. The studies included in this review found favourable results in this regard. The routine provision of postnatal anti-D immunoglobulin was fairly consistent across the studies. Studies found that RhD negative women that delivered an RhD positive infant were given anti-D immunoglobulin between 95-100% of the time [12,19,24,25].

Sensitizing events

As defined earlier, potential sensitizing events can occur at any time throughout the pregnancy and can have devastating consequences. Out of the 18 articles included in this review 8 articles examined the provision of anti-D immunoglobulin when potential sensitizing events occur [13,23,24,26-30].

The testing of RhD status is an integral step in the prevention of RhD alloimmunization. In situations for which potential sensitizing events present themselves pregnant women were often discharged without having their RhD status tested. Further, pregnant women that were discharged may have been RhD negative consequently raising the opportunity for RhD alloimmunization to occur. A retrospective study conducted in Canada in 1990 (prior to national guidelines), found that the RhD status of pregnant women discharged from the emergency department was performed in 86% of all the women discharged [27]. A more recent study conducted in the US found that 89% of women with potential sensitizing events had their RhD status documented and/or tested [13]. A small study exploring the effectiveness of a nurse practitioner led early pregnancy clinic found that all RhD negative women presenting to the clinic had their RhD status tested and received appropriate prophylaxis [26].

This review found that the provision of anti-D immunoglobulin was low in situations for which potential sensitizing events occur. A recent US study found that although 89% had RhD status testing, only 54% of those that were RhD negative actually received the prophylaxis and was lower in second and third trimesters [13]. In an older study conducted in the UK, adherence was looked at prior

to 12 weeks and after 12 weeks gestation in women experiencing potential sensitizing events based on available guidelines at the time; in each instance the provision of anti-D immunoglobulin was suboptimal [24]. For example, in the second and third trimester "more than 25% of women in the large maternity unit, and over 33% in the smaller unit" did not receive anti-D immunoglobulin [24].

Gestational age appears to be a factor in the suboptimal provision of anti-D immunoglobulin. A retrospective study looking at the management of women presenting the emergency department prior to 12 weeks gestation found that of 112 patients 97 were discharged without having their RhD status tested [30]. A survey study conducted in Australia found that general practitioners would offer anti-D immunoglobulin in only 57% of cases of threatened miscarriages [29]. The general practitioners were also more likely to provide anti-D immunoglobulin if the patient presented with heavy bleeding or if the pregnancy was non-viable [29]. Interestingly, this study found that in cases of threatened miscarriage, "rural doctors were more likely than urban doctors to offer anti-D in this situation (66% vs. 55%; difference, 11%; 95% CI, 1% to 22%)" [29]. An earlier study in the UK "found a significant level of noncompliance with published recommendations in relation to routine screening for antibodies, administration of anti-D immunoglobulin and Kleihauer testing" [23]. Although this study is older and guidelines have since changed, the findings suggest there was an issue with the provision of anti-D immunoglobulin less than 20 weeks gestation [23].

Discussion

The literature provides evidence that there are opportunities for quality improvement in the delivery of prophylaxis in routine and clinically significant situations. RhD negative women are not being consistently tested for their RhD status in clinically significant situations and are consequently not provided anti-D immunoglobulin when required. The categories of practice, policy, education, and research were chosen to discuss the results as it pertains to each category. The attempt is to provide suggestions and guidance in each domain.

Practice

There is a need for an increased efficiency with the provision of anti-D immunoglobulin, particularly in situations of potential sensitizing events. The existing research provides the evidence that anti-D is not always given at the right time or at all; although, in controlled environments such as maternity wards RhD negative women are receiving prophylaxis post-delivery almost 100% of the time.

Only two studies discussed the woman's role in the decision to receive anti-D immunoglobulin [18,21]. In some instances the women made well-informed decisions based on their current health and relationship status. In MacKenzie et al's [21] study, they found a small number of women increasingly denying prophylaxis in the 1990s. The authors entertained the notion that this rise in refusal of anti-D was attributed to "a growing anxiety about possible infection from the administration of blood products during the decade, and such anxiety may well have been exacerbated when the preparation previously used for RhD prophylaxis was withdrawn because of concerns relating to variant Creutzfeldt–Jakob disease transmission" [21]. These results suggest that there is a need for improved communication amongst health care providers and RhD negative women, between departments (such as laboratories and emergency departments), and between health care providers involved in the continuum of care.

The studies included in this review span twenty-two years, the earliest study dating back to 1992. The last ten years has seen only six studies addressing this topic despite recent guideline development and implementation [12,13,17,18,21,31]. These five studies (and one review) continue to find opportunities for improved management of RhD negative pregnancies, particularly in situations for which sensitizing events occur. Guidelines on the prevention of RhD alloimmunization do not provide strong recommendations for situations involving sensitizing events, particularly in the first trimester. This is a result of a paucity of evidence regarding the effectiveness of anti-D immunoglobulin in the first trimester after a sensitizing event [16,32]. This lack of evidence is one of the reasons guidelines are lacking strong recommendations. Consequently, the delivery of anti-D immunoglobulin continues to be problematic and quality improvement remains suboptimal.

Few studies provide recommendations for an improvement in the delivery of anti-D immunoglobulin. The most recent Canadian study suggests that improved communication and patient education for RhD negative pregnant women would potentially improve adherence. The same study suggests that a checklist system, such as the one described in the results section discussing post-natal administration of anti-D immunoglobulin would be helpful in antenatal situations. A team-based approach involving nurses with specific checklists in place and/or a clinic specific to the administration of anti-D immunoglobulin are other recommendations put forth by Koby et al. [12]. These suggestions need to be integrated into the management of RhD negative pregnancies both in hospital and primary care settings. These interventions need to be evaluated for effectiveness and quality improvement.

Policy

The longest retrospective study of 15 years conducted in the UK, provides data that there has been consistent

errors of omission or late delivery of anti-D immunoglobulin [17]. This study is important because it covers a lengthy period of time in reporting of anti-D immunoglobulin mismanagement but it also covers the period of guideline implementation. Throughout the 15 years of reporting new guidelines were disseminated. Despite the new guidelines mismanagement continued to occur. Perhaps continued issues are due to an increase in healthcare providers reporting or a lack of uptake or clarity of the guidelines, but nevertheless an issue regarding the delivery of anti-D immunoglobulin still occurred. Inevitably there is room for improvement in the delivery of anti-D immunoglobulin and the need for clearer guidelines with implementation plans and evaluation to ensure the uptake of evidence.

In several studies conducted in acute care settings, such as emergency departments, pregnant women with potential sensitizing events did not receive optimal care. This suggests that there are opportunities for this clinical setting to develop interventions that perhaps integrate RhD testing and the increased delivery of anti-D in clinically significant potential sensitizing situations. The opportunity for quality improvement in the management of RhD negative pregnancy is imperative.

Education

Thorpe's review article is an example of an educational attempt to improve the quality of care for RhD negative pregnant women with a focus on blunt trauma [31]. In Nova Scotia there is an active continuing medical education program and reporting system for RhD negative pregnancies [33]. These two examples provide strategies for continued education in this area. Based on the results of this review continued education should focus on routine antenatal and potential sensitizing situations. In addition, continued education regarding communication would help to improve the quality of care by ensuring the issues related to mismanagement are not caused by communication factors. An Australian study found that rural physicians were more likely to deliver anti-D immunoglobulin in situations of threatened miscarriages than urban physicians [29]. Although the definition of rural is not provided and the study is a self-reported survey of individual practices, an exploration into what aspects of rural practice and/or education that lead to the increased provision of anti-D in situations of threatened miscarriage by rural physicians would be helpful.

The definition of shared-care states that patients are provided with the opportunity to engage and collaborate in health care decision-making [34]. Only two studies mentioned the role of RhD negative women in the management of their pregnancy [18,21]. The limited literature in this area requires further exploration. Shared care and patient engagement literature provides evidence that patients require knowledge and information in order to engage in their care. Therefore, it is suggested that women need to be informed of their blood type, perhaps prior to pregnancy, and educated about RhD factor and the risks that lie therein.

Research

The retrospective cohort methodology is an appropriate method in researching the use of anti-D immunoglobulin in clinical settings [35]. It would be helpful to have more studies utilizing population-based data, large multi-center studies involving prospective approaches or retrospective approaches, and more studies in Canada, Australia, and the US. Further research is required to understand the factors associated with suboptimal provision of anti-D immunoglobulin in situations where potential sensitizing events occur. As Koby et al. [12] suggest, errors of omission can occur in situations where the decisions are physician-dependent. However, only one study provided the factors involved in the omission of or late administration of anti-D immunoglobulin [17]. The factors involved poor documentation, misinterpretation of laboratory results, issues with storage of the prophylaxis, and communication between departments. In addition, a better understanding of women's knowledge and experiences with RhD negative pregnancies and its possible implications would provide further insight into RhD alloimmunization. Once there is a basic understanding interventions may be developed and trialed for effectiveness.

Limitations

The limitations of this scoping review lie within the literature retrieved and included. The studies included span across several decades with the first article published in 1992 [27]. In addition, these included studies have been conducted in four different countries. The majority of articles were conducted in the UK. This means that the results of these studies are not necessarily generalizable across various countries, amongst varying clinical guidelines, with current clinical guidelines, and within different settings. Due to these limitations conducting a further systematic review of the literature is not recommended.

Conclusions

The included articles offer a glimpse into the management of RhD negative pregnancies in various countries with existing national guidelines. The existing evidence indicates an opportunity for quality improvement in situations where potential sensitizing events are not at routine times in pregnancy, such as miscarriage or fetal demise early in pregnancy. Routine care for the prevention of RhD alloimmunization in pregnancy and postpartum appears to be fairly consistent. The paucity of recent literature in this area leads to a recommendation for further research.

Additional files

Additional file 1: Figure S1. Potential sensitizing events.
Additional file 2: Table S1. Matrix of included articles.
Additional file 3: Figure S2. Flowchart of review process.

Abbreviations

APH: Antepartum haemorrhage; CVS: Chorionic villus sampling; FBS: Fetal blood sampling; HDFN: Hemolytic Disease of the Fetus and Newborn; IUD: Intrauterine death; UK: United Kingdom; US: United States.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

TF conceived of the review, carried out the searches, coordinated the review process, and wrote the draft manuscript. RP, MJR, DC, BG, and TF participated in the development of the design of the review, reviewed articles, and helped to draft the manuscript. CT helped to draft the manuscript. All authors read and approved the final manuscript.

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Author details

[1]Northern Medical Program, University of Northern British Columbia, 3333 University Way, Prince George, BC V2N 4Z9, Canada. [2]Northern Health - Corporate Office Suite 600, 299 Victoria St., V2L 5B8 Prince George, BC, Canada.

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doi:10.1186/s12884-014-0411-1
Cite this article as: Fyfe *et al.*: Appropriate provision of anti-D prophylaxis to RhD negative pregnant women: a scoping review. *BMC Pregnancy and Childbirth* 2014 **14**:411.

Appendix B

Updated scoping review search strategy

Database(s): **Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R)** 1946 to Present
Search Strategy:

#	Searches
1	Hospitalists/
2	Physicians, Family/
3	(emergency adj3 physician*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
4	Obstetrics/
5	obstetrician*.tw.
6	Nurse Practitioners/
7	Midwifery/
8	Nurse Midwives/
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10	exp Emergency Service, Hospital/
11	(acute adj3 care).tw.
12	(emergency adj3 department*).tw.
13	"Obstetrics and Gynecology Department, Hospital"/
14	Obstetrics/
15	(primary adj3 care).tw.
16	exp Primary Health Care/
17	outpost*.tw.
18	exp Ambulatory Care Facilities/
19	exp Hospital Units/
20	Birthing Centers/
21	"Rho(D) Immune Globulin"/
22	exp Immunoglobulins/

23	Antibodies, Anti-Idiotypic/
24	(anti-d adj3 (immunoglobulin or immune globulin or prophylaxis or immunoprophylaxis)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
25	rhogam.tw.
26	winrho.tw.
27	21 or 22 or 23 or 24 or 25 or 26
28	exp Pregnancy/
29	Emergency Medical Services/
30	exp Maternal Health Services/
31	Hospitals, Maternity/
32	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 29 or 30 or 31
33	Pregnant Women/
34	28 or 33
35	9 or 32
36	27 and 34 and 35
37	exp Blood Group Incompatibility/
38	(rh adj3 (alloimmunization or sensitization or isoimmunization or incompatibility)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
39	(rhesus adj3 disease).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
40	37 or 38 or 39
41	36 and 40
42	(rh adj3 (alloimmunization or alloimmunisation or sensitization or isoimmunization or isoimmunisation or incompatibility)).tw.
43	37 or 39 or 42
44	27 and 35 and 43
45	34 and 44
46	limit 45 to English language

Appendix C

Board of Record
University of Northern British Columbia

3333 University Way, Prince George, BC V2N 4Z9

UNBC UNIVERSITY OF NORTHERN BRITISH COLUMBIA

Certificate of Ethical Approval for Harmonized Minimal Risk Health Study

Also reviewed and approved by:

Northern Health ☒

Principal Investigator:	Primary Appointment:	Board of Record Approval Reference #:
Trina Fyfe	**UNBC - Graduate Reearch**	**E2016.0413.032.00**

Study Title: **Prevention of RhD alloimmunization in Northern British Columbia**

Study Approved: **May-19-2016** Expiry Date: **May-18-2017**

Research Team Members:

Sponsoring Agencies:

Documents Included in this Approval: 2016.05.16.E2016.0413.032.00 Fyfe revised 2016.05.16

This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence.

The Board of Record (as noted above) has reviewed and approved this study in accordance with the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2, 2014).

The "Board of Record" is the Research Ethics Board designated on behalf of the participating REBs involved in a harmonized study to facilitate the ethics review and approval process. In the event that there are any changes or amendments to this approved protocol, please notify the Board of Record.

In respect of the identified study, I certify, as representative of this Research Ethics Board that:

Board of Record Research Ethics Board Representative

Name: Paul Siakaluk **Title:** Acting Chair, UNBC REB

Signature: for Paul Siakaluk M. Isabel Hartley **Date:** May-19-2016

Appendix D

northern health
the northern way of caring

Northern Health Regional Office
600-299 Victoria Street, Prince George, BC V2L 5B8
Telephone: (250) 565-2649, Fax: (250) 565-2640
www.northernhealth.ca

May 20, 2016

Trina Fyfe
School of Health Sciences
University of Northern BC

Trina.fyfe@unbc.ca

File # RRC H 2016-0013-H (Fyfe)
UNBC file: E2016.0413.032.00

RE: Prevention of RhD alloimmunization in Northern British Columbia

On behalf of the Northern Health Research Review Committee, I would like to thank you for your application for research approval.

The study has received ethical approval through the BC Harmonized Ethics Review process (Certificate of Ethical Approval issued by UNBC Research Ethics Board as the Board of Record dated May 19, 2016) and achieved operational approval through the Northern Health Research Review Committee.

Sincerely,

Tamara Checkley, Chair, Research Review Committee

cc. Kelly Gunn, VP Primary & Community Care and Clinical Programs

Appendix E

UNIVERSITY OF NORTHERN BRITISH COLUMBIA

RESEARCH ETHICS BOARD

MEMORANDUM

To: Trina Fyfe
CC: Geoff Payne

From: Henry Harder, Chair
Research Ethics Board

Date: June 2, 2016

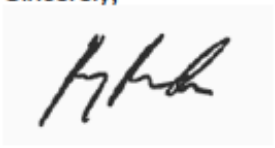
Re: **E2016.0413.032.00(a)**
Prevention of RhD alloimmunization in Northern British Columbia

Thank you for submitting amendments to the above-noted proposal to the Research Ethics Board (REB).

The amendments have been approved until the date as provided in the original protocol approval for this project (i.e. May 18, 2017). Continuation beyond that date will require further review and renewal of REB approval. Any further changes or amendments to the protocol or consent form must be approved by the REB.

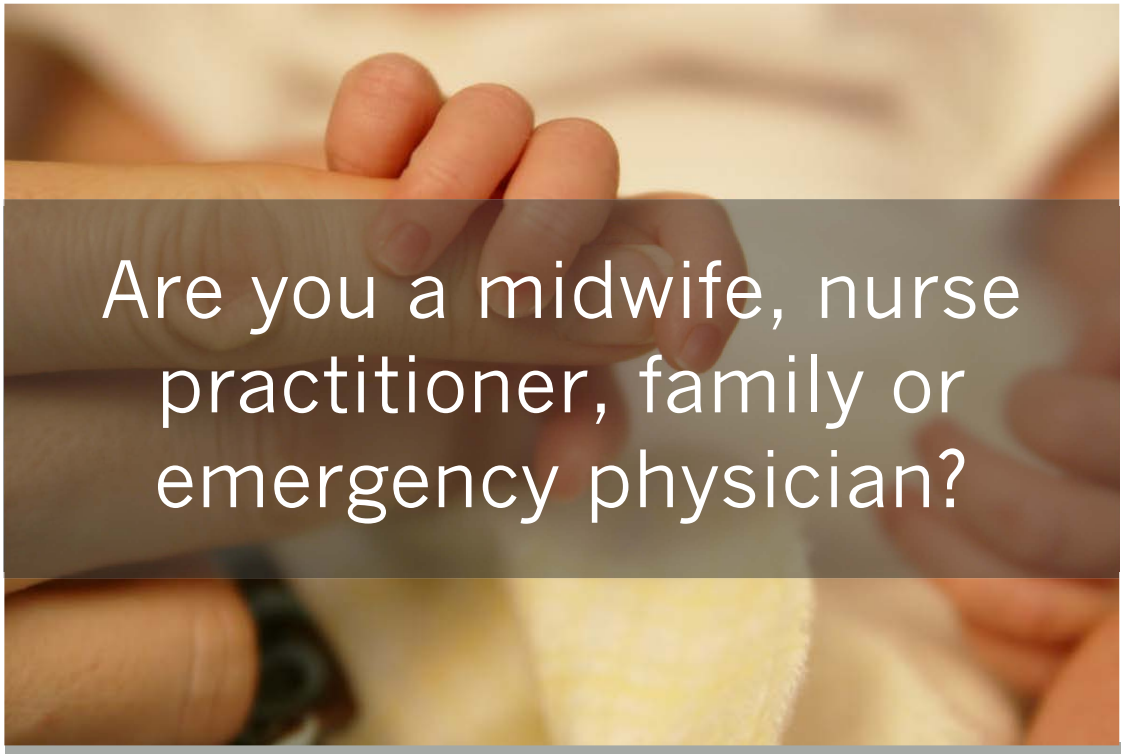
Good luck with your research.

Sincerely,



Dr. Henry Harder
Chair, Research Ethics Board

Appendix F



PLEASE PARTICIPATE!

Prevention of RhD alloimmunization in Northern BC: Research study

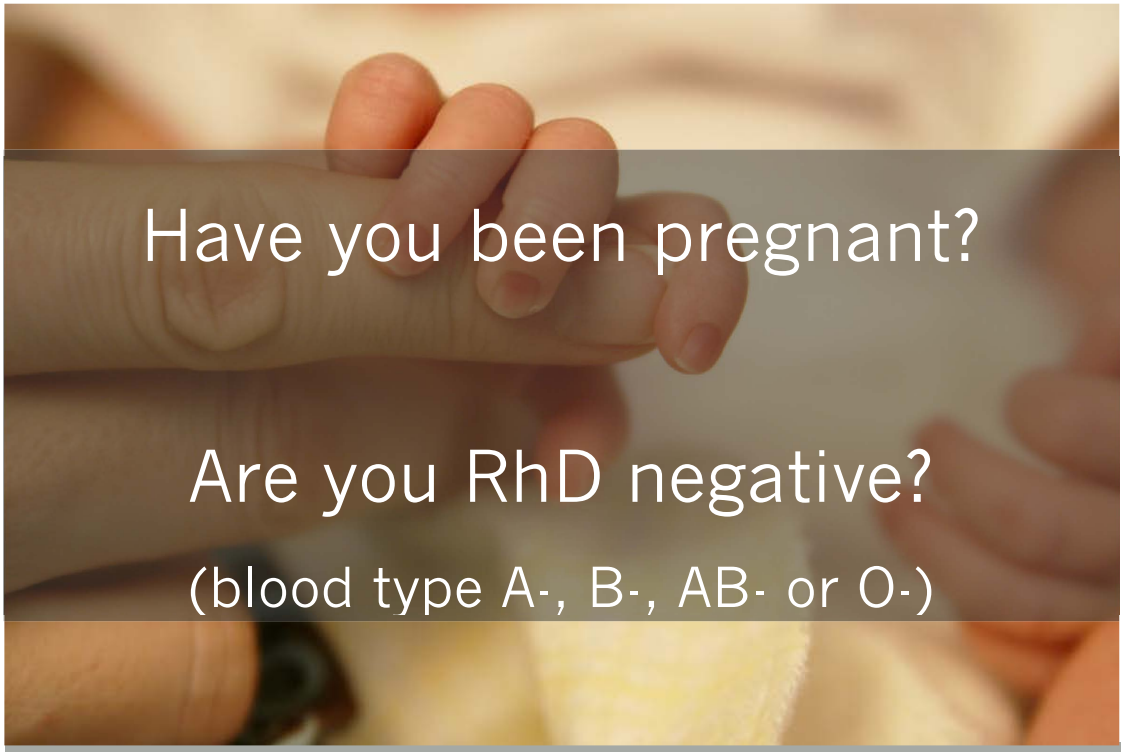
I am a doctoral candidate and this study is for partial completion of a PhD in Health Sciences at the University of Northern British Columbia (UNBC). I am interested in exploring the experiences of caring for pregnancies of RhD negative women in northern British Columbia. If you are interested in sharing your experience(s) with me in an interview, please contact me for more information.

This study has been reviewed by the University of Northern British Columbia's Ethics Review Board and Northern Health's Research Review Committee.

Trina Fyfe, Doctoral Candidate,
School of Health Sciences,
University of Northern British Columbia

250-961-3933
trina.fyfe@unbc.ca

Appendix G



PLEASE PARTICIPATE!

Prevention of RhD alloimmunization in Northern BC: Research study

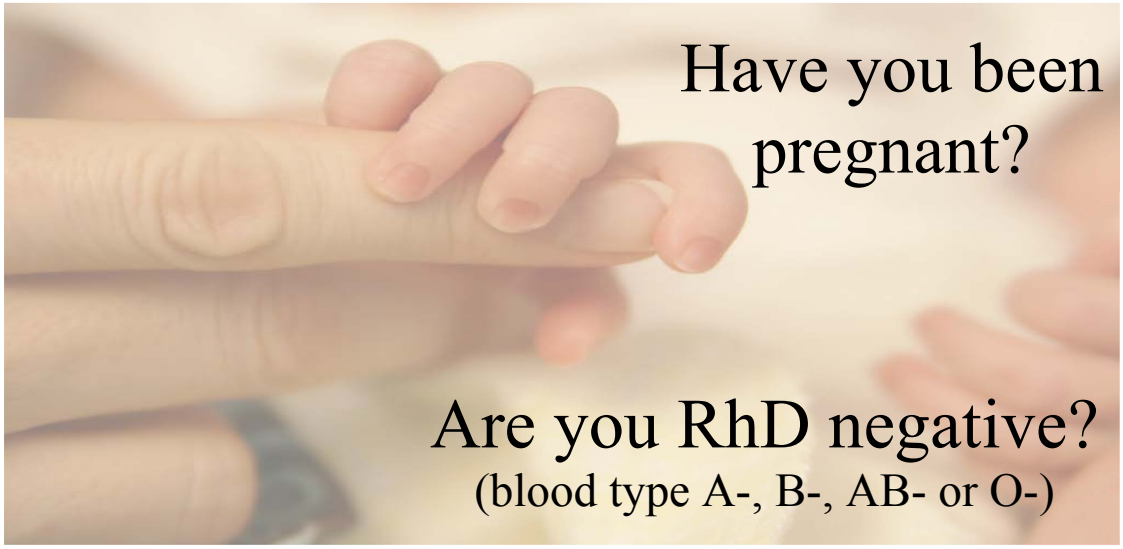
I am a doctoral candidate and this study is for partial completion of a PhD in Health Sciences at the University of Northern British Columbia (UNBC). I am interested in exploring the experiences of RhD negative women with pregnancy (since 2004) in northern British Columbia. If you are interested in sharing your experience(s) with me in an interview, please contact me for more information and/or to participate.

This study has been reviewed by the University of Northern British Columbia's Ethics Review Board and Northern Health's Research Review Committee.

Trina Fyfe, Doctoral Candidate,
School of Health Sciences,
University of Northern British Columbia

250-961-3933
trina.fyfe@unbc.ca

Appendix H



PLEASE PARTICIPATE!

Prevention of RhD alloimmunization in Northern BC: Research study

I am a doctoral candidate and this study is for partial completion of a PhD in Health Sciences at the University of Northern British Columbia (UNBC). I am interested in exploring the experiences of RhD negative women with pregnancy (since 2004) in northern British Columbia. If you are interested in sharing your experience(s) with me in an interview, please contact me for more information and/or to participate.

Contact:

Trina Fyfe
Doctoral Candidate
School of Health Sciences
University of Northern British Columbia
250-961-3933

This study has been reviewed by the University of Northern British Columbia's Ethics Review Board and Northern Health's Research Review Committee.

Trina.Fyfe@unbc.ca 250-961-3933
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Trina.Fyfe@unbc.ca 250-961-3933
Trina.Fyfe@unbc.ca 250-961-3933

Appendix I

Interview and Focus Groups with Healthcare Providers - Participant Questionnaire

1. What kind of health care provider are you?

   ☐ Physician
   ☐ Midwife
   ☐ Nurse practitioner
   ☐ Other: _____

2. If you are a physician, what is your discipline (check all that apply)?

   ☐ Family
   ☐ Emergency
   ☐ Obstetrics
   ☐ Other: _____

3. What year did you begin practicing? (year) _____

4. Is your practice fee for service?

   ☐ Yes
   ☐ No

5. How would you describe the geographic location of your practice?

   ☐ Rural
   ☐ Urban
   ☐ A bit of both
   ☐ Neither
   ☐ Don't know

6. Do you work within a care team? If yes, can you please describe your practice:

Appendix J

RhD negative women – Participant Questionnaire

1. What is your blood type?

   ☐A

   ☐B

   ☐AB

   ☐O

   ☐Not sure

2. What is your Rhesus status?

   ☐Rh +

   ☐Rh –

   ☐Not sure

3. What is your month and year of birth? (MM/YYYY)

   ☐

4. What is the highest level of schooling you have completed? (If currently enrolled, highest degree received.)

   ☐No schooling completed

   ☐Kindergarten to grade 8

   ☐Some high school, no diploma

☐ High school graduate

☐ Some college or university, but no degree

☐ Trade/technical/vocational training

☐ Bachelor's (Undergraduate) degree

☐ Master's degree

☐ Professional degree

☐ Doctorate degree

☐ Other:

5. Have you even been pregnant? *(Pregnancy defined as knowingly been pregnant, whether or not the pregnancy was viable, terminated, miscarried or carried to full-term with a live birth.)*

☐ Yes

☐ No

Appendix K

Interview Guide for Health care providers

Confirm:

1. *Participation in the interview is voluntary*
2. *Participant's may choose to withdraw at any point*
3. *Ask: Do you understand your rights as a participant, and provide verbal consent? [Or thank for returning the signed informed consent].*

Research question: How do health care providers make decisions regarding the care of RhD negative pregnancies in northern British Columbia?

1. Tell me about a time you had to make a difficult decision or a decision regarding a medical incident you were unfamiliar with.
    a. What information did you use?
        i. Did you use a guideline? If so, tell me about your experience using the guideline(s).
    b. Who was involved in the decision-making process?
    c. What was the outcome(s)?
    d. What would you do the same or differently the next time you are faced with a difficult decision?
2. Tell me about a time when you managed a pregnancy for which the woman was RhD-negative.
    a. What decisions needed to be made?
    b. What information did you use?
    c. Who was involved in the decision-making process?
    d. What was the outcome(s)?

e. What would you do the same or differently the next time you manage an RhD-negative pregnancy?

3. Is there anything else you would like to share about decision-making and/or managing RhD-negative pregnancies?

Appendix L

Interview Guide for RhD negative women that have been pregnant

Confirm:

1. *Participation in the interview is voluntary*
2. *Participant's may choose to withdraw at any point*
3. *Ask: Do you understand your rights as a participant, and provide verbal consent? [Or thank for returning the signed informed consent].*

Research question: How do RhD negative women in northern British Columbia experience pregnancy?

Is there anything you would like to share before we begin?

1. In your own words what does it mean to be RhD negative?
    a. What does it mean in the context of pregnancy?
2. When did you first learn you are RhD negative?
    a. Who told you? When were you told? How were you told?
    b. What questions did you have?
    c. How did you answer those questions?
3. Tell me about your experience(s) being pregnant and RhD negative.
    a. What decisions needed to be made?
    b. What information did you use?
    c. Who was involved in the decision-making process?
    d. What were the outcomes?
4. What advice would you have for another RhD negative women who is pregnant for the first time?
5. What advice would you have for healthcare and healthcare providers regarding the management of RhD negative pregnancies?

Appendix M

UNBC UNIVERSITY OF NORTHERN BRITISH COLUMBIA

Information Letter / Consent Form for Interviews with Health Care Providers

May 15, 2016

Prevention of RhD alloimmunization in Pregnancy in Northern British Columbia

Project Lead: Trina Fyfe

University of Northern British Columbia

Prince George, BC V2N 4Z9

Trina.Fyfe@unbc.ca and/or (250) 960-5195

This study is for partial completion of a PhD in Health Sciences at the University of Northern British Columbia (UNBC).

Purpose of Project

You are being invited to take part in this research study because you are a healthcare provider that is involved in perinatal and maternal care. I want to learn more about clinical decision-

making in rural healthcare with a particular focus on the care of pregnancies of RhD negative women.

Your participation is voluntary and you are able to withdraw from the study at any time, without giving a reason. Any information that you may have provided will be securely destroyed. In addition, you do not have to answer any questions that make you feel uncomfortable.

What will happen during the project?

In this study I will ask you about your experience(s) with managing pregnancies of RhD negative women. You will be asked to fill out a brief questionnaire prior to the interview. The interview will be recorded and may take as long as 90 minutes or as little as 20 minutes. It will be dependent on your experience and what you are willing to share. The interviews will be conducted using Skype (if available) or over the phone.

Risks or benefits to participating in the project

You may not see direct benefits with your participation in this study. However, your participation will provide you with the opportunity to share your experience with the use of information, the decision-making process and with the care of pregnancies of RhD negative women. Your experiences may help to improve healthcare practice, particularly as it relates to the specific medical situation looked at in this study.

There is minimal risk in participating in this study. Sharing your healthcare experience with the researcher may be upsetting. If this happens please let me know that you are upset and I will provide you with contact information for counseling and/or support services.

Confidentiality, Anonymity and Data Storage

Your anonymity will be respected. Information that discloses your identity will not be released without your consent. The only people that will have access to this information will be my supervisors, committee members, a transcriptionist and myself. The transcriptionist will be required to sign a confidentiality agreement. All transcripts and documents will be identified only by code number and kept in a locked filing cabinet in a locked office and on a password-protected computer. Subjects will not be identified by name in any reports of the completed study. The information gathered from this study will be kept for 5 years. It will then be securely destroyed [e.g. by shredding paper files, deleting digital files, etc.].

Study Results

The results of this study will be reported in a graduate dissertation and may also be presented at conferences, and published in journal articles. If you would like to be notified when my dissertation will be available in the UNBC Library please check the following box and indicate the best way to reach you:

☐ Please notify me when the dissertation is available via:

Questions or Concerns about the project

If you have any questions about what I am asking of you, please ask me. My name and telephone number are listed at the top of the first page of this form.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the UNBC Office of Research at 250-960-6735 or by e-mail at reb@unbc.ca.

Participant Consent and Withdrawal

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your [for example, employment, class standing, access to further services from the community center, day care, etc.].

Has this study undergone ethics review?

Yes, the University of Northern British Columbia and Northern Health's Research Review Committee have reviewed this research. If you have any questions or concerns about your rights as a participant, or how this study is being conducted, please contact:

University of Northern British Columbia

Research Ethics Board

Phone: (250) 960-6735

Email: reb@unbc.ca

CONSENT (please circle)

I have read or been described the information presented in the information letter about the project:

YES NO

I have had the opportunity to ask questions about my involvement in this project and to receive additional details I requested.

YES NO

I understand that if I agree to participate in this project, I may withdraw from the project at any time up until the report completion, with no consequences of any kind. I have been given a copy of this form.

YES NO

I agree to be recorded.

YES NO

Follow-up information (e.g. transcription) can be sent to me at the following e-mail or mailing address (if applicable):

YES NO

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Signature (or note of verbal consent): _____

Name of Participant (Printed): _____

Date: _____

Statement of Consent

☐	I have read this information letter.
☐	I have had the opportunity to discuss this research study with Trina Fyfe.
☐	I have had my questions answered by them in language I understand.
☐	The risks and benefits have been explained to me.
☐	I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements.
☐	Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate.
☐	I understand that I will be given a copy of this consent form after signing it.
☐	I understand that my participation in this study is voluntary and that I may choose to withdraw at any time, with no consequences of any kind.
☐	I freely agree to participate in this research study.
☐	I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed.
☐	I authorize the inspection of any of my records that relate to this study by Northern Health Ethics Board or The University of Northern British Columbia Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study,

Yes _____ No _____

Participant signature: _____

Participant printed name: _____

Date (day/month/year): _____

Appendix N

UNBC UNIVERSITY OF NORTHERN BRITISH COLUMBIA

Information Letter / Consent Form for Interviews with RhD negative Women

May 15, 2016

Prevention of RhD alloimmunization in Pregnancy in Northern British Columbia

Project Lead: Trina Fyfe

University of Northern British Columbia

Prince George, BC V2N 4Z9

Trina.Fyfe@unbc.ca and/or (250) 961-3933

This study is for partial completion of a PhD in Health Sciences at the University of Northern British Columbia (UNBC).

Purpose of Project

You are being invited to take part in this research study because you are a RhD negative women that has been pregnant after 2004. I want to learn more about how RhD negative pregnancies are managed in Northern British Columbia.

Your participation is voluntary and you are able to withdraw from the study at any time, without giving a reason. Any information that you may have provided will be securely destroyed. In addition, you do not have to answer any questions that make you feel uncomfortable.

What will happen during the project?

In this study I will ask you about your experience(s) with pregnancy as it related to your RhD negative status. You will be asked to fill out a brief questionnaire prior to the interview. The interview will be recorded and may take as long as 90 minutes or as little as 20 minutes. It will be dependent on your experience and what you are willing to share. The interviews will be conducted using Skype (if available) or over the phone.

Risks or benefits to participating in the project

You may not see direct benefits with your participation in this study. However, your participation will provide you with the opportunity to share your experience with health care. Your experiences may help to improve health care practice, particularly as it relates to the specific medical situation looked at in this study.

There is minimal risk in participating in this study. Sharing your health care experience with the researcher may be upsetting. If this happens please let me know that you are upset and I will provide you with contact information for counseling and/or support services.

Confidentiality, Anonymity and Data Storage

Your anonymity will be respected. Information that discloses your identity will not be released without your consent. The only people that will have access to this information will be my supervisors, committee members, a transcriptionist and myself. The transcriptionist will be required to sign a confidentiality agreement. All transcripts and documents will be identified only by code number and kept in a locked filing cabinet in a locked office and on a password-protected computer. Subjects will not be identified by name in any reports of the completed study. The information gathered from this study will be kept for 5 years. It will then be securely destroyed [e.g. by shredding paper files, deleting digital files, etc.].

Study Results

The results of this study will be reported in a graduate dissertation and may also be presented at conferences, and published in journal articles. If you would like to be notified when my dissertation will be available in the UNBC Library please check the following box and indicate the best way to reach you:

☐ Please notify me when the dissertation is available via:

Questions or Concerns about the project

If you have any questions about what I am asking of you, please ask me. My name and telephone number are listed at the top of the first page of this form.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the UNBC Office of Research at 250-960-6735 or by e-mail at reb@unbc.ca.

Participant Consent and Withdrawal

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact.

Has this study undergone ethics review?

Yes, the University of Northern British Columbia Research Ethics Board and Northern Health's Research Review Committee reviewed this research. If you have any questions or concerns about your rights as a participant, or how this study is being conducted, please contact:

University of Northern British Columbia

Research Ethics Board

Phone: (250) 960-6735

Email: reb@unbc.ca

CONSENT (please circle)

I have read or been described the information presented in the information letter about the project:

YES NO

I have had the opportunity to ask questions about my involvement in this project and to receive additional details I requested.

YES NO

I understand that if I agree to participate in this project, I may withdraw from the project at any time up until the report completion, with no consequences of any kind. I have been given a copy of this form.

YES NO

I agree to be recorded.

YES NO

Follow-up information (e.g. transcription) can be sent to me at the following e-mail or mailing address (if applicable):

YES NO

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Signature (or note of verbal consent): _____

Name of Participant (Printed): _____

Date: _____

☐	I have read this information letter.
☐	I have had the opportunity to discuss this research study with Trina Fyfe.
☐	I have had my questions answered by them in language I understand.
☐	The risks and benefits have been explained to me.
☐	I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements.
☐	Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate.
☐	I understand that I will be given a copy of this consent form after signing it.
☐	I understand that my participation in this study is voluntary and that I may choose to withdraw at any time, with no consequences of any kind.
☐	I freely agree to participate in this research study.
☐	I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed.
☐	I authorize the inspection of any of my records that relate to this study by Northern Health Ethics Board or The University of Northern British Columbia Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

I agree to be contacted for future follow-up in relation to this study,

Yes _____ No _____

Participant signature: _____

Participant printed name: _____

Date (day/month/year): _____