

**Exploring young women with disabilities' knowledge of and experiences with
contraception: A multi-method qualitative study in Ontario**

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Abstract

In Canada, women with disabilities are an understudied group when it comes to sexual and reproductive health. Specifically, there is no clarity about women living with disabilities' knowledge of and experience with contraception in Canada. Contraception refers to methods used to prevent pregnancy. Research has shown that the rate of adverse sexual and reproductive health outcomes is higher among youth with disabilities, a group comprising approximately 1 in 7 Canadian over 15 years of age. This study aimed to understand better adolescent and young adult women (13-26 years of age) with disabilities' knowledge of and experiences with contraception in Ontario by launching an online survey and conducting semi-structured interviews. The findings show that revisions to service models and healthcare attitudes towards sexually active women with disabilities are necessary. This study recommends that sexual education be revised to include people with disabilities, people of different sexual orientations, and equality between men and women's reproductive responsibility.

Au Canada, les femmes vivant avec un handicap sont un groupe sous-étudié en matière de santé sexuelle et reproductive. Plus précisément, il n'y a pas de clarté sur les connaissances et l'expérience des femmes handicapées en matière de contraception au Canada. La contraception fait référence aux méthodes utilisées pour prévenir la grossesse. La recherche a montré que le taux de problèmes de santé sexuelle et reproductive est probablement plus élevé chez les jeunes avec handicaps, environ 1 Canadien sur 7 de plus de 15 ans. Cette étude visait à mieux comprendre les connaissances et les expériences des adolescentes et des jeunes femmes adultes (de 13 à 26 ans) vivants avec handicaps sur la contraception en Ontario en lançant un sondage en ligne et en menant des entrevues semi-structurées. L'analyse conclut que des révisions des modèles de services et des attitudes en matière de santé à l'égard des femmes handicapées sexuellement actives sont nécessaires. Cette étude recommande que l'éducation sexuelle soit révisée pour inclure les personnes handicapées, les personnes d'orientations sexuelles différentes, et l'égalité entre la responsabilité reproductive des hommes et des femmes.

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Abbreviations and acronyms

Action Canada	Action Canada for Sexual Health & Rights
ADHD	Attention deficit and hyperactivity disorder
CVR	Contraceptive vaginal ring
DMPA	Depot medroxyprogesterone acetate
EAP	Exceptional Access Program
EC	Emergency contraception
ECPs	Emergency contraceptive pills
GAD	Generalized anxiety disorder
IDI	In-depth interview
IUD	Intrauterine device
LGBTQ	Lesbian, gay, bisexual, transsexual and queer
JIA	Juvenile idiopathic arthritis
OCPs	Oral contraceptive pills
ODB	Ontario Drug Benefit
OHIP	Ontario Health Insurance Plan
SOGC	Society of Obstetricians and Gynaecologists of Canada
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
UNFPA	United Nations Population Fund
UPA	Ulipristal acetate
WHO	World Health Organization

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Chapter 1: Introduction

Contextualizing sexual Health for women living with disabilities

The need to provide comprehensive sexual and reproductive health (SRH) education and services to adolescents and young adults (13-26 years of age) is critical. The umbrella term SRH includes “maternal health, contraceptives, family planning, sexually transmitted infections, HIV prevention, safe abortion and post-abortion care, infertility and fertility options, and reproductive cancer” (Action Canada for Sexual Health & Rights, 2017, p. 11). Under the Canadian Charter of Rights and Freedoms, access to this information is a human right. An essential starting point in this education is information surrounding contraception, which the Society of Obstetricians and Gynaecologists of Canada (SOGC) refers to as methods used to prevent pregnancy (Contraception - SOGC, 2018). Unfortunately, little is known about the use of contraception among Canadian women with disabilities.

In Canada, adolescents and young adults with disabilities are an understudied group when it comes to SRH. Consistent with the World Health Organization (WHO), in this study, we define disability as “impairments, activity limitations, and participation restrictions” (WHO Health Topics: Disabilities, 2020, p.1). McCarthy (2009) asserts that “relatively little research” has been done to gain insight into contraception use among women with disabilities and their experiences. Due to this negligence, information on sexual health-related outcomes in this population is mostly undocumented. Therefore, it is unclear precisely the rates of unintended pregnancy and sexually transmitted infection (STI) acquisition are within this group, among other key health indicators. Yet, the little research that does exist produces worrying statistics.

The Canadian Women’s Foundation (2016) published a report showing that women between the ages of 15 - 24 are 18 times more likely to experience sexual assault, with disabled

women who are institutionalized being at exceptionally high risk. Furthermore, another survey showed that women with disabilities were twice as likely to have experienced sexual assault in the past 12 months, regardless of age (DAWN, 2020). When looking to the general population to gain a more global view of SRH outcomes, statistics indicate that unintended pregnancy rates are high, and one in three women will have an abortion throughout their reproductive lives (Norman, 2012). Regarding Canadian adolescents, approximately 40,000 teenage girls become pregnant each year (Al-Sahab et al., 2012). Canadian studies examining contraception use among abortion patients found that 36% were not using any contraception during intercourse that resulted in pregnancy (Wiebe, 2013), and 50% relied on condoms alone (Black et al., 2009). Studies in Ontario suggest that women and girls are at significant risk of unintended pregnancy and STIs acquisition (Sokkary et al., 2013; Black et al., 2009). These broader statistics can help draw inferences on what could be occurring among women with disabilities in Canada.

Multiple studies across the globe assert that the rate of adverse SRH outcomes is likely higher among youth with disabilities. A significant factor lies in the likelihood of this population having more limited knowledge of contraception and STI prevention strategies than their peers, not living with a disability (Williams et al., 2014). Reasons for this may include having fewer opportunities away from caregivers to learn about sexual behaviours, having difficulty accessing information, and experiencing challenges in the domain of communication and literacy (Williams et al., 2014). On top of difficulty independently locating information, research has shown that caregivers can often struggle with supporting people with disabilities in topics such as sexuality and SRH (Williams et al., 2014). Studies suggest that people with disabilities' reproductive rights have been, and continue to be, neglected for reasons reflective of both systems barriers to education and service delivery and social assumptions about the sexual

desires of people with disabilities (Ly et al., 2009; Tiley et al., 2012). The WHO (2005) has recognized that individuals with disabilities, a population of approximately 1 billion people worldwide, have not had their needs met by mainstream SRH services. Unfortunately, this is not a recent phenomenon.

Historical context: Healthcare for women with disabilities in Canada

In Canada, during the beginning of the 20th century, health services for individuals with disabilities were austere and aimed primarily to institutionalize, with strict segregation based on sex (Ledger et al., 2016). Women with disabilities during most of the 20th-century context did not benefit from human rights; they were viewed as “incapable and dependent on others,” which encouraged the institutionalization of women with mental health issues and intellectual and physical disabilities (Galer, 2015).

In keeping with the socio-political perspective at the time, Alberta and British Columbia passed legislation in 1926 and 1933, respectively, that legally permitted non-consensual sterilization of persons with disabilities under the pretense of therapy (Ledger et al., 2016; Tiley et al., 2012). Women with disabilities were targeted because of societal beliefs that “deficiencies” would inevitably be passed down (Tiley et al., 2012). This policy was also supported by deeply held views that women with disabilities would not be adequate caregivers and assumptions that sterilization would provide them with the possibility to live outside of institutions without the fear of becoming pregnant (Tiley et al., 2012). Involuntary sterilization existed in Canada until 1972; between 1926 and 1972, approximately 2,832 individuals with disabilities survived coercive sterilization in Alberta alone, including children (Tiley et al., 2012). Survivors have described experiencing a “deep sadness” at the inability to have children

and felt that it made it impossible for them to have normal relationships. They were also forced to reveal their disability (Tiley et al., 2012). The effect of this history must be taken into consideration today, as it has negatively impacted women with disabilities throughout contemporary history. Fortunately, social and health services began to explore alternative perspectives following the First World War.

As Canadian veterans returned from war with inconceivable injuries and amputations, demands for appropriate services for people living with disabilities were publicly voiced (Galer, 2015). The movement continued into the 1950s and 1960s; organizations petitioned against institutionalization and demanded the expansion of community services (The Canadian Encyclopedia, 2020). As advocacy grew, Canada became the first country to grant constitutional protections to people with physical or mental disabilities (Pooran & Wilkie, 2005). The Canadian Charter of Human Rights passed in 1982, with section 15 declaring that “every individual in Canada – regardless of race, religion, national or ethnic origin, colour, sex, age or physical or mental disability – is to be considered equal” (Heritage Canada, 2017). This permitted women living with disabilities access to legal and social protection. However, this population remains marginalized.

Current relevance and significance

People with disabilities in Canada continue to experience adverse outcomes in many sectors, as is made clear because they account for 50% of discrimination lawsuits in Canada (Spagnuolo & Trew, 2017). Some organizations posit that this is likely a result of underrepresentation in legislative and political spaces (DAWN, 2020). The DisAbled Women’s Network of Canada (2020) has recently published an example of this underrepresentation, stating

that “upwards of 450,000 Indigenous people identify as having a disability... but it is unknown how many of those people are women, girls, or gender diverse because of inaccurate and insufficient data” (p. 52). Data that does exist from across Canada demonstrate that 24% of women between 15 and 24 years old identify as living with a disability (Government of Canada, 2018). That statistic emerged from the 2017 Canadian Survey on Disability, which included male and female Canadians 15 years of age and older who qualified under the criteria of having everyday activities limited due to a long-term condition or health-related issue (Government of Canada, 2018). The top categories of disability, according to the survey, included pain-related disabilities (15%), flexibility-related disabilities (10%), and mental health-associated disabilities (7%) (Government of Canada, 2018). Overall, it appears that a quarter of Canadian girls and women identify as living with a disability and require healthcare that reflects this, but injustices continue to prevail. In fact, girls with disabilities are the least likely group in Canada to access SRH rights (DAWN, 2018).

In February 2017, Action Canada for Sexual Health & Rights (Action Canada) submitted a review to the United Nations Committee on the Rights of Persons with Disabilities, which discussed at length how current SRH barriers infringe on this population’s rights. The concise document describes present violations of the Convention on the Rights of Persons with Disabilities (Action Canada, 2017). Article 17 of the Convention asserts that “every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (United Nations Enable, 2017, p.1). However, in violation of this article, the review claims that “women with disabilities are often treated as if they have no control, or should have no control, over their sexual and reproductive choices; they may be forcibly sterilized or forced to terminate wanted pregnancies, based on the paternalistic justification that it is “for their own

good” [or] without their informed consent” (Action Canada, 2017, p.9). The organization recognized that women with disabilities could be “denied access to information and communication, including comprehensive sexuality education,” (Action Canada, 2017, p.11). This could be based on harmful stereotypes that assume that they are asexual and do not require such information on an equal basis with others, as well as the fact that information is not available in accessible formats (Action Canada, 2017, p.11).

Furthermore, Article 24 of the Convention demands that establishments “recognize the right of persons with disabilities to education with a view to realizing this right without discrimination and on the basis of equal opportunity” (United Nations Enable, 2017, p.1). Addressing the lack of inclusion that youth with disabilities face regarding information is critical. As the data demonstrate, health services for women with disabilities are in demand from nearly a quarter of Canadian women, including education on contraceptive methods that offer more choice than sterilization (Government of Canada, 2018).

Contraceptive methods currently available in Canada

A variety of contraceptive methods exist, although efficacy depends on several factors such as having knowledge of the range of methods, understanding how to use contraception, possessing skills to use the method correctly, and having motivation (Greydanus et al., 2012). Although adolescents and young women with disabilities can use the same contraceptive methods as the general population, some additional concerns might influence choice. Examples include considerations around interactions with underlying health conditions, medication regimens, and capacity to use the method (Greydanus et al., 2012). Above all, the most relevant factor that women consider, according to the literature, is the efficacy of preventing pregnancy

(Stanback et al., 2015). While appearing simple, this choice can become complicated because women are not always well informed when choosing contraception methods (Stanback et al., 2015). When attempting to establish a “user-method fit,” efficacy, as well as medical suitability, are part of the decision-making (“Canadian Contraception Consensus Chapter 1, Contraception in Canada,” 2015). These, on top of the most apparent factors: accessibility, affordability, and safety. To understand better the options, contraceptive methods are often categorized in a three-tiered effectiveness model.

There are three options in the first tier of the most effective contraceptive methods available in Canada: sterilization, implants and intrauterine devices (IUDs). Permanent surgical contraception is known as female sterilization or tubal ligation. Tubal ligation is surgical contraception for women who do not wish to have children in the future and is the most effective form of contraception. This method works by preventing the eggs released from the ovaries from reaching sperm (WHO, Reproductive Health and Research, & K4Health, 2018). Tubal ligation is a possible option for women with disabilities because it presents no side effects and requires no continued action. However, this method is also related to the history of coercion and abuse experienced by women with disabilities in Canada and now requires extensive consideration and informed consent. Men can also use sterilization; the surgical procedure is referred to as a vasectomy. This process involves surgically cutting and sealing the tubes that carry sperm so that none is present during ejaculation (Mayo Clinic, 2020).

The second top-tier contraceptive option is the IUD, a long-acting reversible contraceptive method (Hatcher et al., 2018). IUDs are T-shaped devices; one model releases a low dose of levonorgestrel and the other is copper-bearing. The copper-bearing IUD contains no hormones since and relies on the copper to cause a chemical change damaging sperm and eggs

before their union (WHO, Reproductive Health and Research, & K4Health, 2018). The IUD is also a good option for women living with disabilities, although pelvic sensitivity concerns exist as complications (perforations, displacement) may not be detected (Kaplan, 2006). Overall, the IUD is a practical option because it is not user-dependent and is low maintenance. The final option in this tier, according to the effectiveness model, is the implant. Previously, the implant has been unavailable as contraception in Canada, until recently. In May 2020, Health Canada announced it had approved the contraceptive implant, which is now on the health agency's drug product database (Global News, 2020). The implant, which is surgically inserted under the skin of the upper arm, acts by releasing progestin, which can thicken cervical mucus as well as prevent ovulation (Planned Parenthood, 2020). As its function is very similar to the IUD, it presents the same advantages: it is not user-dependent and is easy to maintain. Implants are also long-acting, up to five years and can be removed at any time, which also offers advantages to women with disabilities who need reversible contraception (Planned Parenthood, 2020).

In the second tier of contraceptive methods, four more options exist. The first is oral contraceptive pills (OCPs), which inhibit ovulation by preventing the release of an egg, making the uterus inhospitable for implantation, and thickening cervical mucus to prevent sperm from travelling well (Hatcher et al., 2018). Combined OCPs consist of estrogen and progestin and are highly effective at preventing pregnancy (Hatcher et al., 2018). OCPs can regulate menstrual periods and manage blood flow but may challenge some young women with disabilities as they require daily use (Hatcher et al., 2018). They are also not a useful option for patients who have difficulty swallowing (Kaplan, 2006). Another consideration for prescribing OCPs is mobility. As is the case with all estrogen-based methods, limited movement and restricted circulation can increase the risk of blood clots (Kaplan, 2006). In this case, progestin-only OCPs might be

preferable, but the daily timing of administration is more exact, which may present a challenge (Greydanus et al., 2012).

The hormonal patch is another combined hormonal contraceptive option and prevents pregnancy through the same mechanism of action of OCPs (Hatcher et al., 2018). Again, the consistency needed to change the patch after seven days can be challenging for some women with disabilities (Greydanus et al., 2012). However, the literature supports that compliance might be better than with OCPs because weekly and not daily action is needed (Greydanus et al., 2012). The contraceptive vaginal ring (CVR) is another hormonal contraceptive method in tier two available in Canada. The ring uses flexible plastic inserted into the vagina, slowly releasing estrogen and progestin for three weeks (Hatcher et al., 2018). The CVR has the same action mechanism, perfect use failure rate, and lack of STI-prevention benefit as OCPs and the patch. Manual dexterity is a factor with the CVR as the capacity to use it may be limited with some women with disabilities, as it must be removed after three weeks to allow menstruation and replaced after the fourth week (Kaplan, 2006).

Injectable contraception methods, such as depot medroxyprogesterone acetate (DMPA), are also highly effective, working similarly to other methods by preventing ovulation and thickening cervical mucus since it contains progestin (Hatcher et al., 2018). The injections are administered by a healthcare practitioner every three months and are as effective as the hormonal IUD (Hatcher et al., 2018). While injections can be a good alternative for individuals who have contraindications to exogenous estrogen, they present many challenges of their own. These include many adverse side effects such as headaches, dizziness, bloating and discomfort, mood changes, loss of bone density, and weight gain (WHO, Reproductive Health and Research, & K4Health, 2018).

Finally, in the third tier are all forms of barrier methods. The use of barrier methods amongst this group of women is very uncommon, with some sources citing them as ‘never advocated’ (McCarthy, 2009, p. 47). The main appeal of barrier methods is that they offer protection against sexually transmitted infections (Hatcher et al., 2018). STI risk should be discussed and considered in the method selection process for women with disabilities. Still, manual dexterity is a factor as the capacity to use them may be restricted (Kaplan, 2006). Regarding emergency contraception (EC), it should be described and made available to all women. EC is used to reduce pregnancy risk after a sexual encounter and is useful for up to 5 days after unprotected sex (WHO, Reproductive Health and Research, & K4Health, 2018). In Canada, progestin-only emergency contraceptive pills (ECPs) are the most widely used post-coital method. Progestin-only ECPs do not pose a risk to pregnancy already underway and help prevent pregnancy by stopping or delaying ovulation (WHO, Reproductive Health and Research, & K4Health, 2018). Ulipristal acetate (UPA) is also available for use as emergency contraception in Canada. It uses a selective progesterone receptor modulator and is useful up to 5 days following unprotected sex to prevent pregnancy (Fine, 2011). Finally, there is also the copper-bearing IUD that can be a form of emergency contraception when inserted within five days of unprotected sex (Hatcher et al., 2018). However, all EC modalities are underutilized in Canada, especially among vulnerable populations (Canadian Contraception Consensus, 2015). All of these “user-method fit” considerations are to be made in specific relation to each women’s health, although access barriers for women with disabilities can impede these discussions.

Barriers to care for women living with disabilities

Naturally, barriers that impact young people's access to contraception, in general, also impact adolescents and young women with disabilities. However, those with disabilities may face some additional barriers. Publications support that youth with disabilities are often not counselled on SRH issues, including contraceptive methods and the potential adverse side effects of available contraceptives (Greydanus, 2012). This lack of counselling may be due to attitudinal beliefs/informational deficits of healthcare practitioners who do not understand disability and presume their patients are asexual, do not require STI screening, and/or do not desire pregnancy (Kaplan, 2006). Participants in research on maternal health outcomes for women with disabilities in Ontario reported that they lacked access to information or services from healthcare providers and community resources (Tarasoff, 2017). According to a 2018 United Nations Population Fund (UNFPA) international report called *Young Persons with Disabilities: Global Study on Ending Gender-based Violence and Realizing Sexual and Reproductive Health and Rights*, "it's considered unnecessary to inform and educate these girls on the topic; and worse, their decisions are considered not credible and are not respected" (DAWN, 2020, p. 55) Despite this, the report also confirms that women with disabilities are as concerned with sexuality and romantic relationships as their non-disabled peers, making this barrier to information and treatment troublesome (UNFPA, 2018). These preconceived notions contribute to the fact that women with disabilities know the least about reproductive rights and sexuality and have the lowest level of sexual education about HIV transmission and contraception (DAWN, 2020). Research shows that this educational shortfall is most likely related to how sexual education messages are delivered rather than the disability a woman is living with (Braathen et al., 2017). This barrier to education is not, however, unique to healthcare practitioners.

Many parents often struggle to support their children with disabilities in terms of sexual autonomy and identity (Kaplan et al., 2006). Not unlike healthcare workers, parents often “prefer their disabled child to have platonic relationships with low levels of intimacy” and feel uncomfortable about promoting sexual health to their children for uncertainty around appropriateness and necessity (Braathen et al., 2017, p. 12). On top of educational deficits and stigma perpetrated by caregivers and healthcare professionals, women with disabilities also live with accessibility barriers.

Additional hurdles exist around the physical inaccessibility to health services for youth with disabilities. Patients with disabilities frustrated with inaccessible healthcare services talk about “landscapes of exclusion” that communicate that their unique health care needs are “bothersome, unwelcome burden(s) on health facilities” (Kaplan, 2006, p. 451). The exclusion women experience does not omit people living with invisible disabilities, who are often more likely to experience ableism and questions on their right to access certain services (Kattari et al., 2018). Despite all of these challenges, the Canadian government attempts to reconcile accessibility issues, at least when it comes to affording contraception and services.

Recent policy changes in the province of Ontario have made access to contraception more accessible and affordable. The provincial government provides the Ontario Health Insurance Plan (OHIP) to its residents to assist in paying for healthcare services that are medically necessary, such as family doctor visits and most emergency health care services (OHIP, 2018). OHIP includes the Ontario Drug Benefit (ODB) program for those who are eligible: citizens over 65 years of old, individuals using Home Care and Ontario Works programs, people who are part of the Trillium Drug Program, and those enrolled in OHIP+

(Government of Ontario, 2018). The ODB program offers payment assistance for coverage of 4,400 approved prescriptions (Government of Ontario, 2018).

In January 2018, the Ontario provincial government introduced OHIP+, which began providing ODB-approved prescriptions free of cost to children and youth under 25 years of age who were not previously eligible (Government of Ontario, 2018). Previously, young residents of Ontario did not receive a contraceptive benefit for OCPs, CVRs, the hormonal IUD, or UPA which as of 2018, they are eligible for through OHIP+. However, girls and young women wishing to acquire other contraceptive methods have to cover the cost out of pocket or through private insurance (Government of Ontario, 2018). For individuals living with a disability, the price of their chosen method may play a significant role in the decision-making process, considering the “median total income of persons with disabilities [is] \$10,000 less than the median for those without disabilities” (Government of Canada, 2015, p. 21). Conversely, women may request that prescriptions outside of the ODB program be covered through the Ministry’s Exceptional Access Program (EAP). The EAP facilitates patient access to medications outside of the 4,400 approved drugs by the ODB on a case-by-case basis (Government of Ontario, 2018). Likewise, women eligible for the Ontario Disability Support Program can get assistance with prescription drugs, including contraception.

Study rationale

Although research is limited on the topic, recent investigations in the Canadian context reveal the dire need to provide sexual health education and services for women and girls with disabilities. In the previously discussed reviews and reports, it is well established that young people with disabilities experience more exclusion and have far less access to information and

services for various reasons. While these experiences are lightly captured in Ontario, much less is known about improving education and service delivery for this population, including investigating spaces, tools, or interventions to foster more inclusion and better educational outcomes.

My project addresses the current lack of research around women living with disabilities in Ontario and their access to and experiences with contraception, with a specific interest in improving services and information. Through the use of a multi-method qualitative study, the project examines the current context in Ontario for this population in accessing SRH services and explores possible enhancements.

Study objectives and research questions

My thesis's objective is to understand better adolescent and young adult women (13-26 years of age) with disabilities' knowledge of and experiences with contraception in Ontario. These findings can inform efforts to improve SRH education and services. I addressed the following research questions:

- What do adolescents and young adult women with disabilities know about contraception, and where do they obtain information?
- What are adolescent and young adult women with disabilities' experiences with contraception in Ontario?
- What efforts could improve contraceptive information and services in Ontario?

Positionality

As an early childhood educator with a specialization in disabilities, I have experience with this population and organizing, planning, and carefully managing developmentally appropriate curricula. I also have work experience as a bilingual mental health counsellor for children. However, my position as a Caucasian woman living with no disabilities may have influenced the dynamic of conversations and interviews held with participants. Although I am aware of the potentially sensitive issue of living with a disability, I believe that my sincere interest in youth well-being and development allowed me to collect data in a respectful, collaborative way and share it in a meaningful capacity.

Outline of the thesis

The first chapter introduces the landscape of women with disabilities' healthcare in Canada, currently and historically. This concentrates on the experiences pertaining to contraception across the country and reveals barriers that exist. Chapter one also describes the study's rationale, objectives, positionality, and thesis outline. Chapter two presents the study's methodology, ethics and analytic approach followed by chapters 3 and 4 which include results from the online survey responses and in-depth interviews with women living with disabilities who have used contraception in Ontario. Finally, chapter five discusses the results' implications, involves future recommendations, determines limitations and offers a conclusion.

Chapter 2: Methods

After a broad review of the existing global literature, it was clear that a qualitative approach is the most appropriate to address the aforementioned research objectives. To explore the experiences of young women with disabilities' knowledge of and experiences with contraception in Ontario, we utilized a multi-method qualitative approach that included an online survey component and semi-structured interviews with individual members of this demographic.

Component 1: Online survey of youth with disabilities

This project's first component was an online survey of adolescent and young adult women with disabilities in Ontario. Other online surveys from within Dr. Angel M. Foster's research group have informed the survey design (LaRoche et al., 2018). I have adapted the instrument to focus on people with disabilities and based those specifications on surveys from other researchers working in the disability field. This included modification of the instrument and recruitment materials' visual layout to accommodate those with visual impairment.

All adolescent and young adult (13-26 years of age) self-identified women with disabilities living in Ontario were eligible to participate in the survey. There were no other inclusion/exclusion criteria related to the disability, gender identification, sexual orientation, or participants' contraceptive history. The survey was available in French and English only. Although the study was far-reaching in terms of participant eligibility, this approach allowed us to collect a more comprehensive range of information from a potentially heterogeneous group of respondents.

The instrument included five inquiry domains beginning with demographic questions followed by general sexual and reproductive health history. The instrument then focused on contraceptive knowledge assessment questions and questions about where participants obtain information about contraception and contraceptive services. The final domain concentrated on how to improve services for adolescents and young women with disabilities in Ontario. The last page of the survey provided an opportunity for participants to register for a draw (CAD50 gift card, 1 per 50 participants), indicate their interest in receiving a report of the findings, and demonstrate a willingness to participate in an in-depth interview.

Piloting the survey

To ensure that the survey would be understandable for respondents, I undertook a multi-stage piloting process. First, I launched two pilots (in English and French) with Dr. Foster's research group members. The purpose was to verify the integrity of the survey instrument, translation, and internal language consistency. The second stage of the pilot involved community partners who work with the target demographic; I contacted five disability specialists working within Ottawa, Ontario and requested their assistance in preparing the survey. Partners included Planned Parenthood, Spark Lifecare, Citizen Advocacy, CAMH, and Ottawa-Carleton Life Skills. Participants were briefed on the project's purpose and consented to take the survey to provide their expertise and feedback. Community consultants completed the survey autonomously and made notes of areas to improve. We met to review the responses, identify unclear or confusing questions, and clarify the instrument's design and content. In addition, we discussed avenues for recruitment, and I updated and finalized the instrument based on their feedback. All pilot participants received a \$50 gift card for their time and consultation.

Component 2: Conducting in-depth interviews

The second component of the project involved in-depth interviews (IDIs) with adolescents and young adult women with disabilities living in Ontario who have ever used any method of contraception. Interviews allowed me to learn more about women's experiences with contraception education and service delivery. I conducted four in-depth, semi-structured interviews by phone with survey respondents who expressed interest, which lasted about 30 minutes. I completed the semi-structured interviews using a guide I prepared and adapted from previous research from Dr. Foster's group; it expanded on the survey questions. The interview began with demographic questions and questions about general health and SRH history. We then explored the participant's experiences with contraceptive education, service delivery, and use before concluding with questions about improving Ontario's services. Interviewees received a \$25 gift certificate for their time.

Throughout the interviews, I took notes on the participant's contraceptive experiences, opinions, and suggestions on improving the province's services. After the interviews, I engaged in memoing to reflect on the interview processes, examine how my positionalities influenced my interpretation, and identify early themes.

Analytic approach

We used the online website Survey Monkey for fielding the survey; we then exported the results to Microsoft Excel ®. I then analyzed these data using descriptive statistics, including frequencies and cross-tabulations. For the survey's open-ended questions where users wrote in free-form, I analyzed responses for content and themes. For the interviews, I compiled the data,

comprising field notes, memos, and transcripts. I examined the interviews for content and themes using both deductive and inductive techniques. I processed each component of the project separately; in the final analytic phase, I have combined the results paying specific attention to concordant and discordant findings, to be shared through a monograph style thesis.

In preparation for the analytic process, I attended regular group meetings with Dr. Foster and the research group, as well as scheduled individual meetings. Throughout the process, I incorporated feedback received on reports, updates, and poster presentations within the group and thesis advisory committee into the analysis.

Ethics

This study received ethics approval in March 2019 from the Social Sciences and Humanities Research Ethics Board (REB) at the University of Ottawa (File #: S-04-19-3908). The submission included the recruitment materials, study instruments, and consent forms for each project component. The letter of approval from the University of Ottawa REB appears in Appendix A.

Working with a combination of vulnerable sectors (adolescents and individuals with disabilities), I had requested that potential respondents have the option to participate without guardian consent. However, participants could elect to have a guardian present or to participate autonomously, depending on their personal situation and preference.

For the narrative vignettes displayed throughout this monograph, I have anonymized participants' information by masking or redacting any identifying content and using pseudonyms for all participants.

Chapter 3: Survey Results

This portion of the study invited eligible participants to take part in the 34 question online survey. Respondents were eligible if they were between the ages of 13-26, lived in Ontario, identified as women, identified as living with a disability, and were sufficiently fluent in English or French to answer the questions online.

Participant characteristics

Twenty-six women living with disabilities in Ontario responded to the English survey. Participants averaged 22 years in age and ranged between 13 and 26 years old. Regarding ethnicity, interviewees identified as Caucasian (n=18), South Indian (n=1), Black or African-Canadian (n=2), Indigenous (n=6), and Asian (n=3). The women interviewed lived across Ontario, including Eastern Ontario (n=15), Central Ontario (n=7), and Northwest (n=2) and Southwest (n=2) Ontario. Concerning sexuality, most participants identified as heterosexual (n=13), many as bisexual (n=7), and some as queer (n=1) or lesbian (n=2). More specific details can be found in Figure 1. below.

The nature of the disability for these participants included physical disorders such as cerebral palsy (n=1), juvenile idiopathic arthritis (n=1), mobility impairments (n=2), hypermobile spectrum disorder (n=1) and spinal osteoarthritis (n=1). Among mental health disabilities, participants reported living with generalized anxiety disorder (n=5), major depressive disorder (n=10), multiple personality disorder (n=1), bipolar disorder (n=1), post-traumatic stress disorder (n=1) and borderline personality disorder (n=3). Neurological disorders among participants included: autism spectrum disorders (n=3), attention deficit and hyperactivity

disorder (n=1), epilepsy (n=1), fetal alcohol syndrome disorder (n=2), deafness (n=1) and cognitive disorders (n=1).

Participant demographics (N= 26)		
Age	13-15 years old	2 (8%)
	18-20 years old	5 (19%)
	21-23 years old	10 (38%)
	24-26 years old	9 (35%)
Racial/ethnic identification	Black/African-Canadian	2 (8%)
	East Asian/Asian	3 (12%)
	Indigenous	6 (23%)
	South Asian/Indian	1 (4%)
	White/Caucasian	18 (69%)
Gender	Cis-woman	24 (92%)
	Other	2 (8%)
Sexual orientation	Heterosexual	14 (54%)
	Queer	2 (8%)
	Gay/Lesbian	1 (4%)
	Bisexual	7 (27%)
	Unsure	2 (8%)
Region of Ontario	Northeast Ontario	2 (8%)
	East Ontario	15 (58%)
	Central Ontario	7 (27%)
	Southwest Ontario	2 (8%)

Figure 1. Representation of demographic descriptors among survey participants (N=26).

Sexual health education

After collecting demographic information in the first section of the survey, the questioning line aimed to assess what participants know about sexual education and contraception and how they came to this knowledge. While only 54% of participants had ever been to visit a sexual health service for help and advice about relationships, contraception, STIs, or sex, it seemed that there were many possible avenues for obtaining information independently. As shown in Fig. 2, participants reported many sources of information, including the internet (68%), high-school health classes (32%), family doctors (32%), friends (16%), and family (20%).

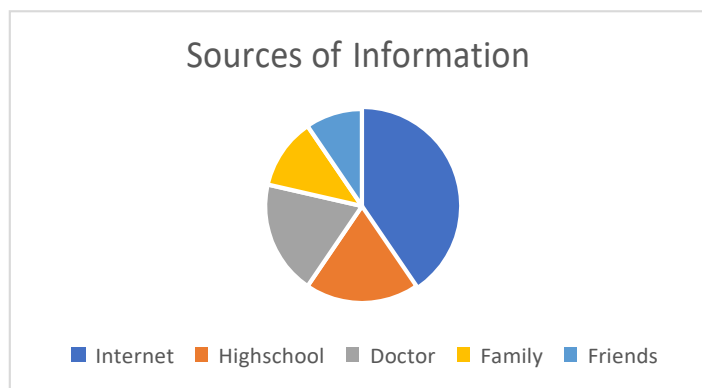


Figure 2. Representation of informational sources for sexual health education among survey participants (n=26).

The survey revealed that the internet came out as a significant factor in participants' knowledge of relationships, sex, and contraception, with 38% feeling that it was very important to their understanding and 46% saying it was somewhat important. When respondents reacted to how essential their parents, other family members, and community members were as sources of information, the results were far less impressive. Only 27% of respondents felt they were very important and 31% reported those were not important sources. It became clear that friends also played a significant role, with 39% of women from the survey feeling friends were very important sources of information surrounding sexual health and contraception and only 13% disagreeing.

The survey also demonstrated that all but 4 participants had had some type of sexual health education in high school. Still, only 12% of participants felt that the information they had received had been totally adequate while 23% of participants stated it had been not really or not at all adequate. Others were unsure whether the high-school education they received had been sufficient or not.

In terms of what respondents would have liked to see added to their sexual education experience, it seems as though other themes of exclusion emerged. The lack of inclusivity in

sexual health education applies to persons living with disabilities but is also present among the Lesbian, Gay, Bisexual, Trans and Queer (LGBTQ) community. Among survey respondents, 46% identified their sexual orientation as something other than heterosexual and many reported feeling extremely stigmatized and underrepresented in sexual health spaces. In fact, 27% of the survey respondents mentioned it in the free-form section, asking what they wish they could have learned.

There was no LGBT sex ed at my school at all. The teacher asked anyone who wanted the class to learn same-sex ed to raise their hand, and for obvious reasons, none of the 14-year-olds in the class did. – Respondent from Ottawa

This sentiment was echoed by a participant who had felt similarly in their experience but included that the disability component was lacking as well as the sexual orientation representation.

We were only taught about hetero able-bodied relationships; some acknowledgement of other sexual experiences would have been beneficial. – Respondent from Ottawa

In addition to sexual orientation exclusion, an additional theme was present when participants responded to what they wish they would have learned. Specifically, many participants felt that the options discussed in their sexual education were limited and unhelpful when it came to contraception.

I would have liked to know more about birth control methods other than just abstinence or condoms. – Respondent from Orleans

I wish that we learned more about non-heterogeneous relationships. Also, I wish that we learned more about plan B. – Respondent from Ottawa

In addition to those desiring less information on condoms, other women living with disabilities felt that resources and information supporting contraception use and how to go about it would have been more beneficial than the conversations they had with educators.

Less info about abstinence and more info on actual contraception and what to do if you actually get pregnant from an unbiased teacher. – Respondent from Ottawa

Alternatives to condoms (or different types - latex is painful for me and I thought it was my fault at first) and resources to reach out to if we need support in case of pregnancy or STI or anything personal in that sense. – Respondent Toronto

Finally, a third theme emerged in the sexual education domain of inquiry. Many participants mentioned feeling as though their education mainly represented female reproductive health but ignored the many purposes of sex in their classes. As a result, many participants thought that the way the knowledge is structured causes imbalances between sexually active men and women.

[I would have liked] more information about sexual health relating to the positive aspects of sex and destigmatizing common perceptions that sex is only for reproduction. Also, destigmatizing elements relating to gender and common stereotypes in society ... and the double standard (i.e. boys are celebrated for being sexually active while girls are often shamed). – Respondent from Ottawa

[The sexual education was] not very comprehensive, designed by adults/parents who have a certain perspective... possibly leaning towards an education that emphasizes sex as something taboo ... rather than something natural and enjoyable and explorable with the right education and preparation. – Respondent from Ottawa

Some participants feel that female sexual health was incomprehensive and limited to the reproductive aspect. They reported that men's sexual health is more positively portrayed, and many women's issues are ignored or stigmatized. Further, they mentioned a disequilibrium between the health topics covered for males versus themselves, leaving women solely responsible for contraception and at risk of violence or vulnerable to abuse.

It would have been more informative if more than just period blood was addressed. Our vaginas do a whole lot more than bleed once a month. – Respondent from Ottawa

If I have to learn about wet dreams as much as I did in junior high, we should spend more time learning about the clitoris. – Respondent from Toronto

I feel like there just needs to be a more comprehensive support and educational system regarding intimate partner violence, especially as it relates to young, mentally ill women and girls who are the most vulnerable. – Respondent from Toronto

Overall, it appears that many of the survey participants felt that their sexual health education in high school and now has been less than complete. They reported feeling excluded in terms of disability representation, sexual orientation representation, and female sexual functions aside from reproduction. As a result, many have found themselves needing to supplement their knowledge through the internet, doctors, and social circles.

Experiences with sexual health services

To understand respondents' general impressions of sexual and reproductive health services in their cities, we questioned them on their experiences with contacting or visiting sexual health spaces. In keeping with the findings above around inclusion in sexual health spaces, one woman felt hesitant to use SRH services based on previous experiences or anecdotes from peers.

I avoid these services because I know other LGBT women who have been mistreated by health services for being gay. – Respondent from Ottawa

As well as issues around inclusivity and acceptance of different sexual orientations, women with disabilities felt unseen when it came to their unique health needs. They reported doctors

who catastrophized their conditions or were unaware of specific interactions between disability treatments and sexual health consequences.

[Sexual health services] were ok, but they didn't always [consider] other medications that a disabled person might be on... I have difficulty getting [lubricated] for sex due to medications. It would have been nice to know [about this side effect] and ways to help, so I didn't feel like there was something wrong with me for so long. – Respondent from Toronto

[Sexual health services are] hit and miss. When a doctor at my first gyno appointment found I had vaginismus, she told me I would never be able to have sex instead of telling me it was normal or about pelvic floor therapy. – Respondent from Brampton

Other participants did feel as though the services were adequate in terms of medical care but did still experience feelings of inaccessibility and judgemental attitudes. In addition to the adequacy, some participants shared they felt that the attitudes in sexual health spaces were not sufficient for “our changing and developing society.”

They are improving and becoming more accessible, but still stigmatized by many.
– Respondent from Waterloo

To understand women with disabilities' sexual health needs further in-depth, we asked them which contraceptives they had ever interacted with; most survey respondents had experience with at least one method. The results demonstrated that 96% of participants did not wish to be pregnant at the time, but 23% had never used contraception, and 8% hadn't in the last month.

As far as contraceptive methods used by the women, there was a wide range chosen. The most popular option among contraception users was the oral contraceptive pill, with 50% of respondents having some experience taking it. The second most popular choice was male condoms, with 31% usage among this group. Figure 3. offers a further look into contraceptive use reported by participants.

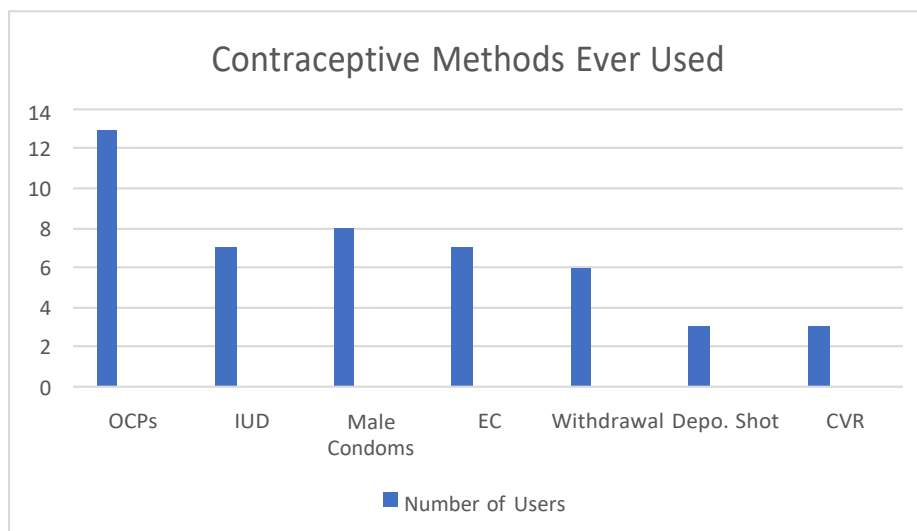


Figure 3. A charted representation of all contraceptives women in the study reported using and the number of users for each method (n= 26).

With 77% of women with disabilities who have taken this survey ever having used one type of contraception or more, it is clear that they are accessing SRH through one channel or another. The need for contraception is relevant, as most women have sought it through their family doctors or other sexual health services. Although the participants could obtain contraception, they still reported feeling stigmatized by sexual orientation or their specific disability-related needs and cross-interactions. They also described feeling excluded by service providers' judgmental attitudes while accessing these services, even when the medical care was satisfactory. Aiming to learn more about how to improve experiences, participants shared their perceived needs and offered suggestions.

Potential areas of improvement

As revealed through participants' sexual education experiences and lived experiences with contraception itself, some issues have arisen that cause sexual and reproductive healthcare

barriers for women with disabilities. When questioning women living with disabilities on what they need to see from their local SRH services, similar subjects arose compared to their educational concerns. These included barriers to accessing SRH services such as stigma and attitudes, the safety and responsibility taught in SRH services aimed towards women but not men, and the specific needs of women with disabilities being widely unachievable.

The majority of survey respondents reported that changes are necessary to remove stigma and promote the normalization of receiving support. They shared that they would feel more welcome in spaces that encouraged all community members and hosted an open dialogue and attitude around seeking health support.

I think [SRH services] could be improved upon if ... healthcare providers first broached the subject of sexual health and asked about contraceptives instead of the patients asking. I think that as a female with a disability, that all specialists and doctors should be more educated on female health and not have any doctors shy away from it.
– Respondent from Ottawa

[We need] less stigma around having mental health issues and more access to counselling and services to help cope with mental health... – Respondent from Orleans

Furthermore, as mentioned when participants voiced how they felt about their experiences with sexual education, many women with disabilities felt that men appear neglected in contraceptive responsibilities or discussions about healthy relationships. This exclusion unfairly places the burden on women living with disabilities to negotiate, which can place them at risk for violence or abuse.

[Women with disabilities need] more open discussions with women AND men about the positive aspects of safe sex, specifically with high-school-aged/young adults. Topics like consent, communication, respect for others' bodies and minds, objectification, among others. I think it's important to have these kinds of discussions with everybody, not just

women, as we all are responsible for ensuring safety and respect in our relationships/partners, not just women. – Respondent from Ottawa

Young women and girls with personality disorders, especially cluster B, need to be taught about what is appropriate in relationships (especially heterosexual relationships) ... Young women need to be educated about what signs of intimate partner violence as well as about what behaviour is appropriate coming from men. – Respondent from Toronto

Finally, the most common barrier to care involves SRH services unadapted to the specific needs of women living with disabilities. Many participants felt that their needs were regularly misunderstood, challenging to request or neglected altogether.

[Women with disabilities need] services that are specific to those with disabilities and are able to address and help with issues that may not come up for those without a disability.– Respondent from Waterloo

[Women with disabilities need access to trustworthy sex ed that doesn't involve face-to-face meetings. Sitting down with a doctor to ask questions is difficult enough with autism, without the added stress of having to navigate socializing and making eye contact. – Respondent from Ottawa

[SRH services] should be more accessible in terms of proximity, availability and relevance to disability. There is not enough sex education in connection to disabilities.

– Respondent from Ottawa

Chapter 4: Interview results

This portion of the study invited eligible participants to take part in the 30 min semi-structured interview following the completion of the survey. Respondents were eligible if they completed the survey and had ever used contraception while residing in Ontario.

Participants characteristics

I conducted four interviews with women living with disabilities in Ontario. Participants averaged 22 years in age and ranged between 21 and 24 years old. In terms of ethnicity, interviewees identified as Caucasian (n=1), South Indian (n=1), and Asian (n=2). The women interviewed lived across Ontario, including Ottawa (n=2), Waterloo (n=1), and Toronto (n=1). The nature of the disability for these participants included: juvenile idiopathic arthritis (JIA), Asperger's syndrome, generalized anxiety disorder (GAD) (n=2), and attention deficit and hyperactivity disorder (ADHD). At the time of the interview, three participants were post-secondary students and all participants worked at least part-time (full-time n=2). Every woman stated that friends and family were primary sources of support, with some mentioning romantic partners (n=2) and others citing therapists/doctors (n=2) or religious groups (n=1).

Experiences with contraception in Ontario

Natalie's story

Natalie is a 24-year-old Asian woman living in Waterloo. She is a college graduate, who lives with generalized anxiety disorder, attention deficit and hyperactivity disorder, and depression. Natalie describes deciding to use contraception with her partner since her anxiety is causing her to panic on a very regular basis that she may be pregnant. So far, this has not been the case.

Since the anxiety caused her so much distress, she spoke to her family doctor about choosing a contraceptive. However, this did not come without challenges as Natalie's anxiety also caused her to worry excessively about potential side effects of contraceptives, as she read on the internet that blood clots and other threats could

accompany specific methods. After receiving comprehensive reassurances from her family doctor that side effects would be minimal, Natalie tried the patch. It worked for a few months, but she always forgot to replace the patch. Eventually, she gave up contraception entirely, as condoms don't suit her partner and are too expensive to buy recurrently.

Presently, Natalie has no desire to become pregnant but uses no contraception. Natalie shares that she is not concerned about this since her antidepressant medication lowers her libido anyway, and she does not often have intercourse.

The women interviewed all lived with one or more disabilities: mental health disorders, a neurodevelopmental disorder, and a physical condition. Two participants are diagnosed with generalized anxiety disorder, which causes immense fear and apprehension daily. When it came to reproductive health, this was no exception. One of them feared being intimate with her partner due to the chance of becoming pregnant. The fear led her to begin researching potential contraceptive options, which in turn led to more stress and anxiety when trying to discern the side effects posing risks to her health.

That is actually the reason we decided to start birth control because my anxiety caused me to panic all the time about it. If my period was like slightly late or a little bit off... my anxiety would kick in, and it was: "Oh my god, I'm pregnant." And I'd take like 5 or 6 pregnancy tests for the next day, and then I realized it was fine, nothing was happening.

I was [also] afraid because all of those stories about birth control hurting my body... I read a lot of stuff on the internet about it can cause a lot of issues to people's bodies, like blood clots and all of that. (Natalie, age 24)

Another participant living with GAD shared in experiencing alarm when trying to consult the internet for contraceptive information. In fact, all participants reported using the internet to supplement their knowledge following doctor's appointments and most agreed it was more distressing to do so. She noted that the sources were confounding and sometimes contradictory, creating more apprehension about using an oral contraceptive pill. However, this participant

experienced difficult and prolonged menstrual periods and so was reasonably motivated to use contraception as a management tool. Despite her concerns, she was referred to a gynecologist to discuss her options.

Online, there was a lot of contradicting information, and it was getting really overwhelming. I was getting like, “oh, will this affect my fertility in the future? Will I be more prone to infection?”... there were all of these different things, and they definitely made me feel a lot more anxious... the information [online] was a lot more kind of various. Like some would say certain things, some would say other things – so I would try to fact check because I was always getting different information about each pill... Yeah, so when I went to see my gynecologist, I had a lot of questions because I had seen a lot of things on the internet (Diane, age 22)

Similarly, to the women living with anxiety disorders, one participant also consulted the internet for further research. During an annual check-up, her family doctor suggested that she consider adding contraception to her healthcare plan. She described her high school sexual education as being “geared toward the general population,” and as a person living with Asperger’s syndrome, she wanted to verify through research that the OCP her doctor recommended would be suitable for her. While her doctor never mentioned any ways in which the contraceptive pill’s side effects might interact with her autism spectrum disorder or any other considerations related to it, she still wanted to further her knowledge.

The family doctor gave me some options in our consultation, and I Googled some of the words that were mentioned to get more information online. I think the primary care providers do a good job... but I know there is a lot of people who do not have family doctors and they might not have access to that regular interaction. (Gloria, age 21)

In terms of side effects, this participant reported no adverse health outcomes and being pleased with her decision. Her experience did not reflect that of another participant, living with juvenile idiopathic arthritis. This condition is a physical impairment, which causes pain and

inflexibility in the participant's hips, elbows and jaw, among other joints. The medication involved in treating this condition did have some side effects that would affect her sexual reproductive health. The methotrexate required to treat idiopathic arthritis can be used in higher doses and in combination with misoprostol to induce a medication abortion.

For this reason, the participant using methotrexate to manage her symptoms learned that if she were to become pregnant, that the fetus would likely not be compatible with life or would suffer severe physical and developmental defects. This risk did not concern the participant as of yet, since she explained that she had not decided if she would have children in the future or not. Although this stark side-effect merits a certain amount of attention and counselling, the participant describes learning about it from reading the packaging of the methotrexate.

A lot of the time it was mentioned in the side effects, but... it was never really a direct conversation to come up about how this might affect – or how I may not be able to do certain things... while I'm on the meds. But that being said I know that – one of the meds I'm on, I would have to go off it for a certain period of time prior to getting pregnant and then I have to be off a bit obviously during my pregnancy (Lois, age 22)

As well as being concerned about side effects, some participants felt that the 'user-fit model' previously discussed did not reflect their situation. One woman living with ADHD and GAD commented that her anxiety substantially decreased when using the contraceptive patch. She explained that it was because she was able to feel at ease that her chances of becoming pregnant were significantly lower than when she and her partner used no contraception whatsoever. However, this solution only lasted approximately six months, until the participant's ADHD became an obstacle to using the contraceptive patch appropriately and effectively.

[The doctor] said that one that probably wouldn't cause so many issues like what I was worried about was the patch, so I had been using that for about six months. But I kept forgetting to put them on, so right now, we just don't use anything. (Natalie, age 24)

Lois' Story

Lois is a 22-year-old woman living in Ottawa while she completes her master's degree. Originally from Thornhill, Lois identifies as Caucasian and a second-generation Canadian. She works part-time as she studies and has been living with juvenile idiopathic arthritis since she was 15 years old.

Since she started receiving pharmaceutical treatment at 18, Lois's doctor and rheumatologist needed to work together to discuss a course that would offer protection against pregnancy and no negative cross-interactions. When she decided to start using an oral contraceptive pill, she worried about the number of medications she took to manage her disability. At this time, she learned that she would be at serious risk of experiencing a dangerous pregnancy resulting in severe defects or fetal death if she became pregnant while taking her treatment. Specifically, Lois was concerned about the methotrexate she takes, which can induce pregnancy loss.

While getting contraceptive support went relatively well for Lois, she describes needing to advocate for herself and make several requests of her general practitioner to pay attention to her reproductive health. Explicitly in terms of her menstruation, which occurs seldom and causes her distress in fear of pregnancy. Currently, Lois is not seeking to become pregnant, and if she decides to do so, she knows she will need to stop her arthritis treatment to allow a healthy pregnancy.

Sexual health education

As most of the participants explained that their primary sources of information and education around contraception use relied on their family doctors or the internet, they also reported other informational sources. All but one participant said they first learned of contraception in high school health classes, mostly around 14 or 15 years old. Although experiences varied, most participants stated that the lessons were rudimentary, at best.

It was in... high school I believe. As part of the [physical education] class, they introduce it for one of the topics... my impressions were something that they just had to speak of because it was part of the curriculum. (Gloria, 21)

As sexual health was brought up as a matter of curriculum, not necessarily reflecting the actuality of the classes, many participants felt that this information did not apply to them or

reflect their reality. For example, half of the interviewees revealed that the only contraception methods discussed involved abstinence and condom use.

Yeah, to be completely honest with you, I didn't really know much about it until I got to [my] Catholic high school and I will actually say that the sexual education curriculum was pretty – not really informative. The only contraception I learned of was abstinence and using the condom, essentially. (Diane, 22)

A participant who attended a public school rather than a religious school shared similar experiences. Teachers and health professionals reduced the emphasis on abstinence and introduced the use of OCPs but no other methods.

When I was in high school, the conversation was mostly about the pill and condoms. (Lois, 22)

Although this revelation can be viewed as positive since all participants shared that pregnancy prevention options were mentioned in high school (although limited), this education left many participants feeling unsure and occasionally not included. One woman described a video where an illustrated man and woman enter a bedroom to perform sexual acts and they are depicted as able-bodied. While her disability is invisible, she noted that they never discussed people with physical disabilities in this context. She posited that anyone with a visible disability would not have felt “represented” in this conversation at all. And in terms of all disabilities in general, a theme of exclusion in school health classes emerged.

Yeah, in terms of sexual health education, I think it's geared more toward the general population. I don't think there's a lot of thought put into the education materials specifically for people with disabilities, at least not from what I've seen. (Gloria, 21)

I think it was definitely more cookie-cutter than ‘how can we adapt this for everybody.’ (Lois, 22)

Diane's Story

Diane is a 22-year-old South Indian woman living in Ottawa. She works two part-time jobs as she completes her bachelor's degree. Diane has been diagnosed with general anxiety disorder. Although she is not sexually active, at 20 years old, Diane consulted her family doctor over painful periods and was then referred a gynecologist for specialized care.

She describes her Catholic high school as uninformative in terms of sexual health, sharing that they mostly recommended abstinence. This, combined with contradictory facts she found on the internet, contributed to her distress about starting an oral contraceptive pill, as her gynecologist recommended. Diane explains that she had a lot of anxiety and concern around the OCP's side effects but was motivated to have less painful periods. After receiving reassurances from her gynecologist and asking many questions, she decided to start the pill.

Diane feels confounding information on the internet and lack of awareness of sexual health services such as Planned Parenthood (she explicitly believed none existed in her city) caused her barriers and undue stress around her reproductive health. Although she does not engage in intercourse and does not plan on becoming pregnant, she uses OCPs to manage her periods and so far has been pleased with its effect.

While most participants explained that their first time learning of contraception was through high school health classes, some learned earlier through their families. One participant shared that their high school sex education program did not impact them because their parent had already explained the female reproductive system at home.

It was good. My mom is really straightforward about stuff; she just answered some questions and explained diagrams and stuff like that. She explained a couple of methods, obviously what can happen if you don't use it... (Natalie, 24)

Only that participant shared that they had ever discussed sexual or reproductive health matters with their parents or family at all. Another participant also reported that the high school health classes did not resonate with her since the options were limited (abstinence and condoms). She did not learn about other contraceptive methods until years later when she began university and met roommates and friends with more knowledge.

Yeah, I was 18. And I know I remember because the first time I had really heard about birth control was I was with my friend and we went – I went with her, and we went to the pharmacy to pick up her birth control [pill] and then that's when she – I didn't know what it was, and that's when she explained to me. (Diane, 22)

With all women interviewed having similar experiences with the school system, they did differ in their social situations and how sexual reproductive health appeared in those spaces. Their varied experiences with researching, selecting and obtaining contraception in Ontario have showcased some recommendations for amelioration.

Potential areas of improvement

In attempting to understand how to support better, educate, and deliver services to young women with disabilities across Ontario, themes appeared in terms of what was lacking. While it's clear from their educational experiences that the high school health curriculum is deficient, they also identified other problem areas. Unanimously, all women agreed that there is a general lack of awareness among women with disabilities about how and where to obtain reliable, disability-specific information on sexual or reproductive health. Every woman interviewed used their family doctor as a resource. Still, as one participant mentioned, they did not know how else to go about it and reflected that others, precisely without family doctors, could be in a difficult position.

[Women with disabilities need] access to the actual contraception itself. Because it's one thing about teaching them, and then the access to actually get that is something else. So maybe it was just my experience; I had a good family doctor maybe. (Gloria, 21)

As far as accessing the actual contraception methods, all participants were successful with their family doctors. But as far as which other services are available to support them, most women could not identify any spaces. One participant noted that they were not aware of any

assistance programs at all in their city, serving people living with her disability. She said that nobody in her life, including health professionals, had ever notified her of any services that would be specific to her needs. Another participant mentioned that she believed there must be spaces in her metropolitan city that offered specified SRH care for women with disabilities, but she has never encountered any. In fact, her online research had led her to American websites such as Planned Parenthood, which she thought looked ideal but believed was strictly American.

I honestly think there's not a lot of services; I think the main thing is there's not a lot of awareness... there's a lot of disconnect, especially in Ottawa, there's not a lot of resources that I know of... I'm sure there are; I've just never like heard of it or seen it kind of thing. [T]here was a lot of resources on Planned Parenthood, which is like the main resource I used, but again a lot of it would say 'go to your nearest Planned Parenthood' and like, we don't have Planned Parenthood in Ottawa. (Diane, age 22)

To her consternation, there is a location in her city. That there is a Planned Parenthood in Ottawa may reflect the lack of visibility of Canadian institutions on the Internet or the dominance of US facilities.

I always hear about things through social media, and I hear about brands and different products on social media so if – like yeah, I didn't even realize Planned Parenthood was in Ottawa! (Diane, age 22)

As a possible future direction, all but one participant shared that social media would be the best way to promote SRH services to women with disabilities. Some of them, having learned of this study on popular social media 'Facebook', reinforced the idea that this was the best way to reach this population at this current time.

I would say social media because a lot of young people use social media as a primary source... (Natalie, age 24)

I always see ads on Snapchat, and Instagram and Facebook, stuff like that. I think that's really important, definitely getting on social media. I always hear about things through social media... (Diane, age 22)

However, aside from increasing awareness and promoting spaces for women with disabilities to practice their sexual reproductive rights, all participants felt that the essential addition to the experience of learning about and obtaining contraception could include coaching or counselling. When asked how to improve services in their respective cities, all respondents felt that a personalized approach, particularly counselling, would be invaluable.

Probably, maybe a phone number or a facility that they can contact where they could speak to someone one on one. Because disability is such a big range, so people with disabilities will have very specific needs, and physical versus mental disabilities, but if they had one on one support that tailors education to the physical disability needs or the mental disability needs, I think that would be helpful. Because I don't think there's one template for all, it's so diverse. (Gloria, 21)

Specifically, both participants living with generalized anxiety disorder felt that this customized approach would have alleviated much of the distress they both experienced. One woman felt that if she were to have had access to a health professional who was well versed in interacting with people living with GAD, she would have received more appropriate counselling for her health, and that experience would have been less troubling.

And I think for the anxiety, I think the main thing is like for information to be more straightforward and not as overwhelming. From what I've been seeing right now, it's a lot of information, and they give you all the negatives and very little of the positives. So definitely, I find as somebody with anxiety, it can kind of really escalate that. (Diane, age 22)

To echo this participant's thoughts, one woman reported that an individualized experience talking with someone such as a coach or a counsellor, not only a medical doctor, may have improved the anxiety that she lived. She felt perhaps this would be useful to other women living with different types of unique health statuses.

I would say a lot of coaching and one on one counselling because people with anxiety such as myself need a lot of reassurance, and that can only be gotten from someone when you're talking to them lot. And so people with anxiety ... or any kind of disability, would need a lot of coaching and reassurance, especially because this topic can be intimidating for some people, so yeah, I feel having someone to talk to would be beneficial. (Natalie, 24)

Overall, it appears that most participants from this segment of the study felt that a more custom and personalized patient approach would have benefitted them in choosing a contraceptive method and plan. With their unique disabilities, limited public education and conflicting information online rendering accessing appropriate material tedious and difficult, a personalized approach would have allowed them to make choices specific to their needs.

Chapter 5: Discussion

Discussion and integration of results

Healthcare for women with disabilities has been slow to progress compared to the general population, and sexual reproductive health is no exception to this trend. While services and accessibility have improved over the decades, research still shows that women with disabilities are understudied and underserved. A pivotal piece to better supporting this population was understanding how sexual education reaches women with disabilities. The survey demonstrated that almost all participants (85%) had had some sexual health education in high school, and for many, this was their first experience learning of contraception. A further examination into some of those experiences with interviewees showed that while sexual education in high schools existed, it was far from adequate for many participants.

Overall, it would appear that almost half of the survey participants felt that their sexual health education in high school had been less than complete. They reported feeling excluded in terms of disability representation, sexual orientation representation and female sexual functions aside from reproduction. Although experiences varied, most participants stated that the lessons were rudimentary, at best. Since sexual health was taught as a matter of curriculum, it often did not reflect the classes' actuality, and students felt that options were minimal. For example, half of the interviewees revealed that the only contraception methods discussed involved abstinence and condom use. Women living with disabilities felt that resources and information supporting diverse contraception use and how to go access it would have been more beneficial than their conversations with educators. This could explain why every participant reported many additional information sources, including the internet, family doctors, friends and family.

Although most respondents felt that their knowledge and understanding lacked, results show that only 54% of participants had ever been to visit a sexual health service for help and advice about relationships, contraception, STIs, or sex. We aimed to find out more about why women with disabilities who felt that their education was lacking did not seek out services to support them. One reason quickly emerged, with over a quarter of respondents making allusions to the issue of discrimination or maltreatment. At least 46% of survey respondents identified their sexual orientation as part of the LGBTQ+ community, and many reported feeling extremely stigmatized and underrepresented in sexual health spaces. This theme of exclusion in educational settings would be ongoing. In high-school sexual health classes, participants noted that same-sex couples or disabled couples were never mentioned or addressed. Many participants speculated that anyone with a visible disability or who is not heterosexual would not have felt represented in this conversation at all.

Further, women felt an unequal burden to take responsibility for sexual health in partnerships. Many participants thought of this as a direct consequence of the educational structure they had experienced. Some participants observed that female sexual health was incomprehensive and limited to the reproductive aspect. Many participants mentioned feeling as though their education mainly represented female reproductive health but ignored the many purposes of sex in their classes. As a result, the way the structure of the knowledge with an emphasis on pleasure for men and an emphasis on pregnancy prevention for women causes imbalances between sexually active men and women. Additionally, they mentioned a disequilibrium between the health topics covered for males, leaving women (especially with disabilities) at risk of violence or vulnerable to abuse.

Given education has not been what most respondents feel was adequate, we can still notice that women with disabilities are accessing SRH services through one avenue or another since only 23% of the women in this study have never used contraception. The need for contraception is relevant, as most women have sought it through their family doctors or other sexual health services.

Although the participants could obtain contraception, they still reported barriers to care. As well as issues around disability inclusivity, male responsibility and acceptance of different sexual orientations, the surveyed women felt unseen when it came to their unique health needs. In this study, women living with disabilities reported doctors who catastrophized their conditions or were unaware of specific interactions between disability treatments and sexual health consequences. This phenomenon is showcased in particular cases where medications used to manage disabilities had harmful effects on sexual health, but there was no discussion of this with the healthcare provider. It's also observed with healthcare professionals disregarding the user-fit model and prescribing contraceptives that were not suitable for the women's disability. Women also described feeling excluded by service providers' judgmental attitudes while accessing these services, even when the medical care was adequate.

In support of women living with disabilities who feel underserved by SRH services in Ontario, we investigated possible improvements. Suggestions included removing barriers to accessing SRH services such as stigma and attitudes, increasing the safety and responsibility taught in SRH services aimed towards men, and making the specific needs of women with disabilities more widely achievable. The majority of survey respondents report that changes are necessary to remove the stigma and promote the normalization of receiving support. They shared

that they would feel more welcome in spaces that encouraged all community members and hosted an open dialogue and attitude around seeking health support.

Finally, the most common barrier to care involved SRH services unadapted to the specific needs of women living with disabilities. Many participants felt that their needs are regularly misinterpreted, challenging to demand, or unresolved. As far as accessing the actual contraception methods, all participants were successful with their family doctors. But as far as which other services are available to offer support, most women could not identify any spaces. Participants noted that they were not aware of any assistance programs in their city, serving people living with their disability and had never encountered any.

However, aside from increasing awareness and promoting spaces for women with disabilities to practice their sexual reproductive rights, many participants felt that the essential addition to the experience of learning about and obtaining contraception could include coaching or counselling. When asked how to improve services in their respective cities, all interviewees felt that a personalized approach would be instrumental. Many respondents felt that perhaps this would be useful to women living with different types of unique health statuses.

Limitations

Following the notion that qualitative research does not intend to be generalizable or representative of any population, these findings are not. This study aimed to analyze and give voice to the experiences of young women living with disabilities in Ontario when accessing or learning about contraception. Although the intent was not to generalize the results, this study's sample size is much smaller than what we had initially projected. The small sample is partly due to difficulty in advertising recruitment materials among this heterogeneous population across the

province. This challenge might indicate that qualitative research in the future might benefit from stricter eligibility criteria, possibly examining experiences among specific disability types.

Furthermore, the global pandemic caused by the COVID-19 virus meant that we halted recruiting earlier than intended due to difficulties accessing university resources as well as challenges with advertising to and enrolling participants.

Finally, Ontario is a large province. Previous studies by Dr. Foster's group show that it is difficult to recruit participants from rural areas. We are aware of this limitation and understand that the survey is not as representative of those communities. However, the survey has provided a snapshot of the knowledge, perspectives, and experiences of adolescent and young adult women with disabilities living in the province.

Conclusion

The need to provide comprehensive sexual and reproductive health education and services to adolescents and young adults is undeniable and considered a human right in Canada. As reviewed, a crucial foundation in sexual education is information surrounding contraception. Unfortunately, little research exists on the use of contraception among Canadian women with disabilities. Studies over the past three decades have demonstrated that people with disabilities' reproductive rights have been and continue to be inaccessible due to barriers to education, unsuitable service delivery and social assumptions. This leaves a massive portion of the Canadian population at risk for many adverse sexual health outcomes, including but not limited to sexually transmitted infections, unwanted pregnancies, sexual abuse and unmanageable menstruation.

Barriers making access to sexual and reproductive health rights unreachable for many Ontarian women with disabilities include landscapes of exclusion where medical services are not adapted to serve women with unique health needs. Survey respondents and interviewees revealed through their testimony, many occasions where disregard of medication cross-interactions or the user-fit models did or could have caused adverse sexual health outcomes. Many Ontarian healthcare professionals have overlooked disability-related health issues when counselling or prescribing contraceptive treatment for their patients.

Another issue widely reported included the atmosphere of exclusion for women living with disabilities unable to locate resources suited to them in their metropolitan cities. This exclusion also extended to sexual orientation. Many women reported fearing sexual health services due to mistreatment and feeling excluded from the care model that traditionally looks at contraception meant for a man and woman. While contraception's primary purpose is preventing pregnancy, we know it can also support menstruation management and infection prevention. Many non-heterosexual respondents felt unwelcome in these spaces due to their disability and their sexual orientation.

Finally, a significant barrier mentioned in practically all survey responses and interviews was the dissatisfaction with the sexual education participants received in formal learning settings, particularly high school. Many reported having difficulty accessing information outside of school and experiencing challenges discovering suitable services or Canadian resources from the internet. On top of problems independently finding information, participants shared frustration with the topics breached in these lessons, specifically contraception use being limited to abstinence and condoms. Most respondents also shared that the inequality of information shared with males and females in high-school health classes lead them to feel yet again excluded

or burdened with the responsibility of pregnancy and infection prevention. Many expressed feeling oppressed by the ignored topics, such as consent, safety and bodily functions unrelated to reproduction.

Overall, this addition to the literature supports the idea that women with disabilities' sexual health rights are at serious risk due to barriers, including insufficient sexual education, environments of exclusion, and healthcare professionals' assumptions or misinformation. The exploration concludes that adjustments to service models and healthcare attitudes towards sexually active women with disabilities are necessary. Further, this study recommends that sexual education be revised to include people with disabilities, people of different sexual orientations and equality between men and women's reproductive responsibility to better support young women with disabilities in their sexual health autonomy.

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Appendix

Appendix A: REB Approval Letter

 Université d'Ottawa Bureau d'éthique et d'intégrité de la recherche	03/05/2020  University of Ottawa Office of Research Ethics and Integrity	
CERTIFICAT D'APPROBATION ÉTHIQUE CERTIFICATE OF ETHICS APPROVAL		
Numéro du dossier / Ethics File Number	S-04-19-3908	
Titre du projet / Project Title	Exploring young adults with disabilities' knowledge of and experiences with contraception: A multi-methods qualitative study in Ontario	
Type de projet / Project Type	Recherche de professeur / Professor's research project	
Statut du projet / Project Status	Renouvelé / Renewed	
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	03/05/2020	
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	02/06/2021	
Équipe de recherche / Research Team		
Chercheur / Researcher	Affiliation	Role
Angel FOSTER	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Chercheur Principal / Principal Investigator
Stefanie FRAPPIER	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Étudiant-chercheur / Student-researcher
Conditions spéciales ou commentaires / Special conditions or comments		