

**University of Alberta**

Exploring the Experiences of Women who are Wheelchair Bound in Attaining  
Contraceptives: A focused ethnographic study

by

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### ***Abstract***

Contraceptive and gynecological care is an important part of woman's health, whether able bodied or wheelchair bound. After a thorough literature search, the gap in knowledge with respect to contraceptive use in women who are wheelchair bound was evident. Lack of adequate information and options, inaccessible facilities and examination rooms, and uncertainties about contraceptive care by health care professionals all came to surface by reviewing the literature. The purpose of the study was to explore the experiences of women who are wheelchair bound in attaining contraceptive and gynecological care. In using a focused ethnographic approach, ten women completed an online survey and an unstructured interview exploring their experience in attaining contraceptives, with the health care facilities, their relationship with health care providers, and they were asked about what could be done to better their experience. Transcripts of the interviews were analyzed using a structured 10-step interpretive thematic analysis with constant back checking. Although the women differed in their experiences with contraceptives, they were unanimous in the importance of being in control of their sexual health. The gap in knowledge of the various methods was evident and the women agreed they were unsatisfied with the current contraceptive options they were using. The women deemed the suggestion of more accessible contraceptive information advantageous. Improved facilities, especially examination beds with adjustable heights would significantly benefit the experience of women in wheelchairs in attaining gynecological care. Also, having health care professionals being open and educated about the sexual health needs of women who are wheelchair bound would also be beneficial. The women all desired to have individualized contraceptive care, which would allow them to collaborate with their health care providers and select a contraceptive method best suited to them as an individual.

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## **Chapter 1: Introduction, Objectives, & Literature Review**

### ***Introduction***

Contraception use in women dates as far back as the ancient Egyptians; the use of herbicidal concoctions as spermicides and condoms were common contraceptive methods (McLaren, 1990). The desire to prevent a pregnancy can be more important to a woman than conceiving; thus, the demand for a safe, healthy and effective contraceptive for women has been sought after since the time that women knew they could conceive (McLaren). However, even with the large variety of contraceptive options available, there is only a narrow range of contraceptive methods being used by women who are within the reproductive age (Black, Yang, Wu Wen, Lalonde, & Guillbert, 2009). Furthermore, the side effects from many of the contraceptives eliminate many of these options for women and can lead to inconsistent use of the contraceptive (Black, Yang, Wu Wen, Lalonde, & Guillbert, 2009).

Women with disabilities face the same physical and mental changes that occur during puberty including the commencement of their menstrual cycle. With this being said, many of the same issues surrounding menstrual management, including contraceptive care, are raised (Haefner & Elkins, 1991). Women who are wheelchair bound are often neglected when it comes to sexual health issues, as they are often not seen as sexual beings (Richman, 2007). In contrast to this belief, the sexuality of a woman who is wheelchair bound is just as important as the sexuality of a non-wheelchair bound woman. Women who are wheelchair bound face some of the same issues mentioned above and many more. For example the range of contraceptive methods becomes limited due to their health issues, the desire to find safe and effective contraception methods is just as prominent, and the side effects become more important to consider (Kaplan, 2006) There is a lack of gynecological information in contraceptive methods specifically for women who are dependent on a wheelchair and the lack of attention paid in providing contraceptive methods to these women has also become apparent (Kaplan, 2006).

The decision to focus only on women who are wheelchair bound, rather than on women with disabilities is based on several concepts. Individuals who are limited to using a wheelchair are often labeled as asexual solely because they are in a wheelchair. Furthermore, the health risks that are associated with being in a wheelchair, osteoporosis, decreased circulation, thromboembolism,

often negates the need for contraceptives. In addition, there are many other health concerns requiring intervention, which become apparent when in a wheelchair, such as bowel and bladder management, transferring and mobilizing, muscle spasticity and range of motion. Since the population is specific, the lack of focused care directed at women who are wheelchair bound is prevalent and thus, focusing on the population is beneficial.

The general purpose of this study is to explore the experiences and health care practices of women, who are wheelchair bound, in attaining information, contraceptives and gynecological care.

### ***Objectives of Study***

A large amount of studies in the area of contraceptive care and disability are broad, unspecific, and lack transferrable recommendations. There is a significant gap in knowledge in the area of contraceptive use in women who are in a wheelchair. This study focused on gaining insight and exploring the experiences that women who are wheelchair bound have had when seeking out contraceptive care and gynecological care. The study focused on women aged between 18 and 45 years of age who are completely wheelchair dependent. The study included women with all types of disabilities requiring them to use a wheelchair: spinal cord injuries (SCI), multiple sclerosis (MS), Spina Bifida, fibromyalgia, and so forth. The main aim of the study was to gain a better understanding of what women in wheelchair experienced and underwent in order to get contraceptive care, gynecological care and the information and treatment that goes along with it. The study was designed to gain knowledge based on the following objectives:

1. Explore and understand the experiences of women who are wheelchair bound in attaining contraceptives, gynecological care and information regarding contraceptive methods.
2. Unveil the successes and challenges that exist that limit or inhibit women who are wheelchair bound in attaining contraceptives and gynecological care.
3. Gain an understanding of the needs of women who are wheelchair bound in acquiring contraceptives and adequate gynecological care.
4. Compile recommendations that service provider can use when working with women who are wheelchair bound.

### ***Literature Review***

The credible research and information available regarding contraceptive use specifically in women who are wheelchair bound is non-existent. A thorough search of the literature showed a

lack of studies in the area. Most of the literature is generalized to women with disabilities and it only briefly mentions women who are wheelchair bound. As there is such limited literature in the area, exploration and interpretation from associated fields, where women who are wheelchair bound are mentioned, can be adopted. In Alberta, there are approximately 3000 to 4000 people with spinal cord injuries and roughly 25% of them are female (Coulombe, 2012). Although not an extravagant number, their contraceptive care and health needs should not be disregarded.

#### *Lack of Adequate and Appropriate Facilities and Equipment*

Researchers agree that there is a lack in specialized gynecological care for women with disabilities (Kaplan, 2006; Becker, Stuijbergen, & Tinkle, 1997; Beckmann, Gittler, Barzansky & Beckmann, 1989; Schopp, Sanford, Hagglund, Gay & Coatney, 2002; Leavesley & Porter, 1982; Welner, 1997; Welner, 1999; Richman, 2007; Baylor College of Medicine, 2011; Goutard, Baron, Bouton, Penisson-Besnier, Fosse, Aube-Nathier, Havel-Thomassin, Dubas, & Richard, 2009; Sudduth & Linton, 2011; Haefner & Elkins, 1991). Researchers further explain that the facilities and equipment being used by gynecologists and family practitioners are inadequate and inappropriate for women with limited physical mobility and decreased mental abilities (Kaplan, 2006; Schopp et al., 2002; Beckmann et al., 1989; Welner, 1997; Welner, 1999; Richman, 2007; Sudduth & Linton, 2011). Women who are wheelchair bound report having difficulty attaining a gynecological appointment due to practical problems such as the examination table being too high and lack of assistance available for transferring and positioning. (Kaplan, 2006; Becker, Stuijbergen & Tinkle, 1997; Schopp et al., 2002; Welner, 1997; Welner 1999; Sudduth & Linton, 2011). Without accessible facilities and lack of specific gynecological care for women with disabilities, contraceptive care cannot be given appropriately and raises the issue of whether this population is in fact being neglected and are not receiving patient centered care, which is essential (Kaplan, 2006; Welner, 1997; Haefner & Elkins, 1991; Schopp et al., 2002). Although this raises issues of inadequate equipment and accessibility, it does not address the information provided to women who are wheelchair bound seeking contraceptives.

#### *Societal Disregard Towards Sexuality and Women who are Wheelchair Bound*

Attaining contraception for women who are wheelchair bound can be very difficult due to other's perception regarding their sexuality. Some women who are wheelchair bound are not viewed as being sexually capable and they have admitted to feeling "sexually invisible" (Becker, Stuijbergen, & Tinkle, 1997; Richman, 2007; Welner, 1997; Welner, 1999; Baylor College of

Medicine, 2011; Goutard et al., 2009; Haefner & Elkins, 1991). Furthermore, women who are wheelchair bound are often not given contraceptive advice and adequate gynecological care due to the misconceptions that they are not sexually active (Welner, 1999; Welner 1997, Richman, 2007; Sudduth and Linton, 2011; Baylor College of Medicine, 2011; Haefner & Elkins, 1991). Unfortunately, some women who are wheelchair bound and who have a physical disability, were instructed and some encouraged to have complete hysterectomies and tubal ligations, as they were the appropriate and convenient means for contraception (Nosek, Wuermsler & Walter, 1998; Goutard et al., 2009; Welner, 1997). The disregard towards these women who are wheelchair bound as not requiring sexual health care and gynecological advice is evident by the lack of acceptance and disregard towards to concept that they are indeed sexual beings.

### *Contraceptive Methods and Information*

Although there is a diverse and wide range of contraceptive methods available to typical women, it is very difficult to select the best option for a woman who is wheelchair bound or physically disabled especially when many options are eliminated due to their medications, health issues, decreased mobility and personal choices (Kaplan, 2006; Best, 1999; Nosek, Wuermsler, & Walter, 1998; Beckmann et al., 1989; Becker, Stuijbergen, & Tinkle, 1997; Welner, 1997; Welner, 1999; Richman, 2007; Baylor College of Medicine, 2011; Goutard et al., 2009; Sipski, 1991; Haefner & Elkins, 1991). The lack of information and research in regards to the appropriate contraceptives for women who are wheelchair bound is clearly addressed and acknowledged (Kaplan, 2006; Best, 1999; Beckmann et al., 1989; Nosek, Wuermsler, & Walter, 1998; Becker, Stuijbergen, & Tinkle, 1997; Welner, 1997; Welner, 1999; Richman, 2007; Baylor College of Medicine, 2011; Goutard et al., 2009; Sipski, 1991). Although the lack of information in the area is recognized, there has not been any development in the area and there is still a lack of recommendation on the appropriate contraceptive method to be used by the population described. The use of diaphragms, cervical caps and contraceptive sponges is not encouraged as manipulating them and ensuring proper placement in women who are wheelchair bound can be difficult (Sipski, 1991; Welner, 1997; Baylor College of Medicine, 2011). Intrauterine devices can also be contraindicated as they may migrate, which could be difficult to sense due to limited or lack of peritoneal sensation (Nosek, Wuermsler, & Walter, 1998; Kaplan, 2006; Sipski, 1991; Richman, 2007; Baylor College of Medicine, 2011; Haefner & Elkins, 1991). Due to decreased mobility potentially leading to thromboembolic complications, the use of oral estrogen containing contraceptive pills is not recommended in women who are wheelchair bound (Richman, 2007; Baylor College of Medicine, 2011; Welner, 1997; Welner 1999).



With the above-mentioned being unsuitable to women who are wheelchair bound, some of the remaining methods of contraceptive include progestin oral contraceptive pills, Depro Provera, Norplant, and condoms. Progestin oral contraceptive pills and Depro Provera, a progestin injection, are recommended, as there is no risk of thromboembolism; however, there is risk of predisposition to development of osteoporosis (Welner, 1997; Welner 1999; Baylor College of Medicine, 2011; Richman, 2007). Norplant, a sub dermal progestin contraceptive, is not associated with increased risk of development of osteoporosis, but can be difficult to insert into the arm with the presence of any upper body deformities (Welner, 1997; Welner, 1999). Male condoms are recommended as an appropriate method, but the lack of control and independence for the woman who is wheelchair bound is concerning (Richman, 2007; Baylor College of Medicine, 2011; Welner, 1997; Sipski, 1991). Natural family planning or the rhythm method can be used when having difficulty with other contraceptive methods; however, the success of these methods is not accurate or reliable (Baylor College of Medicine, 2011).

It is evident that by the literature there is a limited amount of information surrounding contraceptive and gynecological care in women who are wheelchair bound. It would be highly beneficial if further research could be explore some diverse areas; specifically, areas other than identification of the gap in knowledge surrounding contraceptive use in women who are wheelchair bound. Further investigations could include studies focused on contraceptive methods being used by this population, health care recommendations specific to women who are physically disabled, exploring the needs of the women with a physical disability, and introducing more accessible facilities with specialized health care professionals. The gap in the literature is evident and prominent; however, the recommendations provided by all the studies demonstrate plenty of areas for development and potential future studies.

After thorough exploration of the literature and research studies on contraceptive use in women who are wheelchair bound, more specifically, it is undeniable that there is a need for further investigation in the area. Explicitly, the lack of accessible facilities, societal stigmas towards sexuality and women in wheelchairs, and the lack of credible information on contraceptives leads to the need for further investigation into the experiences, current health beliefs and practices of these women. The literature proves that there is a plethora of reasons behind the obstacles these women must overcome in order to receive gynecological and contraceptive care. With this in mind, there is societal perception towards sexuality in women who are wheelchair dependent. Sexual health is pertinent to everyone, no matter his or her abilities or disabilities. The goal of this study is to understand the experiences of women who are wheelchair bound, the challenges and successes, in

order to determine the needs of the population and to guide health care professionals in providing appropriate care to these women

## ***Chapter 2: Study Design, Methodology, & Data Analysis***

### ***Study Design***

In order to understand the experiences and health practices of women who are wheelchair bound, an ethnographic exploratory study is best suited. The lack of literature on the topic and the outlined desired outcomes of this research would be best approached using a focused ethnographic study design (Morse & Richards, 2002). Ethnography is classically used in social sciences research to understand and analyze cultural and human actions and behaviours (Knoblauch, 2005). Qualitative research is best suited for exploring the objectives, as there is limited credible research in the area of contraceptive and gynecological care for women who are wheelchair bound. Using a focused ethnographic approach as a method to evaluate information on a specific topic and to understand the shared experience within a group of participants that share a specific characteristic, yet they do not necessarily know each other, seems most appropriate (Morse & Richards, 2002). In focusing on understanding their experiences, barriers and health practices, the study will reveal what the populations care needs are. Focused ethnography differs from traditional ethnography as fieldwork, observation, is omitted and interviews become the main source for data collection (Knoblauch, 2005).

### ***Credibility and Trustworthiness***

Credibility and trustworthiness of the data collected was vital in ensuring the data collected was an accurate and truthful representation of contraceptive use in the specific population (Shenton, 2004). Credibility of the research was addressed through many different areas. First, acknowledging the preconceived ideas of the researcher was essential prior to any data collection (Morse & Richards, 2007). As a registered nurse, the opinions and biases were minimized by reviewing data in a variety of ways, comparing the interviews with field notes, and debriefing after each interview. Furthermore, the researcher studied a variety of credible interview training methods to ensure their biases were not breeched during data collection or analysis. The methods used in the research were well established prior to any data collection, which was the best method

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to get the information desired. As far as establishing the preferred method, it is dependent solely on the objectives and the best approach to attain them (Shenton).

Triangulation of the data collected was done through manual transcription, post transcription review to verify accuracy and follow up with some participants to check for truthful representation (Shenton). This guaranteed honesty of the collected data. During analysis, cross checking themes with experienced researchers, specifically in the area of contraception and qualitative research, was done to warrant accuracy. A registered nurse, who works in at the Birth Control Clinic in Edmonton, Alberta and considered to be well versed in the area, reviewed the data analysis and provided credible, trustworthy feedback. A second source that was not as familiar with the area of study, also reviewed the analysis to help solidify the accuracy of the findings. The end goal was partial saturation of the data as complete saturation was unlikely and unrealistic (Shenton). Constant comparison of all the interviews was important to help achieve the greatest level of saturation. This allowed for accurate categorization and facilitate placement of information into previously established themes. A specific and detailed method of data collection and analysis was followed to ensure accuracy and consistency throughout the process. A thorough and well-documented audit trail was kept throughout the research process. The audit trail was chronologically done and could be retraced step by step.

Overall, credibility and trustworthiness was consistent and prominent during the research process to ensure the data collected was an accurate, truthful and honest representation of the participants' experiences.

### ***Methods***

#### ***Sample Selection, Inclusion and Exclusion Criteria***

As there is little literature on the area, the targeted population was represented by a small sample of individuals, who were able to provide the best information. The sample consisted of women who are completely wheelchair dependent and the study did not include women who are ambulatory by any degree. In order to best understand the experiences and barriers women who are wheelchair bound face, it was best to only include those that are obliged to use a wheelchair and have no alternative method of ambulating. The sample was inclusive of women who live in the province of Alberta, to prevent any limitations. Sampling for this study aimed to collect approximately 10 participants who meet the study's criteria, which was met. Focused ethnography sample sizes are usually relatively small and focus more on the quality of data rather than quantity (Morse & Richards, 2002). Using a sample size of 10 is recommended for qualitative studies using

unstructured interviews and an ethnographic approach (Creswell, 2007). The participants had to be female and between the age of 18 to 45 years of age, inclusively. From the literature, the ages ranged significantly, from 16 to 70 years of age; however, for the study, 18 to 45 years of age was selected because there is an increased risk for reproductive issues after the age of 45 (Welner, 1999; Goutard et al., 2009; Becker, Stuifbergen & Tinkle, 1997; Kaplan, 2006; Schopp et al., 2002). The study excludes women who have any cognitive or mental disabilities as to focus solely on the physical restriction and consideration when using contraceptives.

### *Recruitment*

To gather subjects, non-random convenience selective sampling methods were used. (Wood & Ross-Kerr, 2006). In collaboration with community agencies, Canadian Paraplegic Association and the University of Alberta, participants were recruited using the Recruitment Poster (Appendix A). Letters of support were received from both the Canadian Paraplegic Association and Options Sexual Health Association (Appendix B). In coordination, with the agencies such as Canadian Paraplegic Association (CPA), the poster was published in a variety of different ways such as their electronic newsletter, "Wheel-E", email database and by personal and private contact by the CPA-Alberta division. An employee of CPA contacted several women who met the inclusion criteria and with their permission, their contact information was provided to the study. To facilitate recruitment a snowball sampling was also used, where participants were asked to encourage others to join the study that met the criteria. In considering the chance of dropouts, sample selection will be ongoing (Streubert & Rinaldi-Carpenter, 2011). Eight of the participants were recruited through the Canadian Paraplegic Association. Two of the participants were found through snowball effect through the University of Alberta. All of the participants voluntarily agreed to participate in the study and were well informed of the study, its requirements and benefits. Furthermore, if a participant refused to have their experience and information shared at any point in time, this was honored and the information would be removed from the study, although this did not occur. This further supported the decision to have a continuous sample selection to ensure that enough participants are used to collect enough data (Morse & Richards).

### *Methods of Data Collection*

To collect data from the participants, a variety of methods were used. After having volunteered to be in the study, their information was passed along to the researcher. Once received, the researcher contacted the participant and an explanation of the study was provided and their

eligibility to participate in the study was determined. This was done to ensure that the participant could provide appropriate and paramount information pertaining to the area of study (Streubert & Rinaldi-Carpenter, 2011). This occurred over an initial telephone conversation, which was initiated by the researcher to the participant after they had given permission to the community agency. After they meet the criteria for participating in the study, the study was thoroughly explained to the participant and the participant had the liberty to ask questions or voice any concerns. Once a verbal agreement to participate in the study was given by the participant to the research, a meeting was scheduled where the unstructured interview was completed. Documentation of the participant's information, eligibility criteria, interview details, and other demographics were collected and recorded (Appendix C). This meeting took place in location determined by the participant where she felt comfortable, such as their home or in a private room at the University of Alberta (Gerrish & Lacey, 2010). Eight of the interviews took place at the participant's home.

The goal of the meeting was to sign the consent form, ensuring their information collected will be confidential and private, to create a rapport with the interviewer and conduct the interview (Appendix D). Since contraceptive use and sexuality can be uncomfortable for some women to speak about, it is important to ensure a connection and rapport is built prior to further investigation (Morse & Richards, 2002). The interviewer, a registered nurse, will be well versed on how to conduct interviews.

At the beginning of the meeting, an information sheet regarding the research and researcher contact information was given to each participant (Appendix E). This was done to ensure participants have the appropriate contact information if they chose to withdraw from the study. This will also allow the participants some control in the research study. The information sheet outlined the purpose of the study, objectives, participant requirement, risk and benefits to being in the study, and the rights of the participant. Once the information sheet was discussed thoroughly, the participant had time to ask questions and voice any concerns with the study. Once the participant's questions and concerns were addressed, they were asked to sign a consent form to agree to participate in the study. Both the participant and the researcher signed two consents; therefore both parties had a copy at the end.

The initial survey was given to learn about their backgrounds and gain an understanding of their health history and current health practices (Appendix F). The survey was collected using a confidential and trustworthy program, FeedBack Server, utilized by the University of Alberta. In coordination with the University of Alberta technical support team, the survey was created and all data collected was anonymous. A paper format was available at all the interviews in case of

technical difficulties. Confidentiality was maintained by having the participants complete the survey online and in the case when not able to access the Internet, the survey was completed on paper, transferred by the researcher to the FeedBack survey without any identifying codes. With the collection of this data, a better understanding of their current contraceptive use, health reason for using a wheelchair, other medical issues and current sexual relations was established in coordination with the interview. In collecting this information prior to the unstructured interview, a foundation can be laid and ensure their practices are understood superficially (Morse & Richards). This also helped get some background information that may not be discussed in the interview.

Once the consent and survey information is collected, the interview took place at the location where the participant decided and where she felt comfortable. It was predetermined in collaboration with the researcher and the participant to ensure the area was private and allowed for discussion of the subject. The location was chosen to ensure the women felt comfortable, safe and the location was accessible. The location had to allow for audio recording without significant background noise. This interview was unstructured and was audio taped. Although an hour to ninety minutes was allocated to the interviews, the interviews ranged in time from ten minutes to an hour; this was related to the participant's experience and how much they desired to share in the interview. Although video recording is the preferred method of evidence so that facial expressions and body language can be interpreted, the use of audio recordings was most appropriate due to the subject matter (Wood & Ross-Kerr, 2006). The researcher, who has received directions and instruction prior to the interview to ensure an unbiased approach, asked the questions. Training and instruction included details on remaining unbiased when asking the interview questions, not giving any opinions or information, and ways to conduct the unstructured interviews properly. The questions asked were open ended, with probing questions that were asked if the interview begins to get off topic and to help enrich the content (Appendix G). At all meetings, refreshments were offered and provided to ensure a comfortable and pleasant experience. The researcher brought refreshments to the meetings.

### ***Data Analysis***

Using the initial survey data, a descriptive statistical analysis was completed. This allowed for the sample population to be defined and outline the characteristics that are pertinent to the study. A description of age, marital status, health history, current contraceptive use and reasons for

contraceptive care was described and included in the results. This survey was only used as a simple analysis of the sample.

As the data collection method involves unstructured interviews to allow for exploration in the area, structuring unstructured data requires critical and creative analysis (Wood & Ross-Kerr, 2006). To configure and analyze the interviews, the audio recordings need to be transcribed to a written document (Morse, Swanson & Kuzel, 2001). To ensure triangulation of the data, various methods were used to verify the results, manual transcription and multiple cross-examines were completed (Huberman & Miles, 1994). Also, the goal is partial saturation of the data; key themes and concepts are repeated. Partial saturation is essential to determine if there are significant findings from the research study (Wood & Ross-Kerr, 2006). After the interviews were transcribed, the interview was replayed and the transcripts were reviewed to ensure accuracy and the interviews were transcribed verbatim. At this point in time analysis could take place. Initially it was planned to use N-VIVO, a computer program for analysis. However, manual transcription was used because of feasibility and financial reasons. After the interview had taken place and was recorded, the researcher, using the audio recordings, transcribed the interview manually. Any field notes specific to the interview were added into the transcripts to ensure consistency between the raw data and the transcribed data.

To analyze the data manually, a ten-stage process was used that was created by adapting a fourteen-stage analysis outlined by Burnard (1991) and a six-stage process outlined by Kvale (1996). The ten-stage process for analysis is categorized into four main phases of analysis and is summarized in a table (Appendix H). The first phases are filtering and categorizing. Immediately after the interview, notes were written. Categorization of data was considered and different ways to do so were noted. Each transcript was read to determine some of the larger themes and notes were made at the same time. This was repeated several times to gain more themes and write more notes. Each category was clearly defined and was unique to prevent any overlap from another category. Therefore, establishing categories based on the data, rationalizing the choice of the category and ensuring they are appropriate for the data using manual technique increased the validity of the data analysis (Huberman & Miles, 1994). The descriptive summaries of each data category are essential in adequate and precise data analysis (Morse, Swanson & Kuzel, 2001).

The second phase was the condensing, organizing, and integrating phase. This included condensing, organizing, and integrating the data and narrowing down the headings and themes while removing the repeated ones. The headings and themes were grouped under higher order headings. The transcripts were reviewed using the categories and headings. To help organize the

information extracted from the interviews, frequency tabulations for each category were developed (Wood & Ross-Kerr, 2006). These frequencies indicate for each category how often a response occurred and how many subjects gave the same response. By examining and analyzing the frequencies of the data, saturation was determined (Wood & Ross-Kerr). Saturation is when data collection and analysis occurs until no new themes, issues, concepts or ideas emerge, signaling that the concepts of the study have been completely unveiled and assembled (Gerrish & Lacey, 2010). Furthermore, placing the data in charts, graphs and tables allowed for a clear, organized analysis and adds an element of more concise presentation of the findings. This facilitated understanding of the content analysis and allowed for determining saturation (Gerrish & Lacey).

Finally, the focus of the third phase was to gain understanding and meaning of the data. Short narrations describing key points were noted, and comparisons between the interviews were made. The narratives were shared with some of the participants and then were linked up to what is found in the literature and how it corresponds to the research objectives.

Throughout the analysis of the data, the findings were cross-examined and verified by external references. This was done to ensure accuracy, validity, and rigor within the study.

### ***Ethical Considerations***

As the research is completely dependent on the participation of individuals and on the sharing of personal information, it is very important to ensure their rights are protected throughout the study. When recruiting participants, no individual was directly approached or contacted to be involved in the study. All potential participants were contacted by community agencies, Canadian Paraplegic Association, and a member of the agency explained the study to them. Once the individual gave verbal consent to provide their information to the researcher, the community agency did so. The researcher, who then explained the study, contacted the potential participants: the requirements, benefits and risks, voluntary participation, and freedom to leave the study at any point in time. The participants who did agree to participate in the study were well versed in what the study entailed and the ability to leave the study.

Every participant was required to provide documentation with their informed consent to be research subjects (Appendix D). This consent ensured that they understand the study being conducted, what was required of them and how their identity and information was protected. At the meeting, the researcher and the participant reviewed the information sheet and signed two consents, one for the participant and one for the researcher. This was done face to face and in a private and confidential area, which was chosen by the participant. The Standard Consent Template

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suggested by the Health Research Ethics Board was adapted for use in the study (Appendix D). An information sheet outlining the study, requirements, and how information will be used was given to each participant at the initial meeting (Appendix E). Furthermore, a contact email address and phone number was provided to ensure the participant could communicate to the researcher in case a meeting needed to be rescheduled or the participant had any questions or concerns.

In order to ensure they remained anonymous, a number code was assigned to their file and the information collected went under the number and not their name. All electronic files were password protected onto a computer and external storage device. This file were encrypted and protected as to ensure there is no possible way of exposure of their identity.

The transcript hardcopies have no personal identifications of the participants, only the number code given at the beginning of the study. The participants were encouraged during the interview to refrain from using any names including physicians, partners, and friends; however, if they so happened to use names, they were changed to ensure privacy and confidentiality. As the data is to be accessible for five years after collection, an encrypted and password protected USB flash drive at the University of Alberta is available. To access the information, it will be with permission by the supervising department and not for personal use. If at any point the participant decided to withdrawal from the study, they were completely allowed to do so and their information will be destroyed appropriately.

The benefits to the participants were not provided in financial means. Participation in the study may have facilitated self-reflection in regards to contraceptive use and sexual health. This could have in turn allowed for evaluation of current practices and its satisfaction of their needs. Many people find benefit in knowing their contributions will help others in the future. There are no physical risks to the participant and no potential for harm by participating in the study. If a participant were to become distressed when speaking about their past, resources were available; however, this was unnecessary.

For the research to progress, the Human Ethics Review Board at the University of Alberta approved all aspects of the study prior to any advancement in the study (Appendix I).

### **Chapter 3: Journal Article**

To disseminate the research findings, it was collaboratively decided that a journal article submission would be best suited for the research. After deliberation and discussion, *Sexuality and Disability* journal was selected as a great option to submit to. Following their guidelines, the following section is the journal article submission.

#### ***Introduction***

The desire to prevent a pregnancy can be more important to a woman than conceiving; thus, the demand for a safe, healthy and effective contraceptive for women has been sought after since the time that women knew they could conceive (McLaren, 1990). The sexuality of a woman who is wheelchair bound is just as important as the sexuality of a non-wheelchair bound woman. However, even with the large variety of contraceptive options available, there is a narrow range of contraceptive methods being used by women who are within the reproductive age; furthermore, the side effects from many of the contraceptives eliminate many of these options for women and can lead to inconsistent use (Black, Yang, Wu Wen, Lalonde, & Guillbert, 2009). Women who are wheelchair bound face some of the same issues and more, for example the range of contraceptive methods becomes limited due to their health issues, the desire to find safe and effective contraception methods is just as prominent, and the side effects become more important to consider (Kaplan, 2006). The lack of focused care directed at women who are wheelchair bound is prevalent and thus, focusing on the population is beneficial. The general purpose of this study was to explore the experiences and health care practices of women, who are wheelchair bound, in attaining information, contraceptives and gynecological care.

#### ***Objectives of Study***

A large amount of studies in the area of contraceptive care and disability are broad, unspecific, and lack transferrable recommendations. There is a significant gap in knowledge in the

area of contraceptive use in women who are in a wheelchair. The study was designed to gain knowledge based on the following objectives:

1. Explore and understand the experiences of women who are wheelchair bound in attaining contraceptives, gynecological care and information regarding contraceptive methods.
2. Unveil the successes and challenges that exist that limit or inhibit women who are wheelchair bound in attaining contraceptives and gynecological care.
3. Gain an understanding of the needs of women who are wheelchair bound in acquiring contraceptives and adequate gynecological care.
4. Compile recommendations that service provider can use when working with women who are wheelchair bound.

### ***Literature Review***

A thorough search of the literature showed a lack of studies in the area. Most of the literature is generalized to women with disabilities and it only briefly mentions women who are wheelchair bound. As there is such limited literature in the area, exploration and interpretation from associated fields, where women who are wheelchair bound are mentioned, can be adopted. In Canada, 155,000 people require a wheelchair and in Alberta, there are XX number of women who are wheelchair bound.

#### **Lack of Adequate and Appropriate Facilities and Equipment**

Researchers agree that there is a lack in specialized gynecological care for women with disabilities (Kaplan, 2006; Becker, Stuijbergen, & Tinkle, 1997; Beckmann, Gittler, Barzansky & Beckmann, 1989; Schopp, Sanford, Hagglund, Gay & Coatney, 2002; Leavesley & Porter, 1982; Welner, 1997; Welner, 1999; Richman, 2007; Bayor College of Medicine, 2011; Goutard, Baron, Bouton, Penisson-Besnier, Fosse, Aube-Nathier, Havel-Thomassin, Dubas, & Richard, 2009; Sudduth & Linton, 2011; Haefner & Elkins, 1991). Researchers further explain that the facilities and

equipment being used by gynecologists and family practitioners are inadequate and inappropriate for women with limited physical mobility and decreased mental abilities (Kaplan, 2006; Schopp et al., 2002; Beckmann et al., 1989; Welner, 1997; Welner, 1999; Richman, 2007; Sudduth & Linton, 2011). Women who are wheelchair bound report having difficulty attaining a gynecological appointment due to practical problems such as the examination table being too high and lack of assistance available for transferring and positioning. (Kaplan, 2006; Becker, Stuijbergen & Tinkle, 1997; Schopp et al., 2002; Welner, 1997; Welner 1999; Sudduth & Linton, 2011). Without accessible facilities and lack of specific gynecological care for women with disabilities, contraceptive care cannot be given appropriately and raises the issue of whether this population is in fact being neglected and are not receiving patient centered care, which is essential (Kaplan, 2006; Welner, 1997; Haefner & Elkins, 1991; Schopp et al., 2002).

#### Societal Disregard Towards Sexuality and Women who are Wheelchair Bound

Some women who are wheelchair bound are not viewed as being sexually capable and they have admitted to feeling “sexually invisible” (Becker, Stuijbergen, & Tinkle, 1997; Richman, 2007; Welner, 1997; Welner, 1999; Baylor College of Medicine, 2011; Goutard et al., 2009; Haefner & Elkins, 1991). Furthermore, women who are wheelchair bound are often not given contraceptive advice and adequate gynecological care due to the misconceptions that they are not sexually active (Welner, 1999; Welner 1997, Richman, 2007; Sudduth and Linton, 2011; Baylor College of Medicine, 2011; Haefner & Elkins, 1991). Some women who are wheelchair bound and who have a physical disability, were instructed and some encouraged to have complete hysterectomies and tubal ligations, as they were the appropriate and convenient means for contraception (Nosek, Wuermsler & Walter, 1998; Goutard et al., 2009; Welner, 1997). The disregard towards these women who are wheelchair bound as not requiring sexual health care and gynecological advice is evident by the lack of acceptance and disregard towards to concept that they are indeed sexual beings.

### *Contraceptive Methods and Information*

Although there is a diverse and wide range of contraceptive methods available to women, it is very difficult to select the best option for a woman who is wheelchair bound or physically disabled especially when many options are eliminated due to their medications, health issues, decreased mobility, and personal choices (Kaplan, 2006; Best, 1999; Nosek, Wuermser, & Walter, 1998; Beckmann et al., 1989; Becker, Stuijbergen, & Tinkle, 1997; Welner, 1997; Welner, 1999; Richman, 2007; Baylor College of Medicine, 2011; Goutard et al., 2009; Sipski, 1991; Haefner & Elkins, 1991). The lack of information and research in regards to the appropriate contraceptives for women who are wheelchair bound is clearly addressed and acknowledged (Kaplan, 2006; Best, 1999; Beckmann et al., 1989; Nosek, Wuermser, & Walter, 1998; Becker, Stuijbergen, & Tinkle, 1997; Welner, 1997; Welner, 1999; Richman, 2007; Baylor College of Medicine, 2011; Goutard et al., 2009; Sipski, 1991). Although the lack of information in the area is recognized, there has not been any development in the area and there is still a lack of recommendation on the appropriate contraceptive method to be used by the population described. The use of diaphragms, cervical caps and contraceptive sponges is not encouraged as manipulating them and ensuring proper placement in women who are wheelchair bound can be difficult (Sipski, 1991; Welner, 1997; Baylor College of Medicine, 2011). Intrauterine devices can also be contraindicated as they may migrate, which could be difficult to sense due to limited or lack of peritoneal sensation (Nosek, Wuermser, & Walter, 1998; Kaplan, 2006; Sipski, 1991; Richman, 2007; Baylor College of Medicine, 2011; Haefner & Elkins, 1991). Due to decreased mobility potentially leading to thromboembolic complications, the use of oral estrogen containing contraceptive pills is not recommended (Richman, 2007; Baylor College of Medicine, 2011; Welner, 1997; Welner 1999).

With the above-mentioned being unsuitable to women who are wheelchair bound, the remaining methods of contraceptive include progestin oral contraceptive pills, Depro Provera, Norplant, and condoms. Progestin oral contraceptive pills and Depro Provera, a progestin injection, are recommended, as there is no risk of thromboembolism; however, there is risk of predisposition

to development of osteoporosis (Welner, 1997; Welner 1999; Baylor College of Medicine, 2011; Richman, 2007). Norplant, a sub dermal progestin contraceptive, is not associated with increased risk of development of osteoporosis, but can be difficult to insert into the arm with the presence of any upper body deformities (Welner, 1997; Welner, 1999). Male condoms are recommended as an appropriate method, but the lack of control and independence for the woman who is wheelchair bound is concerning (Richman, 2007; Baylor College of Medicine, 2011; Welner, 1997; Sipski, 1991). Natural family planning or the rhythm method can be used when having difficulty with other contraceptive methods; however, the success of these methods is not accurate or reliable (Baylor College of Medicine, 2011).

The goal of this study is to understand the experiences of women who are wheelchair bound, the challenges and successes, in order to determine the needs of the population and to guide health care professionals in providing appropriate care to these women

### ***Study Design***

In order to understand the experiences and health practices of women who are wheelchair bound, an ethnographic exploratory study was best suited because of the lack of literature on the topic and the outlined desired outcomes (Morse & Richards, 2002). Ethnography is classically used in social sciences research to understand and analyze cultural and human actions and behaviours (Knoblauch, 2005). Qualitative research is best suited for exploring the objectives, as there is limited credible research in the area of contraceptive and gynecological care for women who are wheelchair bound. Using a focused ethnographic approach as a method to evaluate information on a specific topic and to understand the shared experience within a group of participants that share a specific characteristic, yet they do not necessarily know each other, seemed most appropriate (Morse & Richards, 2002). Focused ethnography differs from traditional ethnography as fieldwork and observation is omitted and interviews become the main source for data collection (Knoblauch, 2005).

## ***Methods***

### ***Sample Selection, Inclusion and Exclusion Criteria***

As there is little literature on the area, the targeted population was represented by a small sample of individuals, who were able to provide the best information. The sample consisted of women who are completely wheelchair dependent and the study did not include women who are ambulatory by any degree; it was best to only include those that are obliged to use a wheelchair and have no alternative method of ambulating. The sample was inclusive of women who live in the province of Alberta. Sampling for this study aimed to collect approximately 10 participants. Focused ethnography sample sizes are usually relatively small and focus more on the quality of data rather than quantity (Morse & Richards, 2002). The participants had to be female and between the age of 18 to 45 years of age, inclusively. For the study, 18 to 45 years of age was selected because there is an increased risk for reproductive issues after the age of 45 (Welner, 1999; Goutard et al., 2009; Becker, Stuijbergen & Tinkle, 1997; Kaplan, 2006; Schopp et al., 2002). The study excludes women who have any cognitive or mental disabilities as to focus solely on the physical restriction and consideration when using contraceptives.

### ***Recruitment***

To gather subjects, non-random convenience selective sampling methods were used. (Wood & Ross-Kerr, 2006). In collaboration with community agencies, Canadian Paraplegic Association and the University of Alberta, participants were recruited using the Recruitment Poster (Appendix A). Letters of support were received from both the Canadian Paraplegic Association and Options Sexual Health Association (Appendix B). In considering the chance of dropouts, sample selection was ongoing (Streubert & Rinaldi-Carpenter, 2011). All of the participants voluntarily decided to participate in the study and were well informed of the study, its requirements and benefits.

### ***Methods of Data Collection***

After having been contacted by a community agency and volunteering to be in the study, their information was passed along to the researcher. The researcher contacted the participant by

phone and only after they met the criteria for participating in the study, the study was thoroughly explained to the participant and the participant had the liberty to ask questions or voice any concerns. Once a verbal agreement to participate in the study was given by the participant to the researcher, a meeting was scheduled. Documentation of the participant's information, eligibility criteria, interview details, and other demographics were collected and recorded (Appendix C). The participant determined the meeting location where she felt comfortable, such as their home or in a private room at the University of Alberta (Gerrish & Lacey, 2010). The goal of the meeting was to sign the consent form, ensuring their information collected will be confidential and private, to create a rapport with the interviewer and conduct the interview (Appendix D). At the beginning of the meeting, an information sheet regarding the research and researcher contact information was given to each participant (Appendix E). Once the participant had an opportunity to ask questions, they were asked to sign a consent form to agree to participate in the study. Both the participant and the researcher signed two consents; therefore, both parties had a copy at the end.

Then, the initial survey was completed to learn about their backgrounds and gain an understanding of their health history and current health practices (Appendix F). The survey was collected using a confidential and trustworthy program, FeedBack Server, utilized by the University of Alberta. Then the interview took place in a location predetermined in collaboration with the researcher and the participant. The interview was unstructured and was audio taped. Although an hour to ninety minutes was allocated to the interviews, the interviews ranged in time from ten minutes to an hour; this was related to the participant's experience and how much they desired to share in the interview. The questions asked were open ended, with probing questions that were asked if the interview begins to get off topic and to help enrich the content (Appendix G).

### ***Credibility and Trustworthiness***

Credibility and trustworthiness of the data collected was vital in ensuring the data collected was an accurate and truthful representation (Shenton, 2004). Credibility of the research was

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addressed by acknowledging the preconceived ideas of the researcher prior to any data collection (Morse & Richards, 2007). As a registered nurse, the opinions and biases were minimized by reviewing data in a variety of ways, comparing the interviews with field notes, and debriefing after each interview. Furthermore, the researcher studied a variety of credible interview training methods to ensure their biases were not breached during data collection or analysis. As far as establishing the preferred method, it is dependent solely on the objectives and the best approach to attain them (Shenton).

Triangulation of the data collected was done through manual transcription, post transcription review to verify accuracy and follow up with some participants to check for truthful representation (Shenton). This guaranteed honesty of the collected data. During analysis, cross checking themes with experienced researchers, specifically in the area of contraception and qualitative research, was done to warrant accuracy. The end goal was partial saturation of the data as complete saturation was unlikely and unrealistic (Shenton). Constant comparison of all the interviews was important to help achieve the greatest level of saturation. This allowed for accurate categorization and facilitate placement of information into previously established themes. A specific and detailed method of data collection and analysis was followed to ensure accuracy and consistency throughout the process. Overall, credibility and trustworthiness was consistent and prominent during the research process to ensure the data collected was an accurate, truthful and honest representation of the participants' experiences.

### ***Data Analysis***

Using the initial survey data, a descriptive statistical analysis was completed. This allowed for the sample population to be defined and outline the characteristics that are pertinent to the study. A description of age, marital status, health history, current contraceptive use and reasons for contraceptive care was described and included in the results. This survey was only be used as a simple analysis of the sample. As the data collection method involves unstructured interviews to

allow for exploration in the area, structuring unstructured data requires critical and creative analysis (Wood & Ross-Kerr, 2006). To ensure triangulation of the data, various methods were used to verify the results, manual transcription and multiple cross-examinations were completed (Huberman & Miles, 1994). Also, the goal is partial saturation of the data; key themes and concepts are repeated, partial saturation is essential to determine if there are significant findings from the research study (Wood & Ross-Kerr, 2006).

To analyze the data manually post transcription, a ten-stage process was used that was created by adapting a fourteen-stage analysis outlined by Burnard (1991) and a six-stage process outlined by Kvale (1996). The ten-stage process for analysis is categorized into four main phases of analysis and is summarized in a table (Appendix H). The first phases are filtering and categorizing; immediately after the interview, notes were written and categorization of data was considered in different ways. Each category was clearly defined and was unique to prevent any overlap from another category. Therefore, establishing categories based on the data, rationalizing the choice of the category and ensuring they are appropriate for the data using manual technique increased the validity of the data analysis (Huberman & Miles, 1994). The second phase was the condensing, organizing, and integrating phase, including condensing, organizing, and integrating the data and narrowing down the headings and themes while removing the repeated ones. By examining and analyzing the frequencies of the data, saturation was determined (Wood & Ross-Kerr). Finally, the third phase was understanding and meaning the data. Throughout the analysis of the data, the findings were cross-examined and verified by external references. This was done to ensure accuracy, validity, and rigor within the study.

### ***Ethical Considerations***

As the research is completely dependent on the participation of individuals and on the sharing of personal information, it is very important to ensure their rights are protected throughout the study. Every participant was required to provide documentation with their informed consent to

be research subjects (Appendix D). A contact email address and phone number was provided to ensure the participant could communicate to the researcher in case a meeting needed to be rescheduled or the participant had any questions or concerns. In order to ensure they remained anonymous, a number code was assigned to their file and the information collected went under the number and not their name. All electronic files are password protected and files were encrypted to ensure there is no possible way of exposure of their identity.

The transcript hardcopies have no personal identifications of the participants, only the number code given at the beginning of the study. As the data is to be accessible for five years after collection, an encrypted and password protected USB flash drive at the University of Alberta is available. If at any point the participant decided to withdrawal from the study, they were allowed to do so and their information will be destroyed appropriately. The benefits to the participants were not provided in financial means. There are no physical risks to the participant and no potential for harm by participating in the study. For the research to progress, the Human Ethics Review Board at the University of Alberta approved all aspects of the study prior to any advancement in the study (Appendix I).

### ***Analysis & Discussion***

#### ***Online Survey***

The study was successful in recruiting 10 women from the Edmonton, Alberta area to complete an online survey and an interview. The information collected in the online survey and the demographic participant information sheet provided insight into the population studied. The average age of the women in the study was 35 years old, ranging from 26 to 45 years of age. Four of the women were single at the time, one was previously divorced and the remaining five women were married. Six of the women have full time employment, two of the women are homemakers, one woman is a student and the one remaining participant was unemployed at the time of the study. Three of the women in the study have children and four of the women stated they were

planning on having children. Eight of the women have spinal cord injuries resulting in the full time use of a wheelchair, one woman has Multiple Sclerosis, and one woman has Spina Bifida. The women were asked how long they had been using a wheelchair for and were asked to select an inclusive time frame. One woman has been wheelchair bound for 1 to 2 years, one woman has been wheelchair bound for 5 to 10 years, five women for 10 to 20 years and the remaining three women have been using a wheelchair for over 20 years. All of the women used manual wheelchairs and two women owned motor powered chairs but use the manual wheelchair on a daily basis. The results from the survey are summarized in the following table.

Participant	Occupation	Relationship Status	Have Children	Plan on Having Children	Health issues?	Taking any Medications	Length of time in wheelchair	Mobility Ability	Currently using contraceptives
1	Other	Single	No	No	Yes	Yes	More than 20 years	Waist up	No
2	Homemaker	Married	Yes	Yes	No	Yes	10-20 years	C6	Yes
3	Unemployed	Single	No	Yes	No	Yes	1-2 years	T5-T6	No
4	Designer	In a relationship	No	No	Yes	Yes	5-10 years	T9-T10	No
5	Homemaker	Married	Yes	Yes	No	Yes	10-20 years	T6	No
6	Finance	Married	No	No	No	Yes	10-20 years	T4	No
7	Research	Married	No	No	Yes	Yes	More than 20 years	C6-C7	No
8	Educator	Divorced	No	Yes	No	Yes	10-20 years	C5-C6	Yes
9	Other	Married	No	No	Yes	Yes	More than 20 years	Nipple line and up	No
10	Student	Single	Yes	No	No	Yes	10-20 years	T5-T6	No

Participant	Hourly Mobilizing per day	Reason for wheelchair use	HCP who initiated contraceptive care conversation	Family Physician	Gynecologist	Last Pap smear	Feel like you're getting sufficient sexual health care
1	More than 6	Spina Bifida	No one	Yes	Yes	6 months-1 year	Yes
2	More than 6	Spinal Cord Injury (SCI)	Obstetrician Gynecologist	Yes	Yes	1-2 years	No
3	4-6	SCI	Nurse	Yes	No	6 months-1 year	No
4	More than 6	SCI	Physician	Yes	Yes	2-3 years	No
5	More than 6	SCI	Physician	Yes	Yes	Less than 6 months	Yes
6	More than 6	SCI	Nurse	Yes	No	6 months-1 year	Yes
7	More than 6	SCI	Occupational Therapist	Yes	No	6 months-1 year	Yes
8	More than 6	SCI	Nurse	Yes	No	No answer	No
9	4-6	Multiple Sclerosis	No One	Yes	No	3-5 years	Yes
10	More than 6	SCI	Physician	Yes	No	3-5 years	Yes

### ***Contraceptives: Importance, Experience and Utilized Methods***

The key topics related to contraception and their experiences involved the reasoning for contraceptive use, methods of contraceptives that have been used and are currently being used, and importance of contraceptive care in their lives.

#### ***Reason and Overall Experience***

The women utilize contraceptives for two main purposes: to manage their menstrual cycles and for family planning purposes. "Managing a period every month can be a little dicey" was how one woman explained the difficulties of having a period while being in a wheelchair. As many women who are wheelchair bound have to cope with bowel and bladder elimination, having to manage monthly menstruation along with excretory needs can be difficult. Along with menstrual management, some of the women sought out contraceptives as a method to control some of the

symptoms associated to menstruation. "I've basically used them [contraceptives] for trying to stop my periods and the symptoms that I deal with. I get very ill every month and I can't stand it."

Allowing a woman to control when she can get pregnant is also essential for this population. For some of the participants, getting pregnant could impact their physical health and wellbeing.

Another participant said, "For a woman with a disability there are just so many other issues that come up if you have an unplanned pregnancy. Risks or health concerns are amplified". Along with the physical difficulties that were suggested, many women raised the issue of the strain of an unplanned pregnancy would have on their relationships. "Especially for people in wheel chairs, that if having children is not something they think they can handle or not something that they want, it would be a lot bigger issue for them than it would be for I think an able bodied person". To help quantify the importance of contraceptives for the population, the women were asked to rate on a scale of zero to ten, zero being not important and ten being the most important, the importance of preventing a pregnancy or being in control of preventing a pregnancy. The average of the ratings was 7.7 out of 10, with scores ranging from 4 to 10. The high average indicates truly how significant and imperative contraceptive care is. Half of the women had a positive experience and the other half stating it was negative. One woman explained, "Yes, I had a very good experience seeking out contraception... At each point, I felt confident when I made the choice I made". All the women who stated their experience was positive, related it to being given choice in regards to their contraceptive method and having an open and trustworthy relationship with their health care providers. The women who classified their experience as negative predominantly determined it to be related to the lack of effectiveness of the contraceptive options.

#### *Methods of Contraceptives Used*

Most participants have used male condoms; however, the opinions of the women in regards to using the male condoms were mostly negative. The benefits to using the male condom included ease of use, effectiveness, and prevent pregnancies. The women who did not like using condoms

reported they did not contribute to their sexual health in a positive manner. One woman explained, “condoms I mean, okay, whatever, but if I am in a committed relationship I didn’t want to have to use condoms”. Two of the six women really liked being on the pills because of the straightforwardness of taking the daily pill, the effectiveness and the ability to manage their menstrual cycles. However, the remaining four women did not like the combination oral contraceptives for many reasons including having to take a pill daily, ingestion of systemic hormones and chemicals, ineffectiveness in managing their menstrual cycles, and the side effects. While taking the pills, two of the four women experienced deep vein thrombosis, a side effect of combination oral contraceptives. “I ended up being rushed to the hospital and they found a massive blood clot that was arching both lungs. I ended up in ICU for a few days. They do attribute it to that particular birth control. Now I won’t be able to use any birth control ever again”. Majority of the women enjoyed using the Depo Provera because of the ease of use, effectiveness in preventing a pregnancy, and termination or lessening of their menstrual cycles. The women even explained, “I loved being on Depo Provera! It was just great! I didn’t have a period”. Although two women did not have a great experience on the Depo Provera injection due to ineffectiveness in managing their menstrual cycles and side effects. Many of the women were aware of the side effect of Depo Provera; yet, it did not prevent them from using the Depo Provera.

Some alternative methods used included the contraceptive patch, progesterone-only oral contraceptive pills, intrauterine device, foam, and the rhythm method. The woman who enjoyed using the patch provided reasoning including ease of use, effectiveness in preventing a pregnancy, and success with menstrual management. The reasons that the other woman did not like the patch was solely because it did not provide significant menstrual management and alleviate symptoms associated with her menstrual cycle. The woman using the progesterone-only oral contraceptive was satisfied with the pill because she was between pregnancies and it was the best option at the time. However, she was not content with the concept of taking a pill everyday nor with the lack of

menstrual management it provided her. The only woman using the intrauterine device was displeased with the device, as it did not alleviate the abdominal pain she experiences during her menstrual cycle, and it made the pain worst. The woman using the foam did not find any relief with her menstruation, but did admit that using the foam and a male condom was an easy method to use. The rhythm method was suggested to a woman as her only option other than condoms, she explained, "Like you use it to get pregnant so, I'm sure if people want to use it to avoid pregnancy, it would work just as well", but it was not an effective method of contraceptive for her.

#### *Idealistic and Non-Idealistic Method of Contraceptive*

Not one of the women are using a contraceptive that they are fully satisfied with nor is the method they are currently using their idealistic method. Although the search to find a perfect contraceptive to manage their menstruation continues, four of the women's partners have had or are planning on having a vasectomy to prevent any pregnancies.

Depo Provera is the most popular contraceptive and determined to be the most idealistic due to its ability to decrease or eliminate completely their periods, ease of use, and effectiveness in preventing a pregnancy. Oral contraceptive pills yielded mixed results. Many women were attracted to the pills because of ease of use, able to regulate menstrual cycle independently, previous history of taking the pill prior to being in the wheelchair, and reassuring as menstruation occurs once a month. One woman explained, "It's just a safe and easy option. It makes you regular or you can continuously take the pill so you don't get it [period] as well". In comparison, more women did not want to take oral contraceptives, "I just think birth control pills are a pain in the butt. I take a lot of medication already so one more just doesn't float my boat". The daily requirement of taking the medication, the systemic ingestion of chemicals and hormones, potential side effects such as thrombosis, and inability to fully control menstrual cycles, were the main reasons contraceptive pills were not favored. The intrauterine device had many participants uninterested and with many opinions around using this method. The one woman interested in the IUD reasoned that it might



prevent a menstrual cycle, which was her main objective for searching for contraceptives. The remaining nine women voiced concerns such as one woman explained, “to have something inside me all the time it just made me feel really uncomfortable”. Furthermore, many participants felt the price of the IUD was too expensive. “That cost \$350 out of my pocket. I can’t afford \$350, the IUD is not ideal for me”. The concept of not being able to feel the device and inability to sense if something had displaced was another area of concern. “I don’t know if something does go wrong, I wouldn’t feel it. I have no sensation”. The patch had some interest in use based on the ease of use and the effectiveness in preventing a pregnancy. A few participants mentioned condoms, as not being a method of interest because of the unreliability, does not contribute to menstrual management and due to discomfort with use. Two women expressed the desire to undergo a hysterectomy. The reasoning behind choosing a hysterectomy, as their idealistic method, was because no other methods have worked to help them control their menstruation. “I’m still considering it [hysterectomy], because of the mess of having a period. Having a hysterectomy would be awesome!” Although a surgical intervention, the option is deemed to be the best by these two women for their situations.

### ***Accessibility in Health Care Facilities and Staff Support***

The women were asked about their experience in attaining contraceptive care and the accessibility of the health care facilities.

#### ***Accessibility to Gynecological Care and their Facilities***

All the women in the study reported having a family doctor but only four of the women had a gynecologist. Half of the women felt they were receiving adequate gynecological care while the other half were left unsatisfied with the care they were getting. Furthermore, when asked about seeking out gynecological care, many of the women reported difficulty in finding a care provider or adequate care. “My doctor has been trying to find me a gynecologist just to do a basic women’s check-up for the last 2 and a half years. It’s not easy to find one”. Unfortunately, the issue of an

accessible office with adequate, wheelchair friendly equipment was consistently voiced. In order for these women to get gynecological care, they need to be able to access the building, maneuver around the office, be able to enter the exam rooms, and get onto the examination table. One woman explained, "I have never been to an ideal clinic. The exam rooms are always tiny and the tables have always high". Only 2 women currently use a completely accessible facility located at the local rehabilitative hospital, Glenrose Rehabilitative Hospital. The Glenrose offers a free sexual health clinic for women one afternoon a month where women can meet with a gynecologist in a completely wheelchair accessible facility. Eight women do not use the clinic, although 5 of the 10 women are aware that the clinic does exist. All ten women reported that their doctor's offices offered wheelchair parking and the building is wheelchair accessible. However, only half of the women stated that the examination room was large enough for them to get into and move around. The main issue surrounding accessibility in the doctor's office was in regards to the bed height. Because the bed height is fixed and the height is typically set to be at waist height when standing, it is a challenge for someone to transfer from a sitting position. Only 2 women in the study reported that their doctors have an examination table that moves up and down. "The access in regards to the size and the height of the tables and set up of the tables has been less than ideal".

#### *Support Staff Assistance*

The difficulties surrounding the facility and equipment raised questions surrounding if the staff were able to assist in transferring and positioning or not. Only 3 women said their health care facilities had adequate support to help with transferring and positioning. "There's always been 2-3 ladies to help me hop up on to a table, ask me what I need, how I need it done. And always has been a second person in the exam room whenever I do have my paps done". In comparison, 7 of the women said that the reason the staff members were not able to transfer was due to safety reasons and lack of training. "They [support staff] don't feel comfortable transferring because they just don't think they are strong enough and they don't want to hurt themselves". Four of the participants

have resorted to bringing along their partners or a peer to assist them with the transferring and the positioning. “I have to be responsible to do it for bringing my own muscle man with me”, a woman explains about having to ensure her husband accompanies her to appointments in order for her to be able to get onto the table and position. Once on the table, there was the concern of falling off or having the support of a staff member to help with positioning, since the participants lack the ability to control their legs. “The stirrups that are, not good for someone who doesn’t have good leg control. The awkward part about that is that there has to be somebody there to, it’s kind of like having an audience rather than a discussion with your physician when there’s got to be a couple of people there to hold my legs”. The lack of support to help with positioning was prominent among the participants. The women were asked about when they book an appointment, if they were asked about their needs. More specifically, exploring whether the women were asked if they had any health concerns that required special attention, such as mobility or positioning needs. “They don’t ask, are you in a chair”. Only one woman specified that her health care providers ask about her needs. The other women emphasized that they must advocate for themselves. One of the women said, “Oh no I definitely tell them that (I’m in a wheelchair). If you were not to tell them, they would not have anybody there to help you”. Unless the women mentioned they were wheelchair bound, the health care practitioners would not know or be prepared for them. Along with the lack of inquiry about their health needs, the women felt they also required more time for their appointments and needed to ask for the prolonged appointment times. For example, “I’m going to need to book extra time because in order for me to get onto the table, like if we are going to do an exam. It takes longer so it’s really important to make those things clear when you’re booking appointments”. The importance of self-advocacy was reiterated when booking longer appointments.

### ***Contraceptive Care and Health Care Professionals***

The women had mixed relationships with their health care providers surrounding three areas: communication, information, and finally, stereotypes and stigmas.

#### ***Communication***

Contraceptive care for women can be a taboo topic and be difficult to discuss; nine of the ten women reported not having it brought up. "I know that I always initiated any type of conversation about contraceptives with the doctors or nurses. It wasn't ever presented to me" one woman expressed. "I was very disappointed that 23 years ago when I was at the Glenrose that the subject was never ever brought up... Nobody, like I said nobody broached the subject. It was something we just found out all on our own. Nobody did at all". The lack of initiation by health care professionals around contraceptive use has even deterred some of the women. "So it's almost to the point where it's not important to do because it's just so complicated, you need to know the right people. I remember when I first started getting paps and contraceptives, I had no clue and the doctors had no clue, so it was kind of a nightmare". Some of the women felt that raising the issue of contraceptives was related to a lack of comfort and training of the health care professionals. Furthermore, it was vocalized that their health care professionals somewhat frowned upon bringing up the topic of contraceptives. One woman explained, "It seems like a lot of the GPs [general practitioners] don't know a lot about disabilities in general so when you come up with something like contraceptives, it seems like, it's not like it's, like it should be normal but it's not."

The concept of self-advocacy became very prominent alongside with discussing initiation. "I learned at a very young that I had to be my own advocate cause nobody else is going to do that for me. I need to be able to voice my concerns and my issues. I mean other people out there shouldn't be afraid to be their own advocate. I mean you're not going to get judged by bringing up your issues, you know. You're only going to get help faster by being your own advocate". Eight of the ten women expressed the need to be insistent and advocate for their needs when dealing with health care

professionals. Although only one woman was approached about contraceptive care, all the other women reported being their own advocate and the importance of being responsible for asking about contraceptives.

#### *Information on Contraceptive Care*

When contraceptive care was brought up to their health care providers, the reactions of the health care professionals were either receptive or unsure. One woman explained, “ I went seeking contraceptive care and that was just from my GP [general practitioner] back in my hometown. And this was someone who had been my family doctor for years. He took care of me before I was injured and after I was injured. He had in the past had other female patients who had been spinal cord injured so he had a little bit of experience kind of weighing the pros and cons... I never did end up going back to my hometown, to my GP for a pap. He really wanted to just refer me to a female doctor that would become my GP in Edmonton. He just wasn't comfortable crossing that line... He just said that's just not something I want to do for you. And I appreciated that”. Only four women voiced having a positive experience with their doctor when they sought out contraceptives. The other six women felt the doctor was not as comfortable nor were they well versed in contraceptive care for women with a disability. “When the health care professionals haven't dealt with someone with a spinal cord injury before or they don't know enough about a disability or have education enough, you can actually feel... like they don't really know what to do with you”.

Once the conversation had been initiated with their health care providers in regards to contraceptive care, the information they received was minimal. Five of the ten women learned about the various contraceptive methods from their doctors. “When I was first looking for contraceptives, you really had to look around for information on it, you know. Not everyone has information on stuff like that. And most times when I went into a doctor's office I had to ask for it. So it's not out there on a display”. Eight of the ten women were presented only a few options when they sought out contraceptives. Five of the women reported doing their own research online and

using various sites, some credible others not. "I went online a lot so I knew about kind of what options were out there. And I didn't, like I researched a lot... I can't even remember where exactly Yes, I'd just Google it". Some of the women felt the information they were getting from their health care providers was difficult to relate to. "She [health care professional] gave me some paper and again, everything was so text book because she is able bodied and even though she is experienced in the field, it's just very different hearing it from her and she gave me a piece of paper based on study based on what she has heard, you know based on stuff she had researched for. Same thing with sexuality, like as great as the information was that I got from her, I can't relate to it because everything is so foreign. So what I ended up doing is the website that one of my girlfriends suggested and as started talking to other women with spinal cord injury".

#### *Persuasion and Health Care Providers*

When the women sought out contraceptive care from their health care providers, four of the ten women were encouraged to try a method they were not interested in trying. "I would have appreciated not getting the run around and ... about a product that I wasn't even comfortable wanting. Just that was really frustrating but, I just felt like, I got talked into it by my doctor. I don't know how I got talked [into it] because generally I'm a strong person and I don't know how he was able to do that". Along with persuasion by the health care professionals, there were several women that felt they had to convince their doctor to prescribe a specific contraceptive method. "So, it took some discussion and some convincing for him to agree to give me the depo Provera". Most of the women were able to successfully encourage the doctors; however, two of the women are not having the same attainments. "I had brought up the idea of, possibly having a hysterectomy because I'm not looking to have children anyways, so just take everything. And they don't do that just because anymore, you have to have a real reason, in order to have a major hysterectomy done... Yes I really did have to persuade them". Two women are looking to have complete hysterectomies due to menstrual management issues; however they both have struggled to have a doctor agree to do the

procedure. "I was considering actually having a hysterectomy because I have so much pain. I thought that because of the monthly cycle, the cramping and the endometriosis... And I still feel because he is pro baby making. Like he's definitely convinced me to not have any hysterectomy and not to do anything with, like "Oh you'll still have babies, don't do anything more um, to jeopardize that possibility". The women both felt frustrated with the situation and voiced concern in relation to the issue.

### *Stereotypes and Stigmas*

"I've had people assume that nothing works to I don't have sex in my marriage because I'm paralyzed and that you know people have asked my husband and I, did you guys have to go through fertility treatments and so I've had, you know, all of those kind of stereotypical kind of things. Um, but it's still frustrating nonetheless. To have, especially doctors. I've had doctors ask me about like did I have to go through fertility treatments and you know how did I get pregnant. The main stereotypes are that like because I'm paralyzed that I can't have sex or don't have sex. And that even if we did, we would have trouble getting pregnant". Five of the women reported experiencing stereotypes and stigmas from health care professionals with respect to contraceptive and gynecological care. The main stereotypes included being asexual and not wanting to have sex, inability to have sex, inability to reproduce, not requiring contraceptive care, and lack of orgasmic ability. Some of the women felt that once they initiated the conversation around contraceptives, the health care professionals replied in shock of their sexual abilities. "I've said like I have sex. And people are like "Really? You have sex?" " Like they make the assumption that that's not possible. Another thing too, I don't know if you're interested or that you care but it's actually possible for me to achieve orgasm. I definitely think people would make the assumption that not only that I wouldn't have sex but that or maybe could have sex but you know could enjoy it or, or feel it, or anything like that". Although the stereotypes and stigmas existed, it did not prevent any of the

women from attaining contraceptive and gynecological care. Overall, the health care professional and participant relationship in regards to contraceptive care revealed some gaps.

### ***Participant Suggested Improvement***

The experience that women who are wheelchair bound had in attaining contraceptives highlighted gaps in the care they were receiving. The women were asked what could have been done or could be done in the future to improve and facilitate accessibility to contraceptive care.

#### ***Improvements to Contraceptive Options***

With the wide range of contraceptive options available, the women participating in the study reported that more contraceptive options could be beneficial to their population. "I think that the more options that are out there for people, I mean yes it would be harder to make that initial decision, but at least then they have more options to try, before they make that final decision. I mean right now, there's just like a few select that I know of, that I was just even told of, and that I tried. You know, I mean if there were other options out there that seemed even better I would go ahead and try it". Seven of the women suggested more contraceptive options, chemical and non-chemical, would be well received. "There are so many things out there for women but if you're a paraplegic all of a sudden everything is just cut right off. So it would be nice to know if there was a contraception option for women. That would be really nice".

#### ***Improving Information on Contraceptives***

"I wasn't terribly knowledgeable on them [contraceptives] other than taking the pill. I didn't know about all the other types and kinds". The lack of knowledge on contraceptive options was very much apparent when the women were asked. "Providing alternative, providing options and the pros and the cons for those options, or at least having an understanding of, if you're going to take this what can you do to combat some of the side effects. That'd be helpful". The information that was being provided by health care providers about contraceptives was reported to be brief and



limited. "I said I just think there should be more information made available and maybe have information about the different methods with what is good about them and what is bad about them, if they have side effects, and etc. ... Nobody brought it up to me".

Although more information was reported as something that would be beneficial, some women had a different approach to the matter. Accessibility to information about contraceptives was the most reiterated concept by the women. All of the women made mention that the information was not accessible and was difficult to find. One of the women said, "I wish I had some of the stuff more accessible for the patients, and probably just maybe more explanations. It would be good to get at least some type of I don't know, maybe a booklet or something, just get some information or direction. Many times you can go online and get all the different information right? But how do you exactly know which one is the right type or which one is the right one for you, and stuff like that. Just a little more guidance and where exactly to go for that, accessing information". Where the women differed most was in the method and type of information they would find helpful. Two of the women suggested peer support and information on their experience would be beneficial to get contraceptive and gynecological care. "I still believe in that phase, that period of injury to 5 years post injury that people should be exposed to other people living successfully with their disability or whatever it is. And that can lead to all kinds of natural conversations about contraceptive care, choices, how to even approach your doctor to talk about it". Some of the other women felt the information being accessible through the Glenrose Rehabilitation Hospital in Edmonton, Alberta or other local rehabilitation hospitals would be beneficial. "I just have the best relationship with the people at the Glenrose. They are the most helpful and I think people think that they probably can't call them, like they have to for some reason, be part of the Glenrose. Maybe I just am forward but I just call her [sexual health nurse at the Glenrose] for anything. She has never turned me down. Even if she sends the information in the mail, like she is just great". However, only four of the participants knew about the Sexual Health Service at the Glenrose. Along with the local

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**Comment [4]:** Maybe add the word of peer education/counseling

Carolyn Gratton 12-11-15 9:49 AM

**Comment [5]:** As this was a quote, I don't think it would work here. What do you think?

rehabilitation hospital, other community agencies were suggested as being a good place to have information. "I know the CPA that they are really good with information but if somebody doesn't know to call them then how are they going to know how to look and if they publish a magazine and somebody doesn't get it then how do they get the information?" Suggestions of having brochures and booklets were made by six of the women. "It could be like a package, almost like a package that you get when you leave [the hospital]". Six of the women suggested having online accessible information available to women who are wheelchair bound. "I think online information is really critical because especially people in wheelchairs they don't get out in the community as much as maybe some other groups of people and probably having access to the internet and having information on the internet is valuable". The information was suggested that it could be linked to the community agencies and to the rehabilitative hospital to facilitate finding credible and accurate information. Some of the women voiced the concern that there is a large amount of information when they searched and having accurate, relatable, and credible information in one place would be very beneficial. One of the women was suggestive of a conference. "Have a one-day event or even 3-4 hours where you just get women in a room. And then you have like samples or information pamphlet that they can take on the different choices that they can have. Then they could have like gynecologists do like either presentations or actually perform some of the tests with an easily accessible table".

When the women were asked about the type of information that would be beneficial to them, their suggestions seemed unanimous. The content would include information on "all the possible types", "pros and cons of the different methods", and "phone numbers of gynecologists" all focused towards women who are wheelchair bound. Another point that was made by several women was giving more than just "clinical" and "sterile" information about contraceptives. "I believe that there is lots of good information out there. But it's not always easy to find. And, there needs to be some balance between teaching the person to shoot the gun and then teaching them

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how to hunt. Cause those are two completely different things, right? You know, how to negotiate and navigate relationships and intimacy and not just sex and contraceptives... When I was in rehab, the information we got was fairly clinical and that was good but at the same time there is a lot between not having sex and intercourse that wasn't covered. You know what I mean? I had all the information I needed to know about; yes my cycles are going to come back, yes, if I have sex I will get pregnant. I need to use a condom if I'm not on some other sort of birth control. All that. But then there's the in between. How do I get on the couch? How do I discretely talk to my boyfriend about if I have a bladder accident?"

### *Improvements to Health Care Facilities*

With the issues around wheelchair accessibility at health care clinics, all of the women agreed that better health care facilities would greatly benefit attaining adequate contraceptive and gynecological care. "It would be nice to have a doctor with a place set up for people in wheelchairs. It would be really nice to have a really friendly wheelchair accessible environment". Specifically, "larger rooms" and "beds that raise and lower" would make a significant difference. "Like I don't quite understand why they are so high like it doesn't make sense to me", a woman said. The women also reported that having tables that lowered would be beneficial to both the general population as well as the health care system. "I think a lot of gynecologists out there would get a lot more business and get a lot more patients if they provided that for people. It's, this city is huge, there are a lot of people living here and it's not just able-bodied people. We are part of the population too". Creating a wheelchair accessible facility, which included large rooms and examination tables that raised and lowered, was repeatedly suggested as a way to improve the experience.

### *Improvements and Health Care Providers*

Six of the ten women suggested their health care provider could improve when it comes to providing contraceptive and gynecological care. The areas of improvement included "having support staff", "better communication and training", and "individualized care". "If you could have a

staff person there to you know, hold your legs for you, or each leg... It just adds a little more dignity to the process". Also, having staff ask when booking appointments about special needs or assistance required was recommended to better the women's experience. "Because they don't ask, are you in a chair. Well yes I am. You know, speaking over the phone you just don't know, right? So I usually tell them right up front, I'm in a chair. I need these services do you offer them? And if they say no, well you know, it's on to the next person...it would be nice if they did ask though". Communication between the health care providers and participants was an area that many women suggested could improve. Some of the women advocated for increased training around dealing with gynecological and contraceptive needs of women who are wheelchair bound. "Try and prepare people in all helping sorts of roles whether they be nurses, PT, OT, you know, community counselors at CPA to be aware of their own attitudes and beliefs, and as much as possible be comfortable broaching the topic. Rather than waiting for the person to ask. So you know and using teachable moments. I think the more important issue is professionals that are trained to accommodate so asking questions. What are you able to do? Do you have assistance that you can bring with you or are willing to? Or if you're not, do we need to try and arrange and have a lift come and be available if none of us are able to or willing to? Cause it is an expense that is a hardship and I appreciate that, that to a clinic, to many small clinics". Increased awareness of the care differences that women who are wheelchair bound require would improve their overall experience and facilitate attaining contraceptives and gynecological care. "I know that more experience and even just having more experience for the doctors and nurses. I mean, more training, more, like I don't know if they need training but just more awareness that hey just because you have a disability or you're in a wheel chair doesn't mean you're not active in every other aspect of life".

Finally, the women felt that having the health care providers offer individualized care would be a great improvement. Having the care being tailored to each individual person would allow for better experiences with contraceptives. "It would be nice if I could just say, this is what I need and

this is my body and I would have appreciated not getting the run around". Some of the women did agree their "doctors had their best interest at heart" and valued their opinion; however, having a more distinct and personalized patient focused approach was conveyed.

### ***Future Recommendations***

The experiences of women who are wheelchair bound were extensively explored and each of their experiences was conveyed in a unique yet understandable manner. The analysis proves the experiences provided enough information around contraceptive methods used, receiving contraceptives, and gynecological care. The findings exemplified successes and failures of women in wheelchairs seeking contraceptives and gynecological care. With the women suggesting improvements that could be made to contraceptive and gynecological care; the data delivered a substantial list of recommendations and modifications.

### ***Future Recommendations***

In creating a contraceptive option where the side effects would not heighten the preexisting health concerns of a woman in a wheelchair would be well received. Increase information and accessible information about contraceptives specifically targeting women in wheelchairs. The creation of wheelchair accessible facilities in the area that have large exam rooms, adjustable height examination tables, and an area with extra staff would help these women get adequate care. When booking an appointment, have support staff ask patients about their needs to better facilitate care. Evidence supports health care professional initiating conversation around contraceptive and gynecological care. By asking about their contraceptive and gynecological needs, creates an open and comfortable environment that facilitates the conversation. Furthermore, if unsure or not well versed in the area of disability and sexuality, increasing the knowledge base and important health considerations would be advantageous. This would include information on contraceptive care and special considerations for women in wheelchairs, appropriate communication skills, and transferring and positioning patients in

wheelchairs. Although it would seem ubiquitous, really focusing on what the individual desires and providing credible, accurate and reliable information and care. In the end, the patient is responsible and has the final say with respect to their health care. Thus, health care professionals need to be more cognizant and sensitive to their needs and provide the most idealistic and best care possible. The study highlighted many areas of contraceptive care for women who are wheelchair bound that could be thoroughly explored and developed. An information tool could be created that included information of contraceptive methods, benefits and downfalls to each method, sexual health information, relationship information, tips on being an advocate for gynecological care, and a list of local sexual health services specific to women in wheelchairs. The tool could be trialed and gaining feedback from women in wheelchairs and health care providers about the effectiveness, positives and negatives of the tool. This could prove to be beneficial for both the population of wheelchair bound women as well as for health care providers. It would provide consistency of contraceptive care and allow for women to have access to credible information and to health care providers with completely wheelchair accessible facilities. Also, development of a new contraceptive option could be researched as well.

Need to add a true discussion section – ie what does this mean in relation to the literature and your own perspectives which should flow into clinical implications

## **Chapter 4: Analysis & Discussion, Future Recommendations, & Dissemination of Research Findings**

### ***Analysis & Discussion***

*Online Survey*

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Carolyn Gratton 12-11-15 9:49 AM

**Comment [8]:** I was able to trim it down 1000 words, do you think it needs more?

The study was successful in recruiting 10 women from the Edmonton, Alberta area to complete an online survey and an interview. The interviews were scheduled in a location that the participant felt comfortable and was private enough to conduct the interview. Interviews were scheduled for 60 to 90 minutes; however, the interviews lasted on average 38 minutes.

The information collected in the online survey and the demographic participant information sheet provided insight into the population studied. The average age of the women in the study was 35 years old, ranging from 26 to 45 years of age. Four of the women were single at the time, one was previously divorced and the remaining five women were married. Six of the women have full time employment, two of the women are homemakers, one woman is a student and the one remaining participant was unemployed at the time of the study. Three of the women in the study have children and four of the women stated they were planning on having children. The women were all asked about their health history. Eight of the women have spinal cord injuries resulting in the full time use of a wheelchair, one woman has Multiple Sclerosis, and one woman has Spina Bifida. All of the women were using medications at the time for a variety of health reasons. The women were asked how long they had been using a wheelchair for and were asked to select an inclusive time frame. One woman has been wheelchair bound for 1 to 2 years, one woman has been wheelchair bound for 5 to 10 years, five women for 10 to 20 years and the remaining three women have been using a wheelchair for over 20 years. The women were asked about their mobility abilities; mobilizing was defined as moving their body independently without using any external assistive devices. For example, moving their arms or torso. Eight of the women said they mobilized more than six hours a day and two women said they mobilized between 4 to 6 hours a day. All of the women used manual wheelchairs and two women owned motor powered chairs but use the manual wheelchair on a daily basis.

### ***Contraceptives: Importance, Experience and Utilized Methods***

From the interviews, many key themes became prominent from the experiences that women who are wheelchair bound shared. The key topics related to contraception and their experiences involved the reasoning for contraceptive use, methods of contraceptives that have been used and are currently being used, and importance of contraceptive care in their lives.

#### ***Reason for Contraceptive Use***

Majority of the women agreed that they utilized contraceptives for two main purposes: to manage their menstrual cycles and for family planning purposes. "Managing a period every month

can be a little dicey” was how one woman explained the difficulties of having a period while being in a wheelchair. As many women who are wheelchair bound have to cope with bowel and bladder elimination differently than an able bodied women, having to manage monthly menstruation along with excretory needs can be difficult. Another woman more bluntly stated, “being in a wheelchair it sucks bleeding every month”, which solidifies one of the reasons why women seek out contraceptive care.

Along with menstrual management, some of the women sought out contraceptives as a method to control some of the symptoms associated to menstruation. “I’ve basically used them [contraceptives] for trying to stop my periods and the symptoms that I deal with. I get very ill every month and I can’t stand it.” Although menstrual management was a prominent theme found within the participants, all the women stated they sought out contraceptives for family planning and preventing an unwanted pregnancy. One of the women repeatedly said, “I just really don’t want to get pregnant”. Another stated, “If people want to prevent a pregnancy then that’s something that you know, they have control over”. Allowing a woman to control when she can get pregnant is essential for this population and was found in every interview. For some of the participants, getting pregnant could impact their physical health and wellbeing. One woman voiced her concern, “I wanted to be careful because of my situation (MS); we didn’t want an unwanted pregnancy. If I did get pregnant it could potentially make me worst”. Another participant said, “For a woman with a disability there are just so many other issues that come up if you have an unplanned pregnancy. Risks or health concerns are amplified”. Some of the health concerns found included deteriorating health condition, requiring correctional bladder surgery, and increase in severity of current illnesses. Along with the physical difficulties that were suggested, many women raised the issue of the strain of an unplanned pregnancy would have on their relationships. “Especially for people in wheel chairs, that if having children is not something they think they can handle or not something that they want, it would be a lot bigger issue for them than it would be for I think an able bodied person”. Reasoning behind using contraceptives resonated throughout each interview and proved to be significantly important to the participants.

To help quantify the importance of contraceptives for the population, the women were asked to rate on a scale of zero to ten, zero being not important and ten being the most important, the importance of preventing a pregnancy or being in control of preventing a pregnancy. The average of the ratings was 7.7 out of 10, with scores ranging from 4 to 10. The high average indicates truly how significant and imperative it is for these women to have the ability to control conceiving a child. The reasoning for using contraceptives and the importance of having



contraceptives was consistently repeated from participant to participant. “I think they [contraceptives] are the greatest things out there and I don’t know what any of us women would do without them”.

### *Overall Experience in Attaining Contraceptives*

Overall, there was a mixed feeling towards the experience women in wheelchairs had in attaining contraceptives. Half of the women had a positive experience and the other half stating it was negative. One woman explained, “Yes, I had a very good experience seeking out contraception... At each point, I felt confident when I made the choice I made”. All the women who stated their experience was positive, related it to being given choice in regards to their contraceptive method and having an open and trustworthy relationship with their health care providers. The contraceptive methods that were previously used by the women who have had a positive experience were ones they wanted to use. “I just asked my doctor and she never raised an eyebrow or anything like that. She was just really like okay that’s what you would really like to do”. Women who had a positive experience related it to the method regulating their period and preventing pregnancies. The women who classified their experience as negative predominantly determined it to be related to the lack of effectiveness of the contraceptive options. One woman who utilized many contraceptive methods stated, “I really don’t know what is my best option I just know that I’m not comfortable, I don’t feel well and I want some sort of solution”. The inability to find a contraceptive method that provides menstrual management as well as prevents pregnancies, led these women to feeling a plethora of different ways including frustrated, helpless, discouraged, uncertain and a loss of control. The overall experiences of these women are beneficial to explore; however, more can be extrapolated from the specifications of their stories of seeking out and utilizing contraceptives.

### *Methods of Contraceptives Used*

As previously mentioned, many participants have tried numerous different methods of contraceptives. The most commonly used methods included Depo Provera, combination oral contraceptive pills and the Evra patch. Other methods included progesterone only oral contraceptive pills, intrauterine device (IUD), foam, and male condoms. Table 1.1 illustrates the methods and the number of participants that utilized the specific methods.

Table 1.1 Contraceptive Method use by participants

Method of Contraceptive	Number Of participants	Method of Contraceptive	Number Of participants
Depo Provera	5	IUD	1
Male Condoms	7	Patch	2
Combination oral contraceptive pills	6	Rhythm method	1
Progesterone Only contraceptive Pills	1	Foam	1

Most participants have used male condoms; however, the opinions of the women in regards to using the male condoms were mostly negative. The benefits to using the male condom included ease of use, quick in effectiveness, and prevent pregnancies. “Condoms just seem to be the quickest and easiest right now”, one woman, explained about her contraceptive method choice. Many of the women did not like using condoms, as they did not manage their menstrual cycles. Furthermore, the women who did not like using condoms reported they were unreliable; they fell off and did not contribute to their sexual health in a positive manner. One woman explained, “condoms I mean, okay, whatever, but if I am in a committed relationship I didn’t want to have to use condoms”. Although male condoms provide a physical barrier to prevent pregnancies from happening, it does not provide the woman with any contraceptive control.

Combination oral contraceptive pills vary in the amount of progesterone and estrogen found in the different brands and requires daily ingestion of a pill. Six of the women tried the combination oral contraceptive pills and the majority of the women did not have a positive experience with using them. Two of the six women really liked being on the pills because of the straightforwardness of taking the daily pill, the effectiveness and the ability to manage their menstrual cycles. However, the remaining four women did not like the combination oral contraceptives for many reasons including having to take a pill daily, ingestion of systemic hormones and chemicals, ineffectiveness in managing their menstrual cycles, and the side effects. While taking the pills, two of the four women experienced deep vein thrombosis, a side effect of combination oral contraceptives. One of the women was hospitalized due to a pulmonary embolism. “I ended up being rushed to the hospital and they found a massive blood clot that was arching both lungs. I ended up in ICU for a few days. They do attribute it to that particular birth control. Now I won’t be able to use any birth control ever again”. Because these women have limited mobility already, the likelihood they will get a blood clot independent from contraceptives is already

prominent. Many of the women are aware of this risk, “we [people in wheelchairs] have lower mobility and are at a higher risk of getting a blood clot”. Otherwise, the main concern with taking the oral contraceptive pills was the ingestion of a pill containing hormones and chemicals. Many of the women are already taking medications and having to take another pill is not appealing.

Depo Provera is a progesterone-only injection that was widely used with the participants; in fact, 5 of the women used the injection. Majority of the women enjoyed using the Depo Provera because of the facility of use, effectiveness in preventing a pregnancy, and termination or lessening of their menstrual cycles. The women even explained, “I loved being on Depo Provera! It was just great! I didn’t have a period”. Although two women did not have a great experience on the Depo Provera injection due to ineffectiveness in managing their menstrual cycles and side effects. One of the woman stated, “I gained 20 pounds in like 3 months. I came right off of it”; further explaining that such a significant weight change caused difficulty for her to complete her activities of daily living. As mentioned, many of the participants sought out contraceptives for menstrual management purposes and when their contraceptive choice is not satisfying this, they stop using the method. The most concerning side effect of Depo Provera is the potential for bone density loss. Many of the women were aware of this side effect and the predominance bone loss is to women who are wheelchair bound; yet, it did not prevent them from using the Depo Provera.

Some other women used alternative methods including the contraceptive patch, progesterone-only oral contraceptive pills, intrauterine device, foam, and the rhythm method. Two women who used the patch, one was satisfied and the other was not. The woman who enjoyed using the patch provided reasoning including ease of use, effectiveness in preventing a pregnancy, and success with menstrual management. The reasons that the other woman did not like the patch was solely because it did not provide significant menstrual management and alleviate symptoms associated with her menstrual cycle. The woman using the progesterone-only oral contraceptive was satisfied with the pill because she was between pregnancies and it was the best option at the time. However, she was not content with the concept of taking a pill everyday nor with the lack of menstrual management it provided her. Only woman using the intrauterine device was displeased with the device, as it did not alleviate the abdominal pain she experiences during her menstrual cycle, and it made the pain worst. The woman using the foam found the contraceptive to be useful but very messy. She did not find any relief with her menstruation, but did admit that using the foam and a male condom was an easy method to use. The rhythm method was suggested to a woman as her only option other than condoms, which was unsettling to her and made her “quite uncomfortable”. She explained, “Like you use it to get pregnant so, I’m sure if people want to use it

to avoid pregnancy, it would work just as well”, but it was not an effective method of contraceptive for her.

*Idealistic and Non-Idealistic Method of Contraceptive*

Many of the methods currently being used by the participants are not their idealistic method of contraceptive. In element, none of the women are using a contraceptive that they are fully satisfied with nor is the method they are currently using their idealistic method. Although the search to find a perfect contraceptive to manage their menstruation continues, four of the women’s partners have had or are planning on having a vasectomy to prevent any pregnancies. For the women whose partners do have the vasectomy, they are satisfied with the results and find having the vasectomy solves the aspect of preventing a pregnancy.

The knowledge the participants had on the various contraceptive methods varied from minimal to extensive; however they were very knowledgeable about methods they would and would not like to use. In asking them about methods they knew about, would like to use and would not like to use, a better understanding of their needs in relation to their contraceptive options could be analyzed. Table 1.2 highlights the idealistic method and non-idealistic methods the participants would like as contraceptives.

Table 1.2 Desired and Undesired Contraceptive Methods

Contraceptive Method	Participants that want to use	Participants that would not like to use	Unsure or did not suggest
Depo Provera	4	3	3
Oral Contraceptives	3	6	1
Patch	2	1	7
IUD	1	8	1
Condoms		2	8
Hysterectomy	2		8

With the diverse selection of contraceptive options available, the contraceptive methods in table 1.2 highlight idealistically what the participants would like to use. The methods the participants listed were not necessarily contraceptives they have used in the past. Depo Provera is the most popular contraceptive and determined to be the most idealistic. This method was the most idealistic for some women due to its ability to decrease or eliminate completely their periods, ease

of use and effectiveness in preventing a pregnancy. However, the reasons why women were not attracted to using the injection was because of the potential for it to not terminate or decrease their menstrual cycles. "Depo Provera, some people like it some people don't. It just might not stop my period so, not sure about that one".

Oral contraceptive pills yielded mixed results. Many women were attracted to the pills because of ease of use, able to regulate menstrual cycle independently, previous history of taking the pill prior to being in the wheelchair, and reassuring as menstruation occurs once a month. One woman explained, "It's just a safe and easy option. It makes you regular or you can continuously take the pill so you don't get it [period] as well". In comparison, more women did not want to take oral contraceptives and said it would be their least idealistic method. "I just think birth control pills are a pain in the butt. I take a lot of medication already so one more just doesn't float my boat". Due to the daily requirement of taking the medication, the systemic ingestion of chemicals and hormones, potential side effects such as thrombosis, and inability to fully control menstrual cycles, were the main reasons why oral contraceptive pills were not favored as a method.

The intrauterine device had many participants uninterested and with many opinions around using this method. The one woman who voiced interest in using the IUD reasoned that it might prevent a menstrual cycle, which was her main objective for searching for contraceptives. The remaining nine women voiced concern surrounding the intrauterine device including indwelling foreign body, expense of the device, pain on insertion, need for replacement, and inability to feel displacement. Many women worry about the concept of having an implanted device in their body that would last for several years. One woman explained, "to have something inside me all the time it just made me feel really uncomfortable". Along with this came the concern of invasiveness of the process of inserting the IUD and the pain. Furthermore, many participants felt the price of the IUD was too expensive for them. "That cost \$350 out of my pocket. I can't afford \$350, the IUD is not ideal for me". As well as the cost, some women expressed concern with having to replace the IUD and not fully understanding how it worked. The concept of not being able to feel the device and inability to sense if something had displaced was another area of concern in regards to using the IUD. "I don't know if something does go wrong, I wouldn't feel it. I have no sensation", a woman explained about her lack of interest in the IUD. Overall, the women were not keen on using the IUD as a method of contraceptive.

The patch had some interest in use based on the ease of use and the effectiveness in preventing a pregnancy. The concern of using the patch, voiced by one participant, was solely based on her experience and that it did not alleviate symptoms associated to menstruation. A few

participants mentioned condoms, as not being a method of interest because of the unreliability, does not contribute to menstrual management and due to discomfort with use. One woman has allergies to latex and silicone; therefore, when using any condom, it causes an allergic reaction. Two women expressed the desire to undergo a hysterectomy. The reasoning behind choosing a hysterectomy, as their idealistic method, was because no other methods have worked to help them control their menstruation. "I'm still considering it [hysterectomy], because of the mess of having a period. Having a hysterectomy would be awesome!" Although a surgical intervention, the option is deemed to be the best for these two women and their situations.

Although the participants provide suggestions for the idealistic method of contraceptive they would like to use, the key aspect to choosing a contraceptive method involved being presented with all the choices and individualized contraceptive care, which will be discussed in further detail later on. Many of the women were not presented with many options. "There weren't any other options really and there weren't any offered to me", a woman voiced when asked about the options she knew about after listing only 3 methods. Since there are such a wide variety of contraceptives, many women felt presenting all options would be beneficial.

### ***Accessibility in Health Care Facilities and Staff Support***

For women to get adequate gynecological care and contraceptives, a health care professional must be approached. The women were asked about their experience in attaining contraceptive care and the accessibility of the health care facilities. The women were vocal about the accessibility to gynecological care and the facilities, and the support staff assistance at the health care facilities.

#### ***Accessibility to Gynecological Care and their Facilities***

In order to get adequate contraceptive care and gynecological care, women must go to health care facilities. With all the women in the study, they all reported having a family doctor but only four of the women had a gynecologist. Half of the women felt they were receiving adequate gynecological care while the other half were left unsatisfied with the care they were getting. Furthermore, when asked about seeking out gynecological care, many of the women reported difficulty in finding a care provider or adequate care. "My doctor has been trying to find me a gynecologist just to do a basic women's check up for the last 2 and a half years. It's not easy to find one", one participant reported. Unfortunately, the issue of an accessible office with adequate, wheelchair friendly equipment was consistently voiced. When asked about gynecological care and

the health care facilities a few themes became apparent. The lack of accessible exam rooms, issues surrounding staffing, and lack of communication surrounding needs were prominent in the interviews with the ten women.

In order for these women to get gynecological care, they need to be able to access the building, maneuver around the office, be able to enter the exam rooms, and get onto the examination table. Unfortunately majority of the women are unable to do so. One woman explained, "I have never been to an ideal clinic. The exam rooms are always tiny and the tables have always high". Only 2 women currently use a completely accessible facility located at the local rehabilitative hospital, Glenrose Rehabilitative Hospital. The Glenrose offers a free sexual health clinic for women one afternoon a month where women can meet with a gynecologist in a completely wheelchair accessible facility. The room is of adequate size and the examination bed height is adjustable. The other 8 women do not use the clinic, although 5 of the 10 women are aware that the clinic does exist. All ten women reported that their doctor's offices offered wheelchair parking and the building is wheelchair accessible. However, only half of the women stated that the examination room was large enough for them to get into and move around. A woman said, "It was really difficult for me to get in and out of the room". The main issue surrounding accessibility in the doctor's office was in regards to the bed height. "The tables are at my shoulder level so I can't even jump onto it, it's just too high" one of the women explained. Because the bed height is fixed and the height is typically set to be at waist height when standing, it is a challenge for someone to transfer from a sitting position. Only 2 women in the study reported that their doctors have an examination table that moves up and down. "The access in regards to the size and the height of the tables and set up of the tables has been less than ideal".

#### *Support Staff Assistance*

The difficulties surrounding the facility and equipment raised questions surrounding if the staff were able to assist in transferring and positioning or not. When the women were asked, only 3 women said their health care facilities had adequate support to help with transferring and positioning. In compensation for the high tables, one woman said, "There's always been 2-3 ladies to help me hop up on to a table, ask me what I need, how I need it done. And always has been a second person in the exam room whenever I do have my paps done". However, this was atypical from what the other women reported. Many of the facilities did not have the extra staff to help transfer. In fact, 7 of the women said that the reason the staff members were not able to transfer was due to safety reasons and lack of training. "They [support staff] don't feel comfortable

transferring because they just don't think they are strong enough and they don't want to hurt themselves", a participant stated about her experience with transferring. Four of the participants have resorted to bringing along their partners or a peer to assist them with the transferring and the positioning. "I have to be responsible to do it for bringing my own muscle man with me", a woman explains about having to ensure her husband accompanies her to appointments in order for her to be able to get onto the table and position. Once on the table, there was the concern of falling off or having the support of a staff member to help with positioning, since the participants lack the ability to control their legs. "The stirrups that are, not good for someone who doesn't have good leg control. The awkward part about that is that there has to be somebody there to, it's kind of like having an audience rather than a discussion with your physician when there's got to be a couple of people there to hold my legs". The women recounted having muscle spasms in their legs and were concerned about positioning during a gynecological exam. The lack of support to help with positioning was prominent among the participants.

Since the women often seek out health care, the women were asked about when they book an appointment, if they were asked about their needs. More specifically, exploring whether the women were asked if they had any health concerns that required special attention, such as mobility or positioning needs. "They don't ask, are you in a chair". Only one woman specified that her health care providers ask about her needs. The other women emphasized that they must advocate for themselves. One of the women said, "Oh no I definitely tell them that (I'm in a wheelchair). If you were not to tell them, they would not have anybody there to help you". Unless the women mentioned they were wheelchair bound, the health care practitioners would not know or be prepared for them. Along with the lack of inquiry about their health needs, the women felt they also required more time for their appointments and needed to ask for the prolonged appointment times. For example, "I'm going to need to book extra time because in order for me to get onto the table, like if we are going to do an exam. It takes longer so it's really important to make those things clear when you're booking appointments". The importance of self-advocacy was reiterated when booking longer appointments. One of the women went to a gynecologist but they were unable to help her transfer or position. When asked about what accommodations they made to help her find a alternative gynecologist that was wheelchair accessible she replied, "Oh no they didn't. I actually had to do my own research to find my own gynecologist and stuff".

### ***Contraceptive Care and Health Care Professionals***



One aspect of the interviews explored the relationship between the women and their health care professionals, specifically when seeking out contraceptive care and information. The women had mixed relationships with their health care providers surrounding three areas: communication, information, and finally, stereotypes and stigmas. The details related to each section were further investigated and explained.

### *Communication*

Contraceptive care for women, able bodied or disabled, can be a taboo topic and be difficult to discuss. Unfortunately, nine of the ten women reported not having the subject brought up to them and that they were responsible for starting that conversation. "I know that I always initiated any type of conversation about contraceptives with the doctors or nurses. It wasn't ever presented to me", one women expressed. The women were responsible for the initiation of the conversation and the feelings towards doing so was negative. "I was very disappointed that 23 years ago when I was at the glenrose that the subject was never ever brought up... Nobody, like I said nobody broached the subject. It was something we just found out all on our own. Nobody did at all". The lack of initiation by health care professionals around contraceptive use has even deterred some of the women. "So it's almost to the point where it's not important to do because it's just so complicated, you need to know the right people. I remember when I first started getting paps and contraceptives, I had no clue and the doctors had no clue, so it was kind of a nightmare". Some of the women felt that raising the issue of contraceptives was related to a lack of comfort and training of the health care professionals. Furthermore, it was vocalized that their health care professionals somewhat frowned upon bringing up the topic of contraceptives. One woman explained, "It seems like a lot of the GPs don't know a lot about disabilities in general so when you come up with something like contraceptives, it seems like, it's not like it's, like it should be normal but it's not."

The concept of self-advocacy became very prominent alongside with discussing initiation of the conversations around contraceptive care with their health care professionals. "I learned at a very young that I had to be my own advocate cause no body else is going to do that for me. I need to be able to voice my concerns and my issues. I mean other people out there shouldn't be afraid to be their own advocate. I mean you're not going to get judged by bringing up your issues, you know. You're only going to get help faster by being your own advocate". Eight of the ten women expressed the need to be insistent and advocate for their needs when dealing with health care professionals. "You have to you have to be very assertive about your, about your health, more so in this area I would say", a woman explained about having to initiate the conversation surrounding

contraceptives. Although only one woman was approached about contraceptive care, all the other women reported being their own advocate and the importance of being responsible for asking about contraceptives.

### *Information on Contraceptive Care*

When contraceptive care was brought up to their health care providers, the reactions of the health care professionals were either receptive or unsure. One woman explained, “ I went seeking contraceptive care and that was just from my GP [general practitioner] back in my hometown. And this was someone who had been my family doctor for years. He took care of me before I was injured and after I was injured. Was always a pretty straightforward guy so there were no problems with it. He had in the past had other female patients who had been spinal cord injured so he had a little bit of experience kind of weighing the pros and cons... I never did end up going back to my hometown, to my GP for a pap. He really wanted to just refer me to a female doctor that would become my GP in Edmonton. He just wasn't comfortable crossing that line... He just said that's just not something I want to do for you. And I appreciated that”. Some of the other women reported having very supportive and encouraging doctors when the topics of contraception and sexual health were brought up. “I know that with my OB [obstetrician] when I first met with her, she said, “You know it's awesome that you're pregnant”. I've always had great rapport with my specialty doctors so um, so my OB thought it was fabulous”. Only four women voiced having a positive experience with their doctor when they sought out contraceptives. The other six women felt the doctor was not as comfortable nor were they well versed in contraceptive care for women with a disability. “When the health care professionals haven't dealt with someone with a spinal cord injury before or they don't know enough about a disability or have education enough, you can actually feel... like they don't really know what to do with you”.

Once the conversation had been initiated with their health care providers in regards to contraceptive care, the information they received was minimal. Five of the ten women learned about the various contraceptive methods from their doctors. Many of them were presented with only a few options and given limited information about the methods. “When I was first looking for contraceptives, you really had to look around for information on it, you know. Not everyone has information on stuff like that. And most times when I went into a doctor's office I had to ask for it. So it's not out there on a display”. Eight of the ten women were presented only a few options when they sought out contraceptives. “I just broached the subject [with my gynecologist] and said my family doctor is saying that the rhythm method and condoms are really my only option ... But I

would like more information on, on the pill”, stated a woman about only getting offered two options of contraceptives and seeking out further information. Another woman explained how she desired more information about sexual health in general by stating, “When I was in rehab, the information we got was fairly clinical and that was good but at the same time there is a lot between not having sex and intercourse that wasn’t covered”.

Five of the women reported doing their own research online and using various sites, some credible others not. “I went online a lot so I knew about kind of what options were out there. And I didn’t, like I researched a lot... I can’t even remember where exactly Yes, I’d just Google it” explained a woman about doing her own research. Some of the women felt the information they were getting from their health care providers was difficult to relate to. “She [health care professional] gave me some paper and again, everything was so text book because she is able bodied and even though she is experienced in the field, it’s just very different hearing it from her and she gave me a piece of paper based on study based on what she has heard, you know based on stuff she had researched for. Same thing with sexuality, like as great as the information was that I got from her, I can’t relate to it because everything is so foreign. So what I ended up doing is the website that one of my girlfriends suggested and as started talking to other women with spinal cord injury”.

A few of the women stated they did not do their own research as they felt their health care professionals were providing them with sufficient information, even though the women still had to initiate the conversation. “I try and not do my own research on things just cause I freak myself out sometimes”.

Along with the issue not being brought up, some of the women expressed that the timing of bringing up contraceptive care was not ideal. “When you’re in the hospital, there’s the sexual nurse, talk to you about, like very briefly, about it. I say that but while you’re in the hospital that last thing someone like me wants to hear about is sexuality. Because we’ve got 20 million things in our life that just changed. We have 30 million things that we have to figure out what to do. And there’s depression there’s the stress and there’s the, and with some people there’s the suicidal thoughts and sex is the last thing these people want to hear. And when people do hear it, it just goes right past them, right? Because it is not important on their list. So pretty much I say that all the information I got while I was in the hospital I can’t remember, most of it”. Several of the women provided the same insight towards timing of the information provided and offering contraceptive information post discharge from the rehabilitative hospital would be more beneficial.

### *Persuasion and Health Care Providers*

When the women sought out contraceptive care from their health care providers, four of the ten women were encouraged to try a method they were not interested in trying. "I would have appreciated not getting the run around and ... about a product that I wasn't even comfortable wanting. Just that was really frustrating but, I just felt like, I got talked into it by my doctor. I don't know how I got talked [into it] because generally I'm a strong person and I don't know how he was able to do that". The women expressed feeling "pushed", "convinced", "uncomfortable", and "frustrated". All of the women were encouraged to use the IUD, but were not interested in using that method of contraceptive. "I switched GPs and went to a different one it was not very positive just because the GP was very pushy on this IUD". The main reasons for not wanting to use the IUD included not wanting an implanted device due to decreased sensation, and cost of the IUD. Although the health care professional encouraged the device, not one of the four women actually ended up using the IUD.

Along with persuasion by the health care professionals, there were several women that felt they had to convince their doctor to prescribe a specific contraceptive method. "So, it took some discussion and some convincing for him to agree to give me the depo Provera". The participants made mention of having to convince the doctors about methods they wanted to use for menstrual management and family planning purposes. Most of the women were able to successfully encourage the doctors; however, two of the women are not having the same attainments. "I had brought up the idea of, possibly having a hysterectomy because I'm not looking to have children anyways, so just take everything. And they don't do that just because anymore, you have to have a real reason, in order to have a major hysterectomy done... Yes I really did have to pursue them". Two women are looking to have complete hysterectomies due to menstrual management issues; however they both have struggled to have a doctor agree to do the procedure. "I was considering actually having a hysterectomy because I have so much pain. I thought that because of the monthly cycle, the cramping and the endometriosis... And I still feel because he is pro baby making. Like he's definitely convinced me to not have any hysterectomy and not to do anything with, like "Oh you'll still have babies, don't do anything more um, to jeopardize that possibility". The women both felt frustrated with the situation and voiced concern in relation to the issue. One of the women is scheduled to have a partial hysterectomy after extensive discussion with her doctor. The relationship between health care providers and the women in regards to advocating for specific care needs raised the need for individualized, specific contraceptive care, which will be discussed later.

## *Stereotypes and Stigmas*

"I've had people assume that nothing works to I don't have sex in my marriage because I'm paralyzed and that you know people have asked my husband and I, did you guys have to go through fertility treatments and um, yea so I've had, you know, all of those kind of stereotypical kind of things. Um, but it's still frustrating nonetheless. To have, especially doctors. I've had doctors ask me about like did I have to go through fertility treatments and you know how did I get pregnant. The main stereotypes are that like because I'm paralyzed that I can't have sex or don't have sex. And that even if we did, we would have trouble getting pregnant". Five of the women reported experiencing stereotypes and stigmas from health care professionals with respect to contraceptive and gynecological care. The main stereotypes included being asexual and not wanting to have sex, inability to have sex, inability to reproduce, not requiring contraceptive care, and lack of orgasmic ability. Some of the women felt that once they initiated the conversation around contraceptives, the health care professionals replied in shock of their sexual abilities. "I'd say, they didn't come out and say you are not able to have sex; it was more like you shouldn't". Another woman explained, "I've said like I have sex. And people are like "Really? You have sex? " Like they make the assumption that that's not possible. Another thing too, I don't know if you're interested or that you care but it's actually possible for me to achieve orgasm. I definitely think people would make the assumption that not only that I wouldn't have sex but that or maybe could have sex but you know could enjoy it or, or feel it, or anything like that". Although the stereotypes and stigmas existed, it did not prevent any of the women from attaining contraceptive and gynecological care.

Overall, the health care professional and participant relationship in regards to contraceptive care revealed some gaps. The women reported having to self advocate and initiate the conversation about contraceptive care to their health care providers. Many of the women felt confident enough to discuss their gynecological and contraceptive needs with their doctors. Some women felt the doctors lacked the comfort in discussing the matter while others reported their doctors were fairly confident in the contraceptive care they could provide. The information provided by the health care professionals was minimal and the contraceptive options presented were limited to only a few. Some of the women did their own research and wanted to have more relatable information that pertained to their injury. The timing of when the information was provided was also raised; women felt it would be more beneficial to have the information given after discharge from rehabilitation facilities. The persuasion by health care providers to use a specific method of contraceptive was brought to light and the women were not receptive to this nor did they think positively about it.

Some of the women also found they had to advocate and convince their doctor to provide a preferable method of contraception. Half of the women have experienced stereotypes and stigmas around contraceptive care and sexuality from health care professionals. However, none of the women were unable to attain contraceptives because of the stereotypes they faced.

### ***Participant Suggested Improvements***

The experience that women who are wheelchair bound had in attaining contraceptives highlighted gaps in the care they were receiving. The women were asked what could have been done or could be done in the future to improve and facilitate accessibility to contraceptive care. The major improvements that were suggested were concerning contraceptives, information, health care facilities, and health care professionals.

#### ***Improvements to Contraceptive Options***

With the wide range of contraceptive options available, the women participating in the study reported that more contraceptive options could be beneficial to their population. “Yea, cause I’m sitting here going, hmm I don’t think there’s enough”. “I think that the more options that are out there for people, I mean yes it would be harder to make that initial decision, but at least then they have more options to try, before they make that final decision. I mean right now, there’s just like a few select that I know of, that I was just even told of, and that I tried. You know, I mean if there were other options out there that seemed even better I would go ahead and try it”. Seven of the women suggested more contraceptive options, chemical and non-chemical, would be well received. “There are so many things out there for women but if you’re a paraplegic all of a sudden everything is just cut right off. So it would be nice to know if there was a contraception option for women. That would be really nice”, a woman explained about the lack of options for women who are disabled, specifically paraplegics. With the side effects associated to many of the contraceptives, the women reported feeling like their options were limited. They went into further detail about the side effects of the pharmaceutical contraceptives being a concern. “I mean with the pill effecting blood clots so maybe have one that doesn’t have that effect or have something that doesn’t affect your bone density”, a woman suggested about an alternative method that avoided such side effects. Another woman supported the improvement, “If there was such a thing [contraceptives for women in wheelchairs], then I think there would be [interest] because sometimes we have enough to deal with as far as being paralyzed other than having to worry about such things”. The desire for more

contraceptive options that women who are wheelchair bound could use was prominent and recurrent in the suggested improvements.

### *Improving Information on Contraceptives*

“I wasn’t terribly knowledgeable on them [contraceptives] other than taking the pill. I didn’t know about all the other types and kinds”. This was a common and repeated concept by all the women in the study. The lack of knowledge on contraceptive options was very much apparent when the women were asked. The women on average knew about 4 methods of contraceptives. The desire to know about all the options and know more about the options available was prominent. “I would love to be informed of any changes or any contraceptives that are out there now. If I haven’t heard them all then it would be nice to know about them”. Another women stated, “Providing alternative, providing options and the pros and the cons for those options, or at least having an understanding of, if you’re going to take this what can you do to combat some of the side effects. That’d be helpful”. The information that was being provided by health care providers about contraceptives was reported to be brief and limited. “I said I just think there should be more information made available and maybe have information about the different methods with what is good about them and what is bad about them, if they have side effects, and etc. ... Nobody brought it up to me”. Although more information was reported as something that would be beneficial, some women had a different approach to the matter. “The information should be more accessible; it’s there now. I believe that there is lots of good information out there”.

Accessibility to information about contraceptives was the most reiterated concept by the women. “When I was first looking for contraceptives, you really had to look around for information on it, you know. Not everyone has information on stuff like that. And most times when I went into a doctor’s office I had to ask for it. So it’s not out there on a display. Which it should be, it should be free for everybody to take”. Many of the women were in chorus about having more accessible, credible, and relevant information. “The unfortunate is that they have a lot of great information but the way how the information is given back to the people who actually needs it, needs improvement”. All of the women made mention that the information was not accessible and was difficult to find. One of the women said, “I wish I had some of the stuff more accessible for the patients, and probably just maybe more explanations. It would be good to get at least some type of I don’t know, maybe a booklet or something, just get some information or direction. Many times you can go online and get all the different information right? But how do you exactly know which one is

the right type or which one is the right one for you, and stuff like that. Just a little more guidance and where exactly to go for that, accessing information”.

Where the women differed most was in the method and type of information they would find helpful. “What I wanted to hear was from another C6/7 quadriplegic female and their experience... that’s what I wished for, when I was in the hospital”. Two of the women suggested peer support and information on their experience would be beneficial to get contraceptive and gynecological care. “I still believe in that phase, that period of injury to 5 years post injury that people should be exposed to other people living successfully with their disability or whatever it is. And that can lead to all kinds of natural conversations about contraceptive care, choices, how to even approach your doctor to talk about it”, a woman explained about why peer information would be helpful. Some of the other women disagreed and would not find information from other women who are in a wheelchair. “I signed up for some group and I just, I just think they are so, I mean I can see for a new wheel chair user, initially after having some like whether they’ve had a spinal cord injury or whatever but I don’t know, I just have never been a fan of those peer groups or peer stories”.

Some of the other women felt the information being accessible through the Glenrose Rehabilitation Hospital in Edmonton, Alberta or other local rehabilitation hospitals would be beneficial. “I just have the best relationship with the people at the Glenrose. They are the most helpful and I think people think that they probably can’t call them, like they have to for some reason, be part of the Glenrose. Maybe I just am forward but I just call her [sexual health nurse at the Glenrose] for anything. She has never turned me down. Even if she sends the information in the mail, like she is just great”. Having a relationship with the Sexual Health Service at the Glenrose proved to be beneficial for four women and their contraceptive needs. “You could always phone up the Glenrose, call up the Glenrose and they would be willing to offer up suggestions”, another woman suggested if searching for information. The Sexual Health Service at the Glenrose does offer many services along with information, “I know that the Glenrose actually has a Sexual Health Service, a doctor who will come in and I think it’s once a month they do paps and stuff like that for women with disabilities”. The information about contraceptives and gynecological care could be offered through them. However, only four of the participants knew about the Sexual Health Service at the Glenrose. One woman explained, “I think just more advertisement in the media that there are options out there. I know it’s not information that the general public is going to need. It’s not always that important but people need to, people that need it, need to see it”. Along with the Glenrose Rehabilitation Hospital, other community agencies were suggested as being a good place to have information. Four of the women suggested using the community organizations. One of them was the



Canadian Paraplegic Association (CPA). "I know the CPA that they are really good with information but if somebody doesn't know to call them then how are they going to know how to look and if they publish a magazine and somebody doesn't get it then how do they get the information?" Using the community agencies to have access to credible information and to resources within the area for women who are wheelchair bound was suggested.

"They could just send me like a little booklet in the mail, saying, hey, you're a disabled woman, have you considered these contraceptive options?" Suggestions of having brochures and booklets were made by six of the women. "It could be like a package, almost like a package that you get when you leave [the hospital]". Some of the women were less supportive of the idea of a brochure or booklet stating, "Most people these days don't use paper based stuff".

Six of the women suggested having online accessible information available to women who are wheelchair bound. "I think online information is really critical because especially people in wheelchairs they don't get out in the community as much as maybe some other groups of people and probably having access to the internet and having information on the internet is valuable". The information was suggested that it could be linked to the community agencies and to the rehabilitative hospital to facilitate finding credible and accurate information. "If it's easier to find, you'd have less questions because people would be able to find the answers for themselves. Then if they need a little more information after then they can phone up whomever they need to and that sort of thing. I definitely think if they could get more information online, the better". Some of the women voiced the concern that there is a large amount of information when they searched and having accurate, relatable, and credible information in one place would be very beneficial.

One of the women was suggestive of a conference. "Have a one-day event or even 3-4 hours where you just get women in a room. And then you have like samples or information pamphlet that they can take on the different choices that they can have. Then they could have like gynecologists do like either presentations or actually perform some of the tests with an easily accessible table". Another way of presenting the information was in a video that was done by women who are wheelchair bound. "They can take a DVD, with cover on, no one else would know, they could go home in their private lives. At leisure time when they are ready instead of being crammed with all the information when you're at rehab".

When the women were asked about the type of information that would be beneficial to them, their suggestions seemed unanimous. The content would include information on "all the possible types", "pros and cons of the different methods", and "phone numbers of gynecologists" all focused towards women who are wheelchair bound. Another point that was made by several

women was giving more than just “clinical” and “sterile” information about contraceptives. “I believe that there is lots of good information out there. But it’s not always easy to find. And, there needs to be some balance between teaching the person to shoot the gun and then teaching them how to hunt. Cause those are two completely different things, right? You know, how to negotiate and navigate relationships and intimacy and not just sex and contraceptives”. “I was less worried about contraception than I was about intimacy with my boyfriend. Hugging, kissing, hopping on the couch, that sort of thing. When I was in rehab, the information we got was fairly clinical and that was good but at the same time there is a lot between not having sex and intercourse that wasn’t covered. You know what I mean? I had all the information I needed to know about; yes my cycles are going to come back, yes, if I have sex I will get pregnant. I need to use a condom if I’m not on some other sort of birth control. All that. But then there’s the in between. How do I get on the couch? How do I discretely talk to my boyfriend about if I have a bladder accident?” The information that the women wanted varied from being strictly the facts to more relationship development and sexual relationships now that they are wheelchair bound.

### *Improvements to Health Care Facilities*

With the issues around wheelchair accessibility at health care clinics, all of the women agreed that better health care facilities would greatly benefit attaining adequate contraceptive and gynecological care. “It would be nice to have a doctor with a place set up for people in wheelchairs. It would be really nice to have a really friendly wheelchair accessible environment”. Specifically, “larger rooms” and “beds that raise and lower” would make a significant difference. “Like I don’t quite understand why they are so high like it doesn’t make sense to me”, a woman said. As previously mentioned, many of the women were unable to get onto the table for a proper examination and as one woman explained, “I think just having better facilities is kind of a, what really needs to happen is just better facilities so that you know if someone does have an issue and does need to go in for a gynecology exam then they can”. The women also reported that having tables that lowered would be beneficial to both the general population as well as the health care system. “I think a lot of gynecologists out there would get a lot more business and get a lot more patients if they provided that for people. It’s, this city is huge, there are a lot of people living here and it’s not just able-bodied people. We are part of the population too”. Several women provided rationale for the tables as being beneficial to other types of patients, “I understand the cost involved but at least have one or two tables that, there’s lots of elderly population right now, some disabled population that [both] eventually will use [the movable tables] and the cost will be satisfied”. With

the more wheelchair accessible rooms and tables where the height is adjustable, the women felt they would have a better experience with getting contraceptives and gynecological care. Many are aware of the inability to have a completely perfect facility. “They [examination rooms] don’t have to be completely you know set up, because nothing is ever going to be completely set up for every wheel chair and every person but as long as they were you know better equipped to even make the products a little more easy for both the health care professional and the person in the wheelchair”. Creating a wheelchair accessible facility, which included large rooms and examination tables that raised and lowered, was repeatedly suggested as a way to improve the experience. “I mean the less intimidating you can make a place when it comes to getting a pap smear, I mean it’s already not the funnest thing in the world for a woman to do but when you’re disabled... makes it even more awkward”.

### *Improvements and Health Care Providers*

The contraceptive care experience involved interaction between the women and a health care provider. Six of the ten women suggested their health care provider could improve when it comes to providing contraceptive and gynecological care. The areas of improvement included “having support staff”, “better communication and training”, and “individualized care”. Having extra staff available to transfer and help with positioning was proposed. One woman suggested something that could be done to improve care, “Staff that are not afraid to transfer you”. “If you could have a staff person there to you know, hold your legs for you, or each leg... It just adds a little more dignity to the process”, another recommended. Also, having staff ask when booking appointments about special needs or assistance required was recommended to better the women’s experience. “Because they don’t ask, are you in a chair. Well yes I am. You know, speaking over the phone you just don’t know, right? So I usually tell them right up front, I’m in a chair. I need these services do you offer them? And if they say no, well you know, it’s on to the next person...it would be nice if they did ask though”. Simply asking about their needs was voiced to be helpful and favorable. It does require more work and more time but it just, just makes it more equal process for people. But you know right now, we have to ask for that and someone like myself, I’m able to say, I need this. But I know there are people with disabilities that are not forward”.

Communication between the health care providers and participants was an area that many women suggested could improve. “I don’t know if there is a best method for medical staff to bring the subject up other than that: hey, I’m here for you if you have any questions”. Some of the women advocated for increased training around dealing with gynecological and contraceptive needs of

women who are wheelchair bound. One woman thoroughly expressed how important of a role these improvements could potential play. "Try and prepare people in all helping sorts of roles whether they be nurses, PT, OT, you know, community counselors at CPA to be aware of their own attitudes and beliefs, and as much as possible be comfortable broaching the topic. Rather than waiting for the person to ask. So you know and using teachable moments. I think the more important issue is professionals that are trained to accommodate so asking questions. What are you able to do? Do you have assistance that you can bring with you or are willing to? Or if you're not, do we need to try and arrange and have a lift come and be available if none of us are able to or willing to? Cause it is an expense that is a hardship and I appreciate that, that to a clinic, to many small clinics". Increased awareness of the care differences that women who are wheelchair bound require would improve their overall experience and facilitate attaining contraceptives and gynecological care. "I know that more experience and even just having more experience for the doctors and nurses. I mean, more training, more, like I don't know if they need training but just more awareness that hey just because you have a disability or you're in a wheel chair doesn't mean you're not active in every other aspect of life".

Finally, the women felt that having the health care providers offer individualized care would be a great improvement. Being cared for on an individual basis would allow them to "have control over contraception". A woman explained about this need, "I definitely think that, yea not only should there be more women who have a personal physician but they definitely need to have their own gynecologist... and own care. I mean that's equally as important. And, that's definitely not the case". Having the care being tailored to each individual person would allow for better experiences with contraceptives. "It would be nice if I could just say, this is what I need and this is my body and I would have appreciated not getting the run around". Some of the women did agree their "doctors had their best interest at heart" and valued their opinion; however, having a more distinct and personalized patient focused approach was conveyed.

### ***Future Recommendations***

The purpose of this study was to explore the experiences and health care practices of women, who are wheelchair bound, in attaining information, contraceptives and gynecological care. Furthermore, outlined objectives included:

1. Explore and understand the experiences of women who are wheelchair bound in attaining contraceptives, gynecological care and information regarding contraceptive methods.

2. Unveil the successes and challenges that exist that limit or inhibit women who are wheelchair bound in attaining contraceptives and gynecological care.
3. Gain an understanding of the needs of women who are wheelchair bound in acquiring contraceptives and adequate gynecological care.
4. Compile recommendations that service provider can use when working with women who are wheelchair bound.

The objectives were successfully and thoroughly realized in the study.

The experiences of women who are wheelchair bound were extensively explored and each of their experiences was conveyed in a unique yet understandable manner. The analysis proves the experiences provided enough information around contraceptive methods used, receiving contraceptives, and gynecological care. The findings exemplified successes and failures of women in wheelchairs seeking contraceptives and gynecological care. Remarkably, the data collected provided an inside look at exactly how the success and challenges impacted their current situation and views on contraceptives. With the women suggesting improvements that could be made to contraceptive and gynecological care; the data delivered a substantial list of recommendations and modifications. Finally, the recommendations will follow suit exemplifying potentially changes and alterations health care providers could make to improve the overall experience of contraceptive care for women who are wheelchair bound.

#### *Changes to Contraceptive Methods*

- More contraceptive options that women who are wheelchair bound could use. This would include an option where the side effects would not heighten the preexisting health concerns of a woman in a wheelchair. Whether pharmaceutical or not, a contraceptive option that was not indwelling or implanted would be well received.
- More information about contraceptives specifically targeting women in wheelchairs. The information would include the various contraceptive methods, benefits and risks to using each method, and include peer opinions about each method.
- Increase accessibility of information about contraceptives. Using the Internet, brochure, or pamphlet, having the information about contraceptive methods more easily attainable to women who are wheelchair bound. This could be done using community agencies and rehabilitative hospitals.

- More promotion of the Sexual Health Services at the Glenrose Rehabilitative Hospital in Edmonton, Alberta. By having more publicity of the services available specifically for women in wheelchairs, could be beneficial to the population.

### *Facilities*

- Having wheelchair accessible examination rooms. In creating an environment that is wheelchair friendly, women who are wheelchair bound will be able to get adequate gynecological care including proper examinations and regular pap smears.
- Height adjusting examination tables. This single piece of equipment plays the most critical role in facilitating adequate gynecological care in regards to health care facilities. Women who are in wheelchairs would be able to independently transfer onto the examination table and allow them to receive a proper examination pap smear.
- Support staff available for positioning and transferring. Providing staff members that are trained and able to transfer women properly and safely from their wheelchair to the examination table, help with positioning especially with women who have increased spasticity in their legs, and provide patient safety when laying on the examination table would be beneficial.
- When booking an appointment, have support staff ask patients about their needs to better facilitate care when they are in the office for their appointment and allow for the patient to bring assistance if necessary.

### *Health Care Professionals*

- Initiate conversation around contraceptive and gynecological care. By asking about their contraceptive and gynecological needs, whether present or not, creates an open and comfortable environment that facilitates the conversation. Simply providing the opportunity to discuss their sexual health needs, specifically around contraceptives, would be beneficial.
- More training and education around dealing with patients who are wheelchair bound. If unsure or not well versed in the area of disability and sexuality, increasing the knowledge base and important health considerations would be advantageous. This would include information on contraceptive care and special considerations for women in wheelchairs, appropriate communication skills, and transferring and positioning patients in wheelchairs.

- Provide individualized, patient centered care. Although it would seem ubiquitous, really focusing on what the individual desires and providing credible, accurate and reliable information and care. In the end, the patient is responsible and has the final say with respect to their health care. Thus, health care professionals need to be more cognizant and sensitive to their needs and provide the most idealistic and best care possible.

### *Implications for Future Research*

The study highlighted many areas of contraceptive care for women who are wheelchair bound that could be thoroughly explored and developed. An information tool, such as a website or package, could be created that included information of contraceptive methods, benefits and downfalls to each method, sexual health information, relationship information, tips on being an advocate for gynecological care, and a list of local sexual health services specific to women in wheelchairs. The tool could be trialed and gaining feedback from women in wheelchairs and health care providers about the effectiveness, positives and negatives of the tool. This could prove to be beneficial for both the population of wheelchair bound women as well as for health care providers. It would provide consistency of contraceptive care and allow for women to have access to credible information and to health care providers with completely wheelchair accessible facilities. Also, development of a new contraceptive option could be researched as well.

### ***Dissemination of Research Findings***

The research findings will be disseminated in a variety of methods. A truncated version will be provided to the Canadian Paraplegic Association, Options Sexual Health Association, MS Society of Canada, the Sexual Health Service at the Glenrose Rehabilitative Hospital, and to the Alberta Society for the Promotion of Sexual Health. An oral presentation of the research and finding will be given to the Alberta Society for the Promotion of Sexual Health on October 10<sup>th</sup>, 2012. Publication of the study in a peer reviewed journal, such as the Canadian Journal of Sexual Health. Presenting the findings at an applicable and suitable conference will also disseminate the findings. Finally, the findings will be presented and promoted to the Faculty of Medicine, Faculty of Nursing, and the Faculty of Rehabilitative Medicine at the University of Alberta to be included in their curriculum. Any other relevant opportunities to disseminate and present the research findings will be welcomed.

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***Appendix A: Recruitment Poster***

**Exploring Contraceptive Use in Women who are Wheelchair Bound**

Are you interested in participating in a research study?

**Who:** Women aged 18 to 45 who are wheelchair dependent and live in Alberta

**Why:** The main purpose of this study is to better understand the experiences of women who are wheelchair bound in attaining contraceptives and information about contraceptives. The main goals are:

- Explore and understand the experiences of women who are wheelchair bound in attaining contraceptives, gynecological care and information regarding contraceptive methods.
- Unveil the successes and challenges that exist that limit or inhibit women who are wheelchair bound in attaining contraceptives and gynecological care.
- Gain an understanding of the needs of women who are wheelchair bound in acquiring contraceptives and adequate gynecological care.
- Compile recommendations that service provider can use when working with women who are wheelchair bound.

**What:** If you choose to volunteer for the study, you will be asked to complete a survey and an interview.

**Where:** The survey and interview will take place at a location that is convenient for you.

**When:** The survey and interview will be scheduled at a time that works for you.

**How:** If you are interested in sharing your experience in attaining contraceptives and information about contraceptives, please contact me at the following:

Carolyn Gratton, Registered Nurse and Graduate Student in the Faculty of Rehabilitation Medicine  
780 965 9867  
Email: Gratton@ualberta.ca



### **Appendix B: Letters of Support**

Date: March 19, 2012  
Carolyn Gratton  
3-48 Corbett Hall  
University of Alberta  
Edmonton, Alberta T6G2G4

Dear Dr. Shaniff Esmail and Carolyn Gratton;

I am writing to support the “A Focused Ethnographic Study Exploring Contraceptive Use in Women who are Wheelchair bound” research project you will be conducting. This population faces multiple challenges from accessing basic sexual health information to accessing the full range of sexual and reproductive health services that are basic to the lives of modern women. OPTIONS support the thesis objectives and is hopeful the results of the research will benefit women who use wheelchairs. By way of example, OPTIONS is dedicated to the promotion of sexual and reproductive health, but its offices are in a building that is only theoretically wheelchair accessible. Like many service providers, underfunding of our services forces OPTIONS to lease older buildings that were not built to be “wheelchair accessible” and have been poorly retrofitted to increase accessibility.

We are also open to working in collaboration with you to accessing participants for the study. This may include advertising in in our E-news and promoting the study through partnering organizations the provide service and supports to women who use wheelchairs.

This population is underserved and needs a higher level of outreach. Their sexual and reproductive health needs must be better understood to enable the provision of appropriate services to support their sexual and reproductive health. We look forward to collaborating with you and please feel free to contact us if you require any further assistance.

Sincerely,

Larry Brockman,  
Executive Director,  
OPTIONS Sexual Health Association



**Head Office**

305, 11010 - 101 Street  
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Phone: 780 424-6312  
Fax: 780 424-6313  
Toll-Free: 1-888-654-5444  
E-mail: [edmonton@cpa-ab.org](mailto:edmonton@cpa-ab.org)  
[www.cpa-ab.org](http://www.cpa-ab.org)

November 18, 2011

Carolyn Gratton  
3-48 Corbett Hall  
University of Alberta  
Edmonton Alberta, T6G 2G4

Dear Carolyn Gratton and Dr Shaniff Esmail:

I am writing to support the "Contraceptive Use in Women" research project you will be conducting.

The Canadian Paraplegic Association (Alberta) believes in the thesis objectives and is hopeful the results of the research will benefit our female clients/members who use wheelchairs.

We are also open to working in collaboration with you to accessing participants for the study. This may include advertising in our monthly electronic newsletter Wheel-E, in our quarterly magazine "Spinal Columns" or pulling a list of females who use wheelchairs from our data system called "CORE".

If you require anything further, please call me at 780 424-6312.

Sincerely,

Guy Coulombe  
Manager of Client Services



Edmonton (Head Office) • Calgary • Fort McMurray • Grande Prairie • Lethbridge • Lloydminster • Medicine Hat • Red Deer • St. Paul

Charitable Registration Number 11835016 RR0001



## **Appendix C: Demographic Survey**

### **Demographic Survey**

#### **Exploring Contraceptive use in Women who are Wheel Chair Bound**

**Date:** \_\_\_\_\_ **Administrator:** \_\_\_\_\_

**Participant Name:** \_\_\_\_\_ **Code#:** \_\_\_\_\_

**City:** \_\_\_\_\_ **Phone Number:** \_\_\_\_\_

**Email:** \_\_\_\_\_ **Alternate Number:** \_\_\_\_\_

**Age:** \_\_\_\_\_ **Marital Status:** \_\_\_\_\_

*(Between 18-45 years of age)*

**Dependence on Wheel chair:** \_\_\_\_\_  
*(Complete dependence on wheel chair)*

**Injury or health issue requiring wheelchair use:** \_\_\_\_\_

\_\_\_\_\_

**Any other significant health issues:**

\_\_\_\_\_

\_\_\_\_\_  
*(The study focuses only on physical disabilities. Any mental disabilities are not included)*

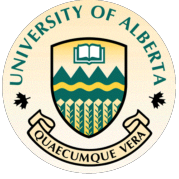
#### **Explanation of Study:**

You have met the criteria to participate in this study. As you are a woman who requires a wheelchair to mobilize and you are between the ages of 18-35. The goal of this study is to better understand what women experience when trying to get contraceptives from their health care professionals. With the information collected, we are hoping to find things that can improve your experience and hopefully help you to get the care you need.

\_\_\_\_\_ *(Initial)* Read information sheet to them outlining what the study entails. If they agree to participate, set up an interview time and place. Give them the contact information required.

**Interview date and time:** \_\_\_\_\_

**Place of interview:** \_\_\_\_\_



**Appendix D: Consent**

**CONSENT**

**Title of Study:** Exploring Contraceptive use in Women who are Wheel Chair Bound

**Principal Investigator:** Carolyn Gratton  
**Study Coordinator:** Dr. Shaniff Esmail

**Phone Number:** 780 965 9867  
**Phone Number(s):** 780 492 0397

	<u>Yes</u>	<u>No</u>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to your records, including personally identifiable health information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you want the investigator(s) to inform your family doctor that you are participating in this research study? If so, give his/her name _____	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		
I agree to take part in this study:		
Signature of Research Participant _____		
(Printed Name) _____		
Date: _____		
Signature of Witness _____		
<i>A Witness line is only required if you anticipate that your participants will be unable to read the consent for themselves. If so, an impartial witness (i.e. not associated with the study team) must be present during the entire informed consent discussion and is witnessing that the participant understood what was discussed (i.e. not just witnessing the signature process).</i>		



I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

*Per ICH GCP this should be signed by the person who is conducting the informed consent discussion (if that is not the Investigator – the person that obtained the consent needs to sign here)*

Signature of Investigator or Designee \_\_\_\_\_ Date \_\_\_\_\_

**THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT**

## **Appendix E: Information Sheet**



### **Study: Exploring Contraceptive use in Women who are Wheel Chair Bound**

#### **Why am I being asked to take part in this research study?**

You have been asked to take part in the research study, as you are a woman who requires a wheelchair to mobilize. You have been asked to be apart of this study as you are between the ages of 18-45. The goal of this study is to better understand what women experience when trying to get contraceptives from their health care providers. With the information collected, we are hoping to find things that can improve your experience and hopefully help you to get the care you need.

#### **What is the reason for doing the study?**

The reason for doing this study is to better understand what women who use a wheelchair go through when trying to get contraceptives. There is not very much information on the area and it is something that is very important to discuss. In doing this study, the things we find out will help us help women with disabilities get the contraceptive care they need.

#### **What will I be asked to do?**

The study will involve 3 steps. The first step is an initial phone call where some questions will be asked to see if you can participate in the study and get some general information about you. The phone call should only take 5-10 minutes. I will also give you contact information for the study in case you have any questions. At this time we will schedule the second part of the study.

The second and third steps of the study are the interview. We will meet in person at a place that you decide and a place you feel comfortable. This part of the study should not take longer than an hour and a half. The first part of this meeting will be to sign a consent form and to fill out a survey about your health and some more information about your current contraceptive use. After that is done, the interview will start. I will ask you a few questions and you will answer them the best you can. I will be audio taping you, so the place where we meet should be quiet and somewhat private.

The recording will be made into a transcript that will be analyzed. The recording will only be used for the purpose of the research and will be destroyed as soon as we get all the information we need from it. Again, no names will be used and we will keep everything confidential.

#### **What are the risks and discomforts?**

There are no risks associated with participating in this study.

**What will you need to do?**

The things you will need to do for this study is complete a survey and an interview that will take about an hour and a half. The study does require some time commitment and we will work with your schedule to make the meetings.

**What are the benefits to me?**

You are not expected to get any benefit from being in this research study. However, your participation in the study may help women in the future in attaining contraceptives from their health care providers and get the information they need to make an informed decision about contraceptive methods.

**Do I have to take part in the study?**

Being in this study is your choice; you can change your mind and stop being in the study at any time. All the information you provided to the study will be removed and destroyed.

**Will I be paid to be in the research?**

At the time of the first interview, food and beverages will be provided to you. Fees for parking and transportation will be reimbursed to you at the time of your interview.

**Will my information be kept private?**

All the information you provide for the study will be kept private. You will be assigned a special code so that your name does not appear on any of the surveys, interview transcripts, or in the research. All the information will be kept in a password locked file and will be inaccessible to the public.

During the study we will be collecting health data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the study or published by the researchers.

After the study is done, we will still need to securely store your health data that was collected as part of the study. At the University of Alberta, we keep data stored for 5 years after the end of the study.

If you decide that you do not want to not participate in the study anymore, all of the information provided by you and about you will be destroyed and removed from the study. You can withdrawal from the study up until September 1, 2012.

**What if I have questions?**

If you have any questions about the research now or later, please contact Carolyn Gratton at 780 965 9867 or by email [Gratton@ualberta.ca](mailto:Gratton@ualberta.ca)

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

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## **Appendix F: Feedback Survey Questions**

### **Questions:** **Exploring Contraceptive use in Women who are Wheel Chair Bound**

These questions will be imputed into the online survey creator, Feedback Survey. They will be completed prior to the interview to gain some background information on the participant.

#### General Questions:

1. What is your occupation?
  - a. Options listed
2. What is your current relationship status?
  - a. Single
  - b. In a relationship
  - c. Married
  - d. Divorced
  - e. Other:
3. Do you have any children?
  - a. Yes
  - b. No
4. Are you planning on having children in the future?
  - a. Yes
  - b. No

#### Current health and health history

1. Do you have any health issues? Please list
  - c. Yes
  - d. No
2. Are you taking any medications? Please list
  - a. Yes
  - b. No
3. How long have you been in a wheelchair?
  - a. Drop down menu with time options
4. What led to you being in a wheel chair?
  - a. Options based on demographic survey
5. How much of your body can you mobilize?
  - a. Description
6. How much mobilizing do you do in a day?
  - a. Less than 1 hour
  - b. 1-2 hours
  - c. 2-4 hours

- d. 4-6 hours
  - e. More than 6 hours
7. Which of the following healthcare professional has initiated any discussion around contraceptive care in the past.
    - a. Drop down menu with time options
  8. Do you have a family doctor?
    - a. Yes
    - b. No
  9. Do you have a gynecologist?
    - a. Yes
    - b. No
  10. When was your last pap smear?
    - a. Time frame options listed.
  11. Do you feel like you are getting sufficient sexual health care? This includes pap smears, STI testing, etc.
    - a. Yes
    - b. No

Are you presently using contraception?

- a. Yes
- b. No

If you answered yes, please proceed with the next section

1. What are you currently using for a contraceptive?
  - a. Oral contraceptive/ The Pill
  - b. Progestin only pills
  - c. Depro Provera
  - d. Norplant
  - e. The patch
  - f. Condoms
  - g. Nuva ring
  - h. Intra uterine device- Mirena
  - i. Other:
2. How long have you been using this method?
  - a. Less than 6 months
  - b. 6 months to 1 year
  - c. 1 year to 3 years
  - d. More than 3 years
3. Is this your preferred method of contraception?
  - a. Yes
  - b. No
4. Why are you taking contraceptives?
  - a. Prevent a pregnancy
  - b. Menstrual management
  - c. Other?
5. What is your primary source of information about contraceptives?

- a. Doctor or health care professional
  - b. Internet
  - c. Friends
  - d. Media
  - e. Books
  - f. Other:
6. How much do you know about contraceptive options? This includes how they work, effectiveness, benefits and side effects.
- a. None
  - b. Less than average
  - c. Average
  - d. More than average
  - e. Expert
7. Would more accessible information on contraceptives be helpful?
- a. Yes
  - b. No

**Appendix G: Unstructured Interview**



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**ALBERTA**

**Questions**

**Unstructured Interview Questions:**

**Date:** \_\_\_\_\_

**Interviewer:** \_\_\_\_\_ **Participant Code:** \_\_\_\_\_

**Questions:**

- 1. Can you tell me about your experience with contraceptives?**
  - a. Were your experiences positive? Negative?**
  - b. What would you have done differently? Kept the same?**
  - c. How do you know about contraceptives and where are you getting your information?**
  - d. What contraceptive method would you ideally like to be using and why? Which one would you not like to use and why?**
  - e. What contributed in making the choice for the method you are presently using?**
- 2. Can you tell me about your experience with the HCP and getting gynecological care?**
  - a. Tell me about the doctor's office and the accessibility of the space**
  - b. What kind of support was available to you to help you transfer, position properly, and get the care you needed**
  - c. Tell me about any stigmas or stereotypes you have experienced towards your sexuality because you are a woman in a wheelchair**
- 3. Can you tell me what you would like to see changed that would make attaining contraceptives better?**
  - a. More information?**
  - b. Better facilities?**
  - c. Different contraceptive options?**
  - d. Accessibility?**
  - e. What could make it easier?**
- 4. What are your thoughts regarding use of contraception**
- 5. Do you have any concerns about using contraception**



**6. What myths have you heard?**

**7. How important is it to prevent a pregnancy and why? Please rate on a scale of 0-10**

***Appendix H: 10 Step Analysis Summary Table***

<b>PHASE</b>	<b>STAGE</b>	<b>PROCESS</b>
<b>1</b> Filtering and categorizing	<b>1</b>	<ul style="list-style-type: none"> <li>- Notes are written immediately post interview</li> <li>- Memos are written about ways of categorizing data</li> </ul>
	<b>2</b>	<ul style="list-style-type: none"> <li>- Each transcription is read to gain a better understanding of some of the larger themes</li> <li>- Quick notes are made</li> </ul>
	<b>3</b>	<ul style="list-style-type: none"> <li>- Each transcript is read again and detailed notes on general themes and major categories are recorded</li> </ul>
	<b>4</b>	Open coding <ul style="list-style-type: none"> <li>- Transcriptions are read again and as many headings and themes are recorded</li> <li>- Fillers deleted</li> </ul>
<b>2</b> condensing organizing and integrating (constant comparison method employed)	<b>5</b>	<ul style="list-style-type: none"> <li>- Condensing, organizing and integrating the data</li> <li>- Headings and themes are narrowed down and repetitious ones are removed</li> </ul>
	<b>6</b>	<ul style="list-style-type: none"> <li>- Heading and themes are grouped under higher order headings</li> </ul>
	<b>7</b>	<ul style="list-style-type: none"> <li>- Transcriptions are reviewed again using the categories and higher order headings</li> </ul>
<b>3</b> understanding and meaning	<b>8</b>	<ul style="list-style-type: none"> <li>- Discovery pages developed</li> <li>- Short narrations briefly describing the primary points are written</li> <li>- Comparisons are made between interviews</li> </ul>
	<b>9</b>	<ul style="list-style-type: none"> <li>- Narratives are shared with participants</li> </ul>
	<b>10</b>	<ul style="list-style-type: none"> <li>- Narratives are linked up to what is found in the literature and how it relates to the research questions</li> </ul>

**Appendix I: University of Alberta Ethics Approval**



**Ethics Application has been Approved**

ID: [Pro00028673](#)  
Title: A Focused Ethnographic Study Exploring Contraceptive use in Women who are Wheelchair Bound  
Study Investigator: [Carolyn Gratton](#)  
Description: This is to inform you that the above study has been approved.  
Click on the link(s) above to navigate to the HERO workspace.

Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta  
Edmonton Alberta  
Canada T6G 2E1

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