



Rhesus D factor (RhD) negative women's experiences with pregnancy: An interpretive description

Trina M. Fyfe^{a,*}, Josée G. Lavoie^b, Geoffrey W. Payne^c, Davina Banner^d

^a Health Sciences Librarian, Northern Medical Program, Faculty of Medicine, University of Northern British Columbia, 3333 University Way, Prince George, British Columbia, V2N 4Z9, Canada

^b Dept of Community Health Sciences, Faculty of Health Sciences, University of Manitoba, #715, 727 McDermot Avenue, Winnipeg, MB, R3E 3P5, Canada

^c Northern Medical Program, University of Northern British Columbia, 3333 University Way, Prince George, British Columbia, V2N 4Z9, Canada

^d School of Nursing, University of Northern British Columbia, 3333 University Way, Prince George, British Columbia, V2N 4Z9, Canada

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ABSTRACT

Background: The development of rh immune globulin (RhIG) for the prevention of Rhesus D (RhD) alloimmunization has significantly decreased the incidence of RhD alloimmunization. Despite long-standing prevention, the experiences of RhD negative women with pregnancy is absent in the literature. **Aim:** The purpose of this study was to explore the experiences of RhD negative women with pregnancy. **Methods:** Utilizing an Interpretive Description approach, semi-structured interviews were conducted with RhD negative women about their pregnancies. This study took place within the geographic context of northern British Columbia (BC). The analysis involved a two-cycle approach to identify themes within the data.

Findings: Sixteen RhD negative women that live in northern BC participated in this study. The analysis identified that RhD negative women are uninformed and want to be involved in the decision-making process regarding the prevention of RhD alloimmunization. The themes that emerged from the interview data were communication, information-seeking behaviour, out of sight out of mind, choice and trust, and patient advocacy.

Discussion: The participants in this study described lacking information regarding the prevention of RhD alloimmunization. They sought information to overcome the gaps in knowledge and a desire to be involved in the decision-making process.

Conclusion: RhD negative women want information and to be involved in the decision-making process in the prevention of RhD alloimmunization. Working with RhD negative women to develop decision-aids and/or other educational tools to aid in the decision-making process are warranted.

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Statement of significance

Problem or Issue

Since the implementation of Rh immune globulin to prevent RhD alloimmunization, the experiences of RhD negative women have not been explored.

What is already known

The development of rh immune globulin (RhIG) for the prevention of Rhesus D (RhD) alloimmunization has significantly decreased the incidence of RhD alloimmunization.

What this paper adds

This qualitative study identified that RhD negative women are not fully informed about the prevention of RhD alloimmunization and want to be involved in the decision-making process.

* Corresponding author.

E-mail address: Trina.Fyfe@unbc.ca (T.M. Fyfe).

1. Introduction

The prevention of Rhesus D Factor (RhD) alloimmunization in higher income countries remains one of the most important medical accomplishments of the last century [1–3]. The prevention program involves the administration of Rh immune globulin (RhIG), both antenatally and post-natally, and remains the gold standard in effective prevention [4–7]. Prior to the development of a prophylaxis, families suffered the loss of the fetus and/or newborn as a consequence of Hemolytic Disease of the Fetus/Newborn (HDF/N). The discovery of the antibody formation in RhD negative women toward RhD positive fetuses was a breakthrough in the identification of HDF/N [8–11]. Once the mechanism facilitating HDF/N onset was determined, the development of a prophylaxis, Rh immune globulin, followed soon after [8]. The implementation of the prevention program in the late 1960s has led to a significant decrease, and near eradication, of RhD alloimmunization in developed countries [1–3]. The plasma derived prophylaxis, if administered at the key time point, prevents RhD negative pregnant women from developing D antibodies during sensitizing events and/or at the birth of an RhD positive newborn.

The 2016 Canadian Paediatric Surveillance Program identified seven cases of RhD alloimmunization resulting in severe neonatal hyperbilirubinemia over a seven month period in 2016 [12]. What is not known from the surveillance data is the underlying cause of RhD alloimmunization, including preventable and non-preventable causes. Based on retrospective studies, there is a risk of the RhD negative pregnant population not receiving RhIG when needed [13–24]. There are many factors that could lead to preventable RhD alloimmunization, such as a RhD negative pregnant woman not receiving RhIG when required, patient refusal, Rh blood group is not determined, RhIG is not readily and/or freely available, but current research does not yet provide that level of evidence [25]. These studies provide evidence that RhD negative women are still at risk of developing antibodies because they may not have their RhD status confirmed and/or not receive RhIG when needed, but the reasons for these lapses in prevention are not fully understood [13]. Further to this, absent from the literature is an exploration of what women know about being RhD negative and pregnant, and if they choose or decline to receive RhIG, and the reasons for refusal.

This study is situated in a vast geographic region of Canada, northern British Columbia (BC), that includes remote and rural locations. Large regionalized health systems struggle to provide equitable care to rural communities due to limited resources, services and healthcare provider recruitment and retention [26–28]. These challenges lead to inequities and can impact the quality of care received by the people in these communities. Absent from the literature are studies that focus on the experiences of pregnant women that are RhD negative and the quality of care they receive in large regionalized healthcare systems.

The purpose of this study was to explore the experiences of RhD negative women with pregnancy and provides recommendations for practice and research. Our research question was: *How do RhD negative women in northern BC experience pregnancy?*

2. Methods

2.1. Study design

The purpose of this study was to explore the experiences of pregnancy for RhD negative women. Interpretive description, an applied approach to qualitative health research, was used to address the research question [29]. The research was informed by an Integrated Knowledge Translation (IKT) strategy, a collaborative

approach to research that requires the engagement of knowledge users across the research process [30]. Knowledge users, including perinatal program leaders, family and emergency physicians, a midwife, an obstetrician, transfusion services supervisor, a rural nurse practitioner and a patient representative, were engaged in the development of the research question, interview guide, reviewing emerging analysis, and informing the knowledge translation plan.

Semi-structured interviews were conducted with RhD negative women to explore their experiences with pregnancy. The themes that emerged from the data provide practical information used to inform the development of health system and practice recommendations.

2.2. Participants and setting

RhD negative women that had been pregnant on or after January 1, 2004 were recruited between June and December 2016. Participants were recruited from communities within the Northern Health Authority (NH) catchment area located in northern British Columbia (BC), Canada. Northern BC is a vast geographic area covering an estimated 617,279 square kilometers of land and includes 17 Local Health Areas [31]. Due to the vast geography, recruitment strategies needed to be wide reaching. The recruitment strategies involved posting recruitment material on northern BC mother and baby Facebook group message boards (with approval from group administrators), posters in NH laboratories and immunization clinics, and posters sent to public libraries located across northern BC.

To be eligible for inclusion, participants were required to self-identify as RhD negative and had been pregnant on or after January 1, 2004. The cutoff date of 2004 was chosen due to the implementation of the 2003 SOGC RhD alloimmunization prevention guidelines. Pregnancy was defined as knowingly been pregnant, whether or not the pregnancy was viable, terminated, miscarried or carried to full-term with a live birth.

Research Ethics Board approval was obtained from the University of Northern British Columbia (UNBC) and NH (E2016.0413.032.00). Prospective participants were given a comprehensive information sheet outlining the objectives of the study, details of participation, how the data will be stored and privacy maintained, and the benefits and risks of participating. Upon agreement, the participants were asked to sign a consent form and verbal consent was given prior to the commencement of the interview. Participants were reminded prior to the interview that they could withdraw from the study at any point.

2.3. Data collection

A brief questionnaire was used to screen participants for eligibility. Participants self-identified as RhD negative, indicated that they were pregnant on or after January 1, 2004 and provided key demographic characteristics, such as their year of birth, highest level of education and number of pregnancies. All seventeen RhD negative women that expressed interest in participating were eligible to participate. One participant was lost to follow-up between the completion of the screening questionnaire and the interview.

Semi-structured interviews ranged from 30–60 min in duration and were conducted over the phone or in-person at a negotiated neutral location by TF using an interview guide. The interviews were digitally-recorded and transcribed verbatim by a professional transcriptionist and participants were assigned unique identifiers to preserve anonymity. The interview guide included questions that asked participants about their knowledge of Rh factor and pregnancy, where they learned the information they had, how they

filled identified gaps in knowledge and general experiences of pregnancy as an RhD negative woman.

In keeping with an Interpretive Description approach to inquiry, data saturation was not utilized to decide when to end data collection. Interpretive description argues that data collection can be a continuous process because each participant brings with them new experiences, values and knowledge [29,32]. Instead, the researcher should focus on patterns and trends, and identify if more data is required if variance remains. In this study, the stakeholder committee provided the researcher, TF, with guidance as to whether there was enough data to see trends and patterns that are applicable to practice.

2.4. Analysis

Interpretive Description encourages the applicability of results to practice [29]. The analysis process involved a two-cycle approach [33]. The first cycle required coding chunks of data. The second-cycle of coding involved assessing the chunks for patterns and trends. These were then clustered according to descriptive themes. Coding software, NVIVO 12, was used to facilitate the coding process [34]. Data were analyzed by the lead investigator TF with peer checking by DB. Additionally, a Stakeholder Committee reviewed the analysis, further confirming the patterns and trends emerging from the data.

2.5. Rigour

We implemented a number of strategies throughout the process of our research study to ensure rigour. First, to establish credibility we invited participants to review the written transcripts of their interviews for accuracy [35]. Second, participants were contacted in the event that there were additional questions arising from the analysis. This only occurred in two instances. Third, participants were also offered the opportunity to review emerging interpretations. None of the participants requested this opportunity. Finally, the findings were compared to existing research and prior scoping review [13].

In addition, the lead investigator sought to promote rigor by engaging in reflexivity. The interviewer is a mother and developed RhD alloimmunization during pregnancy. Although this was not identified at the outset of every interview, the interviewer disclosed this information if the participant asked why this study was of interest to the researcher. The interviewer addressed this personal topic throughout the research process by keeping a reflexive journal to reflect upon assumptions, perceptions and emotions generated by engaging in this study [32,36].

3. Results

Sixteen RhD negative women, mean age of 33 years, were interviewed about their pregnancies. One participant (RhDW04) was lost in follow-up. At the time of the interviews, all the participants were currently residing in communities across northern BC, 14 of the women had multiple pregnancies, and all had some post-secondary training (Table 1).

In congruence with the Interpretive Description approach [29], the interview data were coded and analyzed thematically resulting in the identification of five themes. The theme *Communication* refers to the exchange of information between healthcare providers and participants with a subtheme of *method and timing of information* being an important aspect to the overall exchange. Further to communication, the theme of *Information-seeking behaviour* evolved out of the need for information due to a gap in knowledge and lack of communication. The theme of *Out of sight, out of mind* refers to participants consciously and unconsciously

Table 1
Demographic characteristics of participants (N = 16).

Characteristic	N (%)
Number of pregnancies	
1	2 (12.5)
2	8 (50)
3	2 (12.5)
4	2 (12.5)
5	1 (6.25)
6	0
7+	1 (6.25)
Age group	
<25	0
25–29	2 (12.5)
30–34	7 (43.75)
35–39	5 (31.25)
40+	2 (12.5)
Highest level of education	
Some college or university, but no degree	4 (25)
Undergraduate degree	6 (37.5)
Graduate Degree	1 (6.25)
Trade/technical/ vocational training	4 (25)
Other	1 (6.25)

not concerning themselves about being RhD negative. *Choice and Trust* emerged as a theme referring to participant involvement and preference in the decision-making process during pregnancy. The final theme of *Patient Advocacy* refers to the ability of participants to advocate for themselves and their pregnancy.

3.1. Communication

Communication was a central issue identified by most of the study participants during the interviews. Participants identified that the communication of the RhD alloimmunization prevention program was inadequate, and negatively influenced their experience of pregnancy. One woman stated that the manner used by the healthcare provider to discuss her RhD status and miscarriage was “quite flippant” (RhDW 07), while others commented that they did not feel able to ask questions or get more information during their visits with their health care providers. For two of the participants (RhDW 09, RhDW 07), the busy schedule of the providers was a key barrier to communication. Further, the methods of communication, along with the timing of information, were considered a pattern that emerged as important and, at times, problematic.

3.1.1. Method and timing of communication

The approach and timing of communication related to the prevention of RhD alloimmunization by healthcare providers with RhD negative participants varied. Two participants (RhDW 05 and 16) expressed that providers lacked confidence in their delivery of the information causing feelings of fear and a need to find more information.

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 ... (laughs). (RhDW 05)

The nurse, you know, she said she wasn't sure she was supposed to tell me about my blood type but she said 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)

The timing of information provided during pregnancy about the prevention of RhD alloimmunization was discussed by three of participants (RhDW 16, 14 and 07). Participants described not

receiving information during sensitizing events about Rh factor and RhIG, resulting in a perceived lack of communication.

Like okay that's good, you know, cause usually when you first hear about information if you are pregnant or get an abortion or whatever, your emotions are a little bit, you know, sensitive as it is. You're hear all this other weird stuff and you're like okay what's wrong with me or something, right. It goes through your mind for a few seconds, right. (RhDW 16)

And so we moved up North when I was 4 1/2 months pregnant and I went to the clinic here in [Community X] and told them I needed, because I'm O negative, to get like this injection and I needed it. And they didn't give it to me in time. But then . . . we called the doctor at home and he said go back to the clinic and they'll give it to you right away cause there's a certain window that I was aware of and so after fighting with the clinic staff I got it. But it was kind of a nerve wracking moment cause I didn't really quite know what was going to happen if I didn't get this injection that I was told that I needed . . . (RhDW 14)

One of the participants, RhDW 07, had two miscarriages, the first miscarriage required an emergency dilation and curettage (D&C). She recalled that she was tired and emotional after the procedure. She remembered having a conversation with the attending nurse about RhIG, but did not have a full understanding of what this meant. She stated that she sought information on RhD negative pregnancies only after she was home and feeling better after her miscarriage. The participant stated that having the information delivered to her when she felt tired and emotional made it seem unimportant. The participant recommended that it would be beneficial for patients to receive information in a way that they can take it away and read it at a time when they are ready. Overall, the participants recognized the importance of accurate, timely and confident communication, particularly when faced with a sensitizing event.

3.1.2. Information-seeking behaviour

The need for information on the prevention of RhD alloimmunization was apparent amongst participants. Ten of the participants sought more information, while the other six were content with the level of information provided by their healthcare providers.

Four participants stated that they wanted more information on the prevention of RhD alloimmunization to satisfy their information need (RhDW 02, 07, 09 and 16):

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)

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 . . . Like I don't know any of that. (RhDW 09)

Six participants (RhDW 02, 07, 10, 11, 12 and 13) suggested that RhD negative women should receive patient level information regarding the prevention of RhD alloimmunization during pregnancy. The participants suggested that the information should cover Rh factor and its impact on pregnancy, potential complications, the prevention program, and, in particular, what RhIG is and how it works to prevent the development of antibodies.

Um, definitely explain it more, just talk about it more. I'm not sure if there is room for choice or not, um, so as a mom I wouldn't want my potential future babies to be at risk either, right. But it would be nice to know more about the medicine that we're being given and more about what it means to be Rh negative cause I still don't know. (RhDW 02)

. . . 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)

Because of course we have people who don't vaccinate and all of that, they won't get the flu shot when they're pregnant, they can't clean cat litter and that, so you're administering a blood product to somebody who's growing an embryo and maybe just some education on what effect that has on the developing baby. (RhDW 10)

Participants who reported being uninformed described seeking information to satisfy their information needs. This involved asking their healthcare providers, family and friends, reading pregnancy related books and searching the Internet.

Those who sought information from pregnancy books expressed dissatisfaction stating that the books "put worry and doubt into your head" (RhDW 08) and that one of the 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). Both of these participants sought further information from searching the Internet for more information regarding the prevention of RhD alloimmunization.

The internet was another key source of information for the participants. Four participants (RhDW 07, 09, 12 and 13) stated that they sought information by searching the Internet. They described searching for overviews of pregnancy and being RhD negative, while others specifically looked at the history of HDF/N and the development of RhIG. These women described informally evaluating the information they retrieved searching the Internet. It must be stated that all the participants self-identified as having some post-secondary training and/or education. It is assumed that this level of training/education provided the participants with some evaluation skills used to assess the information found online.

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. (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)

While the majority of the participants received information from their provider or existing sources of information, two participants (RhDW 08, 13) stated that they learned their Rh status from their mothers/parents. Others sought information from family and friends about the process of receiving the RhIG and received supportive reassurance throughout their 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. (RhDW 13)

Contrary to seeking information, one participant stated that RhD status was never something she and her friends discussed during pregnancy:

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)

The need for information was identified by most of the participants and they sought the information from various sources. In some instances, the participants evaluated the information they found online.

3.2. Out of sight, out of mind

Two RhD negative women did not know that their Rh status could have an effect on pregnancy, while others (three participants) consciously chose not to cogitate about it during pregnancy. For two women, their RhD negative status was not a priority because they had other conditions that they stated required more focus and attention (RhDW 02 and 07). Three participants (RhDW 05, 09, 12) chose not to worry about their RhD status in pregnancy because they did not see it as a concern.

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, 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)

... nothing was really different compared to anyone else who would've been pregnant. It's just a shot ... (RhDW 09)

One participant (RhDW 12) discussed the mindful decision not to concern herself with things that might worry her during pregnancy, such as RhD alloimmunization.

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. (RhDW 12)

For these participants their RhD status was not at the forefront of their minds. This demonstrates a level of prioritization that RhD negative women engage in regarding their health concerns during pregnancy.

3.3. Trust and choice

Trust was identified as an important aspect for participants in their experience with the prevention of RhD alloimmunization. Three participants (RhDW 05, 09 and 11) discussed trust with the healthcare systems and with their healthcare providers. These participants stated that their healthcare providers delivered adequate care and used strong words like "trust" and "believe" to describe their dependence on the system that care for their pregnancies.

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

I felt that my midwife was on top of it. I trusted my midwife. I felt that it was a pretty standard thing ... (RhDW 11)

Trust led to a perception of choice to receive RhIG for one participant. RhDW 11 stated that she perceived to have a choice in receiving RhIG during pregnancy and this was based on her providers approach to her care. RhDW 11 described a discussion with her healthcare provider that involved her in the decision-making process for receiving RhIG.

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 ... that I was part of the decision, you know, like even if things had to be done, it was always a discussion (RhDW 11)

The experience of RhDW 11 was not common amongst the participants interviewed for this study. Two participants (RhDW 02 and 05) expressed they did not have a choice in receiving RhIG. It is unclear what the participants understood about RhIG is and why it is important, but RhDW 05, said that she would have opted out of receiving RhIG if she knew her baby would be unaffected. The participant expressed frustration with the prevention program, stating that it was functioning under a worst-care scenario and utilized the phrase "just for kicks" to emphasize that the prevention seems unnecessary, particularly if some of the risk factors could be ruled out (like knowing the paternal Rh factor).

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)

Another participant, RhDW 02, was not aware if receiving RhIG was by choice but did understand the risks that without it, future pregnancies may be at risk. Overall, the participants expressed trust in the healthcare system, but greater attention to informed consent and choice is needed.

3.4. Patient advocacy

Participants struggled to advocate for themselves during their first pregnancy. The interview data from women that had experienced more than one pregnancy used statements that described being uninformed during the first pregnancy and the ability to advocate during the next. 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. (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, a synthetic prostaglandin used to induce labour, to ensure the miscarriage was completed. 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 an early miscarriage and having to demand that she receive RhIG she stated 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)

Participants described being uninformed during their first pregnancy. With subsequent pregnancies, participants told a different story. They knew what to expect, when to expect it, were informed and were comfortable asking their providers for information when they thought it was necessary.

4. Discussion

The purpose of this study was to explore the experiences of RhD negative women with pregnancy within the context of northern BC. The study identified 6 themes RhD negative women experiences with the prevention of RhD alloimmunization during pregnancy. The women in this study stated that they did not understand what RhIG is and how it works to prevent the development of D antibodies. For some women, they trusted their healthcare providers and the system to provide safe care.

A lack of information about the prevention of RhD alloimmunization and the prophylaxis, RhIG, was an important theme. The perceived lack of information is comparable to the findings of Brown et al.'s study that identified women with a history of preeclampsia desired more information about the prevention, development, and potential consequences of preeclampsia [37]. To overcome this lack of information, healthcare providers should ensure that RhD negative pregnant women are provided with verbal and written information to ensure that they are able to make informed decisions.

When there is a perceived lack of information, pregnant women seek information about pregnancy as a means of narrowing a knowledge gap and to normalize, or gain, reassurance about their experiences by viewing the experiences of others [38–41]. In our study, RhD negative women expressed that they were uninformed about being RhD negative and pregnant, the prevention program of RhIG, and the risks of RhD alloimmunization. The lack of understanding for some participants meant that they sought information to overcome the knowledge gap. These participants found information by searching online, looking in books and asking friends and families. Other participants were content with the limited information and did not seek any further information. Participants in this study discussed critical evaluation of what they found online. This is reflective of existing literature that found that women are critical of what they find online [40]. Despite these findings, more research is needed on the critical evaluation skills of people using online information and into the role of the healthcare provider in guiding this process [39,40].

The timing of information was a critical factor to the RhD negative women. When information was presented during a sensitizing event, participants stated that their RhD status was not at the forefront of their mind. They required information to be given to them in a way that allowed them to explore it in detail when they were ready and able to digest the information. Identifying the right time to discuss and present information about the risk of potential short and long-term consequences should be considered [37]. The need for information about the prevention of RhD alloimmunization led to women suggesting that a handout with specific information be readily available in order for them to consider at a point in time that worked for them [37].

The concept of choice in participating in the prevention program was important to some RhD negative women. This resonates with Munro et al.'s work on choice that found women are not aware they had a choice in prenatal screening and some women wanted involvement in the decision-making process [42]. The SOGC recently updated the prevention of RhD alloimmunization guidelines [7]. For the first time, the guidelines address the concept of choice. There is language within the guideline that addresses the paternal certainty of the fetus. Healthcare providers are now provided guidance on the discussion to have with RhD negative pregnant women when there is paternal certainty and RhD status is known of the paternal partner. This language may provide women who want more decision-making power within the provider-patient relationship the opportunity to discuss and decide to opt in or out of the RhD alloimmunization prevention program.

In some countries, fetal RhD genotyping has been implemented to target RhIG administration in RhD negative pregnant women [43–45]. Fetal RhD genotyping uses a sample of maternal blood to determine the Rh factor of the fetus [46,47]. This test reduces the need for RhD negative women to receive RhIG unnecessarily during pregnancy. In Canada, providers request fetal RhD genotyping only when a RhD negative pregnant woman's perinatal screening identifies the fetus to be at high risk for HDFN [48,49]. The SOGC has recommended the implementation of a targeted approach [50]. The recommended approach may help to address the concerns of choice and lack of communication found in this study by only targeting those at risk of HDFN. Future research exploring fetal RhD genotyping and the potential influence this may have on patient decision-making is required. Based on the discussion of choice and the fetal RhD genotyping program, it is recommended that a patient decision-aid be developed that focuses on the prevention of RhD alloimmunization that could lead to discussions with their healthcare provider and ensure that women are able to engage in informed and partnered decision-making.

RhD negative women that have had multiple pregnancies are able to advocate for themselves within the healthcare system. Women, pregnant with their first child experience uncertainty, have a lot of questions, not sure what questions to ask, and are not familiar with the healthcare system and processes [40,41]. The RhD negative women in our study demonstrated an increased ability to advocate for their subsequent pregnancies because they knew what to expect with the RhD alloimmunization prevention program, such as when to receive RhIG, where and how to obtain it, and who should administer the injection. First time mothers that are RhD negative need to be educated about their RhD negative status, how that impacts pregnancy, the potential risks and how it can be prevented. This lack of understanding cannot be left to experiential learning, it should be addressed and provided in a way that women can integrate the new knowledge into the care of their unborn infant.

There are several limitations to this study. All participants in this study self-identified as RhD negative and knowingly had not

developed D antibodies or choose not to disclose that information. Anytime someone self-identifies for a research study there is a risk that they are incorrect. The strict participant criteria were put in place to mitigate any issues regarding the eligibility of participants. The brief questionnaire acted as a screening tool to ensure participants were eligible. In addition, the study was located within one geographical region. It is possible that the experiences of these women may not necessarily be similar to those in another region. Recruitment for the study was challenging, particularly when attempting to recruit women from remote or more isolated areas of the region. Future studies exploring rural and remote regions should identify focused recruitment strategies within each of the target communities to ensure adequate representation.

5. Conclusion

This is the first study to explore the experiences of RhD negative women with pregnancy. This study identified that RhD negative women lack an understanding of the importance of RhD status in pregnancy and how RhD alloimmunization is prevented with RhIG. When faced with a gap in knowledge and a lack of information RhD negative women seek information from various resources, including searching the internet. The participants expressed that they want to be involved in the decision-making, including having information presented in a timely way. The lack of understanding and information stated by the women in this study provides insight into a critical health issue that has been under appreciated and requires general awareness strategies. It is paramount that the experiences highlighted in this study need to inform new policies to address this issue, as well as introduce patient-centred modes of delivering education to promote informed decision-making and choice. Developing a patient decision-aid may be a valuable strategy in promoting more responsive and effective patient care for RhD negative women.

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Ethical statement

This study received ethical approval from the University of Northern British Columbia Research Ethics Board (Approval Reference number E2016.0413.032.00) and received operational approval from the Northern Health Authority Research Review Committee in May 2016.

Conflict of interest

This manuscript is a product of the lead author's doctoral research project completed in 2018 at the University of Northern British Columbia. The submitted manuscript is one aspect of the larger project and focuses on RhD negative women's experiences with pregnancy.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.wombi.2020.01.008>.

References

- [1] A. Zipursky, V.K. Bhutani, Rhesus disease: a major public health problem, *Lancet* 386 (9994) (2015) 651.
- [2] A. Zipursky, V.K. Bhutani, Impact of Rhesus disease on the global problem of bilirubin-induced neurologic dysfunction, *Semin Fetal Neonatal Med.* 20 (1) (2015) 2–5.
- [3] A. Zipursky, V.K. Paul, The global burden of Rh disease, *Arch. Dis. Child Fetal Neonatal Ed* 96 (2) (2011) F84–5.
- [4] H. Pilgrim, M. Lloyd-Jones, A. Rees, Routine antenatal anti-D prophylaxis for RhD-negative women: a systematic review and economic evaluation, *Health Technol. Assess.* 13 (10) (2009) 1–126.
- [5] R.M. Turner, M. Lloyd-Jones, D.O. Anumba, et al., Routine antenatal anti-D prophylaxis in women who are Rh(D) negative: meta-analyses adjusted for differences in study design and quality, *PLoS One* 7 (2) (2012) e30711.
- [6] R.D. McBain, C.A. Crowther, P. Middleton, Anti-D administration in pregnancy for preventing Rhesus alloimmunisation, *Cochrane Database Syst. Rev.* 9 (2015) Cd000020.
- [7] K.F. Fung, E. Eason, No. 133-prevention of Rh alloimmunization. *J. Obstet. Gynaecol. Can.* 40 (1) (2018) e1–e10.
- [8] J. Bowman, Thirty-five years of Rh prophylaxis, *Transfusion* 43 (12) (2003) 1661–1666.
- [9] S.J. Urbaniak, M.A. Greiss, RhD haemolytic disease of the fetus and the newborn, *Blood Rev.* 14 (1) (2000) 44–61.
- [10] A. Charles, E. Friedman (Eds.), *RH Isoimmunization and Erythroblastosis Fetalis*, Appleton-Century-Crofts, New York, 1969.
- [11] L. Dean, Hemolytic Disease of the Newborn. *Blood Groups and Red Cell Antigens*, Bethesda National Center for Biotechnology Information, 2005.
- [12] Canadian Paediatric Surveillance Steering Committee, *Results Canadian Paediatric Surveillance Program*, Canadian Paediatric Surveillance Program, Ottawa, ON, 2016, pp. 2018.
- [13] T.M. Fyfe, M.J. Ritchey, C. Taruc, D. Crompton, B. Galliford, R. Perrin, Appropriate provision of anti-D prophylaxis to RhD negative pregnant women: a scoping review, *BMC Pregnancy Childbirth* 14 (2014) 411.
- [14] P.H. Bolton-Maggs, T. Davies, D. Poles, H. Cohen, Errors in anti-D immunoglobulin administration: retrospective analysis of 15 years of reports to the UK confidential haemovigilance scheme, *Br. J. Obstet. Gynaecol.* 120 (7) (2013) 873–878.
- [15] J. Grant, M. Hyslop, Underutilization of Rh prophylaxis in the emergency department: a retrospective survey, *Ann Emerg Med* 21 (2) (1992) 181–183.
- [16] R.T. Griffey, B.C. Chen, N.W. Krehbiel, Performance in appropriate Rh testing and treatment with Rh immunoglobulin in the emergency department, *Ann. Emerg. Med.* 59 (4) (2012) 285–293.
- [17] L. Koby, A. Grunbaum, A. Benjamin, R. Koby, H.A. Abenhaim, Anti-D in Rh (D)-negative pregnant women: are at-risk pregnancies and deliveries receiving appropriate prophylaxis? *J. Obstet. Gynaecol. Can.* 34 (5) (2012) 429–435.
- [18] I.Z. MacKenzie, P. Bowell, H. Gregory, G. Pratt, C. Guest, C.C. Entwistle, Routine antenatal Rhesus D immunoglobulin prophylaxis: the results of a prospective 10 year study, *Br. J. Obstet. Gynaecol.* 106 (5) (1999) 492–497.
- [19] I.Z. MacKenzie, J. Findlay, K. Thompson, F. Roseman, Compliance with routine antenatal rhesus D prophylaxis and the impact on sensitisations: observations over 14 years, *BJOG* 113 (7) (2006) 839–843.
- [20] S. Mayne, J.H. Parker, T.A. Harden, S.D. Dodds, J.A. Beale, Rate of RhD sensitisation before and after implementation of a community based antenatal prophylaxis programme, *BMJ* 315 (7122) (1997) 1588.
- [21] L. Weinberg, Use of anti-D immunoglobulin in the treatment of threatened miscarriage in the accident and emergency department, *Emerg. Med. J.* 18 (6) (2001) 444–447.
- [22] M.N. Hassan, N.H. Mohd Nor, S.R.J. Noor, S.A. Sukri, R. Mustafa, Red blood cell alloimmunization among Malay pregnant women: a tertiary hospital experience, *Int. Med. J.* 22 (3) (2015) 154–158.
- [23] K.G. Badami, J. Parker, A. Kenny, S. Warrington, Incidence of maternal sensitisation to Rh(D) in Christchurch, New Zealand and reasons for prophylaxis failures, *N. Z. Med. J.* 127 (1388) (2014) 40–46.
- [24] C.J. McCauley, K. Morris, K. Maguire, A review of maternal alloimmunisation to Rh D in Northern Ireland, *Transfus. Med.* 27 (2) (2017) 132–135.
- [25] G.H.A. Visser, G.C. Di Renzo, S.L. Spitalnik, The continuing burden of Rh disease 50 years after the introduction of anti-Rh(D) immunoglobulin prophylaxis: call to action, *Am. J. Obstet. Gynecol.* 221 (3) (2019) 227.e1–e4.
- [26] G. Hearn, M.C. Klein, W. Trousdale, et al., Development of a support tool for complex decision-making in the provision of rural maternity care, *Healthcare Policy* 5 (3) (2010) 82–96.
- [27] D. Snadden, J. Bates, Expanding undergraduate medical education in British Columbia: a distributed campus model, *CMAJ* 173 (6) (2005) 589–590.
- [28] L.Y.T. Uchimura, A. Viana, G.P. Marchildon, Managers and clinicians: perceptions of the impact of regionalization in two regions in Canada, *Healthc. Manage. Forum* 32 (3) (2019) 163–166.
- [29] S. Thorne, *Interpretive Description*, Left Coast Press, Walnut Creek, CA, 2008.
- [30] I.D. Graham, J. Logan, M.B. Harrison, et al., Lost in knowledge translation: time for a map? *J. Contin. Educ. Health Prof.* 26 (1) (2006) 13–24.
- [31] Northern BC Communities Map, Northern health, Prince George, BC, 2011.
- [32] M.R. Hunt, Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work, *Qual. Health Res.* 19 (9) (2009) 1284–1292 9p.
- [33] M.B. Miles, A.M. Huberman, J. Saldana, *Qualitative Data Analysis: A Methods Sourcebook*, 3rd ed., SAGE, Washington DC, 2014.
- [34] NVivo Qualitative Data Analysis Software, QSR International Pty Ltd, 2017 11.4.2 ed.

- [35] J.W. Cresswell, *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*, 3 ed., SAGE Publications, Inc., Thousand Oaks, 2013.
- [36] V. Dickson-Swift, E.L. James, S. Kippen, P. Liangputtong, Risk to researchers in qualitative research on sensitive topics: issues and strategies, *Qual. Health Res.* 18 (1) (2008) 133–144 12p.
- [37] M.C. Brown, R. Bell, C. Collins, et al., Women's perception of future risk following pregnancies complicated by preeclampsia, *Hypertens Pregnancy* 32 (1) (2013) 60–73.
- [38] S. Munro, A. Hui, V. Salmons, et al., SmartMom text messaging for prenatal education: a Qualitative Focus Group Study to Explore Canadian Women's Perceptions, *JMIR Public Health Surveill* 3 (1) (2017) e7.
- [39] J. Prescott, L. Mackie, "You Sort of Go Down a Rabbit Hole . . . You're Just Going to Keep on Searching": a qualitative study of searching online for pregnancy-related information during pregnancy, *JMIR* 19 (6) (2017) e194.
- [40] P. Sayakhot, M. Carolan-Olah, Internet use by pregnant women seeking pregnancy-related information: a systematic review, *BMC Pregnancy Childbirth* 16 (2016) 65.
- [41] S.E. Borrelli, D. Walsh, H. Spiby, First-time mothers' expectations of the unknown territory of childbirth: Uncertainties, coping strategies and going with the flow', *Midwifery* 63 (2018) 39–45.
- [42] S. Munro, J. Sou, W. Zhang, et al., Attitudes toward prenatal screening for chromosomal abnormalities: a focus group study, *Women Birth* 32 (4) (2018) 364–371.
- [43] F.B. Clausen, R. Steffensen, M. Christiansen, et al., Routine noninvasive prenatal screening for fetal RHD in plasma of RhD-negative pregnant women—2 years of screening experience from Denmark, *Prenat. Diagn.* 34 (10) (2014) 1000–1005.
- [44] K. Haimila, K. Sulin, M. Kuosmanen, et al., Targeted antenatal anti-D prophylaxis program for RhD-negative pregnant women — outcome of the first two years of a national program in Finland, *Acta Obstet. Gynecol. Scand.* 96 (10) (2017) 1228–1233.
- [45] M. de Haas, F.F. Thurik, C.P. van der Ploeg, et al., Sensitivity of fetal RHD screening for safe guidance of targeted anti-D immunoglobulin prophylaxis: prospective cohort study of a nationwide programme in the Netherlands, *BMJ* 355 (2016) i5789.
- [46] F.B. Clausen, M.B. Damkjaer, M.H. Dziegiel, Noninvasive fetal RhD genotyping, *Transfus. Apher. Sci.* 50 (2) (2014) 154–162.
- [47] H. Yang, A. Llewellyn, R. Walker, et al., High-throughput, non-invasive prenatal testing for fetal rhesus D status in RhD-negative women: a systematic review and meta-analysis, *BMC Med.* 17 (1) (2019) 37.
- [48] Vancouver Diagnostic Services, *Fetal Genotyping from Maternal Plasma BC_PN-08*, Canadian Blood Services, Vancouver, BC, 2017.
- [49] Diagnostic Services British Columbia/Yukon, *Year in Review January – December 2018*, Canadian Blood Services, Vancouver, 2018.
- [50] J.-A. Johnson, K. MacDonald, G. Clarke, A. Skoll, No. 343—routine non-invasive prenatal prediction of fetal RHD Genotype in Canada: the time is here, *J. Obstet. Gynaecol. Canada* 39 (5) (2017) 366–373.