Therapeutic factors influencing the disclosure process of human immunodeficiency virus (HIV) status on perinatally infected children and adolescents in Manitoba

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Abstract

Most cases of pediatric human immunodeficiency virus (HIV) are perinatal infections that are vertically transmitted from mother to child. Since these children can live longer with antiretroviral therapy, more emphasis has been placed on increasing their quality of life. In Manitoba, children born with HIV are typically from immigrant or refugee families, Indigenous communities, and/or in the foster care system. Health care providers disclose the child's HIV status on a case-by-case basis, but there are no specific guidelines for this Manitoban population. The World Health Organization (WHO) and the American Academy of Pediatrics (AAP) provide the current recommendations for disclosure to children and adolescents with HIV, but do not provide specific information regarding culturally diverse populations. Phone interviews were conducted in a subset of children perinatally infected with HIV in Manitoba to determine therapeutic factors that influence the HIV disclosure process. A comparison of the results to the WHO and AAP guidelines showed similar aspects. Each participant had a unique disclosure process that was tailored to their situation. However, it was difficult to determine the exact factors that contributed to the disclosure process due to the limited data collected. Sufficient supports appeared to be in place for these children throughout the disclosure process as no major concerns were voiced. Due to logistics and time constraints, interviews with Indigenous participants were not completed. Further research with the caregivers and health care providers are needed to provide additional perspectives in the disclosure process.

1. Introduction

Human immunodeficiency virus (HIV) can be transmitted vertically from mother to fetus resulting in perinatal infection. Perinatal infections can be acquired anytime during pregnancy, delivery, or breastfeeding (1) and are the leading cause of pediatric HIV infections (2). In 2018, there were 259 infants perinatally exposed to HIV in Canada (3). Five of these infants were infected with HIV and the primary cause was decreased access to antiretroviral therapy (ART) (3). This small subset of children who are diagnosed with HIV continue to live healthy lives because of continuous ART (4). As a result, more focus is placed on improving the quality of life of these children.

Improving the quality of life in children with HIV starts with understanding their perspective of their diagnosis. These children discover their diagnosis through a process called disclosure. Disclosure is where the child or adolescent is told their HIV-positive status (4). There are two types of disclosure: full disclosure and partial disclosure. Full disclosure involves providing full information about the child’s HIV-positive status (4). Partial disclosure includes a degree of secrecy around the diagnosis. For example, the term “HIV” is not mentioned, and the child is told they need medicine to prevent them from getting sick and blood work to monitor the “good cells” (4). The disclosure of an HIV-positive status is a process that requires an ongoing discussion and evolves over time (4).

Due to the stigma associated with HIV, there are many psychosocial effects on children who are perinatally infected with HIV. It is important to determine the therapeutic factors to disclosure to help minimize the barriers to health care access and support. There have been many attempts to create guidelines specific to certain populations. However, there are no HIV disclosure guidelines regarding the Canadian and specifically the Manitoban population of pediatric HIV patients. Identifying therapeutic factors and barriers to the HIV disclosure process can facilitate the creation of population-specific guidelines. These guidelines can assist patients, caregivers, and health care workers when navigating the HIV disclosure process.

1.1 HIV Stigma and Psychosocial Effects

HIV stigma comes from misconceptions about HIV transmission and the lack of awareness about the condition (5). Since stigma around HIV is still present, people may be reluctant to discuss their condition (6). This lack of discussion may affect their personal interactions. For example, adolescents interested in pursuing intimate relationships may hesitate to disclose their status to others. There is a desire to maintain confidentiality while also preventing HIV exposure (6). They may not know how to navigate the discussion or how to approach the topic when necessary. A previous study interviewing perinatally HIV-infected adolescents reported that many felt a sense of guilt when they were unable to share their status with friends, but also feared rejection by friends if they disclosed their status (7). Adolescence is a time of change and self-discovery. This can be challenging when also dealing with the implications of an HIV-positive diagnosis.

Moreover, fear of rejection can lead to feelings of isolation and loneliness (8). Perinatally HIV-infected youth exhibit higher rates of depression, anxiety, and behavioural disorders than youth in the general population (9). Mental health is a large aspect that must be addressed in this population as there are many barriers to accessing resources. Contextual factors contribute to the evolution of mental health issues, especially for those living with this chronic and stigmatized condition (10). Relationships are key in shaping the outcomes of children and adolescents perinatally infected with HIV. It is important to acknowledge the influence of caregiver interactions and home environments (11), while also listening to the adolescent and working with them to understand their needs and fears. A literature review from 2012 by Persson and Newman about HIV-positive youth found that articles rarely considered the resilience, foresight, coping strategies, or life skills the youth may have developed because of their condition (12). Emphasizing their strengths rather than their weaknesses allows them to feel more responsible for their health. Proper guidance and education during the disclosure process can help identify these strengths, allowing them to make informed decisions about their care as they transition into adulthood.

1.2 Factors Affecting HIV Disclosure

Various factors influence the decision to disclose, such as the child's age, cognitive skill, and developmental maturity (4). The likelihood of disclosure increases with age as the child develops the cognitive ability to understand their situation (13). Some children discover their diagnosis, either accidentally or on their own, before they are formally told (14). The repeated hospital visits can lead the child to make connections and feel like they have "always known" about their condition (14).

A 2013 systematic review by Krauss et al recommended other contextual factors such as culture and caregiver characteristics that can influence disclosure (13). In certain cultures, parents or caregivers may be reluctant to tell the child their diagnosis for fear of self-disclosure and stigma (15). Parents may feel guilty for their role in transmission, which can affirm their fear of rejection by the child (15). The disclosure process affects not only the child but also intrafamilial relationships. Children in the foster-care system who are cared for by non-biological guardians may not feel that same guilt as HIV-positive parents. Foster parents may choose to reserve disclosure for certain situations, for example, when an adolescent becomes sexually active or becomes severely ill (16). However, most information has been anecdotal as there is limited evidence regarding the perspectives of foster parents caring for HIV-positive children.

There has been discussion throughout the literature regarding who should inform the child of their HIV-positive status. The debate is between the physician/designated health care provider or the caregiver. One review of HIV disclosure practices indicated that most caregivers preferred a doctor to disclose the HIV status to the child, whereas most of the health care providers encouraged the caregivers to disclose at home in a familiar environment (17). These opposing views come from the varying comfort levels of caregivers and health care providers as well as the desire to create a comfortable environment. Caregivers may not know how to approach the topic or how to manage the emotional distress the child may feel after disclosure (18). Most health care providers feel that their role is to prepare the caregiver for the disclosure and help the child understand their condition (19). Recent studies suggest that health care providers should receive training so they can assist caregivers in navigating the disclosure process (19, 20). Access to peer support groups may also decrease the caregiver burden for psychosocial care specifically in adolescents after disclosure (21). The presence of training and support available at the time of disclosure affects the entire process of disclosure.

A longitudinal analysis with approximately 400 children showed that HIV disclosure should not be delayed for fear of a negative impact (22). A literature review on HIV disclosure in children reported disadvantages to disclosure (e.g., emotional trauma to child and child divulging status to others) and advantages (e.g., improved ART adherence) (23). These studies recognize that disclosure is an important aspect of patient care and identify the need for evidence-based guidelines for specific populations. However, they do not provide detailed information about the disclosure process. These articles highlight the importance of determining optimal strategies in disclosing HIV diagnosis.

1.3 Current Guidelines on HIV Disclosure

Health care providers and caregivers have historically chosen to disclose a child's HIV status on a case-by-case basis (4). Disclosure is a complex process that has social and emotional impacts throughout a child's growth. A recent study showed that early disclosure (i.e., before 12 years old) gave the child more time to process their condition (24). This time allowed the child to "feel just like everyone else" and normalize living with HIV (24).

Recommendations about disclosure to children and adolescents with HIV were previously taken from pediatric oncology guidelines (22). These guidelines were chosen as a baseline for HIV disclosure because of their long-term benefits to emotional health, improved self-esteem, and improvement in parent-child relationships after disclosure (22). In 1999, the American Academy of Pediatrics (AAP) released guidelines on HIV disclosure to children and adolescents. They suggest that the decision to disclose a child's HIV status should be an individualized process (25). Considerations should include the child's age, psychosocial maturity, family dynamics, and clinical context (25). Disclosure of an HIV-positive status is strongly encouraged to occur during the child's school-age years and over multiple visits to assess the child's coping capacity and knowledge (25). If a younger child becomes symptomatic and interested in their condition, the AAP recommends discussion about the condition, but not necessarily disclosure of the HIV-positive diagnosis. Older symptomatic children that require hospitalization should be told their HIV status through a controlled environment with the caregiver(s) and knowledgeable health care providers present as they may have a better capacity to understand their situation (25). With adolescents, the AAP recommends that they are told their HIV status, so they are well informed to make proper decisions about their health. Disclosure will also allow them to appreciate the potential consequences of certain life choices including aspects of their sexual behaviour. Once disclosure occurs, emphasis should be placed on facilitating coping strategies (25).

More recently in 2011, the World Health Organization (WHO) developed guidelines on HIV disclosure counselling for children up to 12 years of age (26). The WHO recommended that school-aged children should be told their HIV-positive status, while younger children be "told incrementally to accommodate their cognitive skills and emotional maturity in preparation for full disclosure" (26). The intention to promote the child's well-being should guide the decision to disclose to the child (26). The decision should also consider the effect on the caregiver relationship and minimize the risk to the child's well-being (23). The caregiver should have input on whether the health care provider and/or other family members should assist in the disclosure process (26). The WHO guidelines also suggest having multiple sources of support both on the personal (e.g., children's friends, caregivers' peers) and institutional (e.g., schools) level. These supports can include education around HIV, skill-building, counselling, and support from people with firsthand experiences (26). Both the AAP and WHO have similar recommendations regarding the timing and context of the disclosure (Table 1). However, the AAP includes information about disclosure to adolescents. Both guidelines take general approaches to HIV disclosure and provide a good foundation for caregivers and health care providers.

Table 1: American Academy of Pediatrics (AAP) and World Health Organization (WHO) pediatric human immunodeficiency virus disclosure guidelines

	American Academy of Pediatrics (1999)[25]	**World Health Organization (2011)**[26]
Age	School aged	School aged (specifically 6-12 years old)
Disclosure to Younger Children	• If symptomatic and interested→ partial disclosure • If told diagnosis→ address fear and misperceptions	• Told incrementally in preparation for full disclosure
Disclosure to Older Children	• If symptomatic and requiring hospitalization→ full disclosure discussed and planned with parents • Adolescents→ full disclosure with encouragement of parental involvement	No guidelines specific to adolescents
Process	• Individualized, over multiple visits, controlled environment, and with knowledgeable professionals • Consider child's coping capacity/knowledge, complexity of family dynamics, and clinical context • Caregivers counselled by knowledgeable health care professional	• Not isolated event • Consider child's cognitive/developmental ability • Choosing who discloses to child should consider child's well-being and effect on caregiver relationship • Caregivers and health care workers help child manage HIV stigma
Disclosure Follow-up Considerations	• Emphasis on coping strategies	• Personal and institutional support • Increase availability and accessibility of treatment

Additionally, an HIV-Disclosure Toolkit developed in the United States attempted to be more specific with HIV disclosure guidelines. The toolkit provides suggested ages for "full" and "partial disclosure". The age of full disclosure is between 7-14 years old and should target the age of 12-14 years old (4). The age for partial disclosure is between 5-10 years old (4). This toolkit highlights high yield topics that are relevant to the disclosure process. These topics include guidance and checklists for health care workers, caregivers, and adolescents on disclosure. The toolkit also incorporates various stakeholders that play a part in the life of a(n) child/adolescent as they navigate through the diagnosis. Although informative, the current guidelines do not provide specific information regarding culturally diverse populations and may not apply to local populations.

1.4 Canadian Perinatal HIV Population

In Canada, most children perinatally infected with HIV are of African/Caribbean or Indigenous descent (3). In 2018, 54.5% of perinatally exposed infants were born to mothers who identified as black, 22.8% identified as Indigenous, and 16.2% identified as Caucasian (3). Approximately 45% of mothers whose infants were perinatally exposed to HIV immigrated from Africa (3). It is also important to note that Indigenous women are overrepresented in cases of perinatal HIV infection because of the barriers they face to accessing HIV testing and care. These barriers can include the cultural norms about disclosure to outsiders, lack of readiness, feelings of shame, fear of testing positive, and fear of being judged (27). There is limited Manitoba-specific demographic data for this population, potentially due to the small number of perinatally infected HIV pediatric patients in Manitoba. However, anecdotally the Manitoban population is similar to the national statistics.

Caregivers and health care workers play an integral role in the disclosure process as they provide support and education during and after disclosure (4). There are little to no guidelines specific to Indigenous peoples and immigrants/refugees. Guidelines would help determine an effective and more therapeutic approach to disclosing HIV to children within Manitoba. The cultural values of the Indigenous people tie in aspects of mental, emotional, spiritual, and physical health that may not be addressed in the current guidelines. Those of African descent may also have values and beliefs that are different from Western populations. The diversity of the Canadian and more specifically the Manitoban population is rarely accounted for in current HIV disclosure guidelines. This project aims to determine therapeutic factors that influence the HIV disclosure process on perinatally infected children and adolescents in Manitoba. Factors that hinder this process may help identify barriers to care. These barriers can be addressed to improve access to supports for these pediatric patients and their caregivers. These factors may also highlight differences between the current HIV disclosure guidelines and future guidelines tailored towards a Manitoban-specific population.

2. Methods

To investigate the therapeutic factors and barriers to the disclosure process among perinatally infected HIV pediatric patients in Manitoba, a qualitative approach was chosen to allow for flexibility in analyzing the data (28). Since there is limited research on the disclosure process among perinatally infected HIV patients in Manitoba, a qualitative approach may help highlight key ideas for further investigation.

2.1 Participant Recruitment and Criteria

Participants were recruited on a volunteer basis. A preliminary participant list was created by determining current pediatric HIV patients receiving care at the HIV clinic at the Health Sciences Centre (HSC) Children's Hospital in Winnipeg, Manitoba. The inclusion criteria for the participants were as follows: 1) is diagnosed with HIV, 2) is a current pediatric HIV patient, 3) had their status disclosed, and 4) has consented to the interview. Participants were notified approximately two weeks before their appointment to allow enough time to consider enrolment in the study.

2.2 Data Collection

Individual phone interviews of 15-20 minutes in length were used to determine what participants liked and disliked from their HIV disclosure process. Phone interviews were chosen considering the current COVID-19 restrictions in Manitoba during the study recruitment.

Manitoba was under the Critical (red) level during the time the interviews were conducted (see Appendix A). Interview questions included items such as: "How old were you when you found out you had HIV? How did you find out? What supports (e.g., counselling, information on condition, etc.) do you wish you had?" (see Appendix B). Structured interviews were chosen to generate preliminary data about the gaps in the HIV disclosure process within this Manitoban population and if the current disclosure process is appropriate. The participants were able to review their responses after the interview to ensure accuracy and completeness. This review was done by verbally reporting each typed response to the participant. Participant characteristics such as immigrant or refugee family background, ethnic background, and involvement in foster care were also collected. Responses were kept confidential and recorded on a password-protected computer to ensure security.

2.3 Data Management and Confidentiality

The entire interview was conducted via phone and in a private space. No one outside of the research team had access to the responses and participant information. No information revealing any personal information such as the participant's name or phone number will leave the University of Manitoba. The names of the participants were not used in the study analysis. Each participant was assigned a designated number that was only traceable through a master list on a password-protected computer. Data analysis was performed on password-protected computers with the study data stored on an additional password protected file. The participant's responses will be confidentially destroyed seven years after the completion of this study. If the results of this study are presented in a meeting or published, the participants of the study will not be identified.

2.4 Risks and Discomforts to Participants

Some questions may trigger some psychological or emotional responses. If the participants felt any discomfort with the questions, they did not need to answer them. Their decision to take part in this study was voluntary. The participants had the option to decline participation or withdraw from the study at any time. The HIV Program at HSC has psychosocial supports available. This was reiterated with the participants in the event questions triggered unexpected psychological or emotional responses.

2.5 Participant Benefit and Cost

Being a participant in this study may not benefit them directly, unless their future children become infected with HIV. However, the information gained may help other people who access HIV care in the future. There are no direct costs to the participants to participate in the interview. No payment or reimbursement for any expenses related to taking part in this study occurred.

2.6 Ethics

Consultation with the First Nations Health and Social Secretariat of Manitoba (FNHSSM) was conducted to ensure the interviews were performed respectfully with Indigenous participants. A proposal was submitted to the Health Information Research Governance Committee as part of the FNHSSM, however formal written approval is pending. Since this study required human participants, an ethics proposal was submitted to and approved by the Health and Research Ethics Board (H2020:371 HS24180). Informed verbal consent was obtained from parents or legal guardians for participants under the age of 18.

2.7 Data Analysis

After the interview data was collected, the responses to each question were summarized. The interview questions were mapped onto these guidelines where possible to highlight the similarities and differences between the guidelines and the participants' experiences. The comparison between their responses and the AAP and WHO guidelines generated a list of recommendations to consider when adapting the HIV disclosure guidelines in a Manitoban context. The gaps in knowledge identified through the interviews emphasize the need for further research in these areas. This information was written in report format and presented at the Master of Physician Assistant Studies Capstone presentation day.

3. Results

3.1 Participant Demographics

The participant demographics are summarized in Table 2. There was a total of four participants which were of African descent. All the potential participants who were asked to participate agreed to complete the interview. Unfortunately, due to logistics and time constraints, interviews with Indigenous participants were not completed at this time.

Table 2: Summary of participant demographics (n=4)

Characteristic		**Number (%) of Participants**
Age	≤ 12 years old > 12 years old	3 (75%) 1 (25%)
Ethnicity	African	4 (100%)
Refugee or Immigrant	Refugee Immigrant	2 (50%) 2 (50%)
Age Entered Canada	≤ 12 years old > 12 years old	3 (75%) 1 (25%)
Foster Care (past or present)	Yes No	1 (25%) 3 (75%)

3.2 Disclosure Process

Many of the participants expressed that they did not remember how they were told their HIV-positive status. Two out of the four participants mentioned that they were told in the hospital by a doctor. One participant said a parent told them, while the other was told in their home country but was unclear of the situation. Three of the participants were between the ages of 7 and 9 when they were told about their HIV diagnosis, while the last participant was told in their teenage years.

When asked about their feelings regarding the disclosure, half of the participants said they “didn’t really think much of it” (Participant 4). Another participant mentioned that they were “pretty surprised” (Participant 2) about their diagnosis, while another said, “at the time I didn’t really know what it [HIV] is” (Participant 1).

The participants had different reasons to explain what they liked or disliked about their disclosure process. One reason a participant liked their disclosure process was because it was a “good way to let me know why I'm taking medicine" (Participant 1). Another reason was because they had “good doctors and support”. One participant responded, “I do not like that I have it [HIV]” (Participant 2), while another mentioned that they “don't really know” what they liked about their disclosure process because they “haven't really thought much about it" (Participant 4).

3.3 Concerns About Condition and Effect on Life

Three out of the four participants had no concerns and did not feel worried about their condition at the present time or at the time of disclosure. However, one other participant did mention worries “about getting sick” (Participant 3) when they missed taking their medicine. The three participants under the age of 12 did not believe that their diagnosis had any effect on their life at this point. On the other hand, the one participant who was older mentioned they “do not like to hurt [themselves] with something pokey” (Participant 1). This participant also mentioned that they are sometimes "afraid to go closer to them [people]" (Participant 1). When asked about additional supports, all four participants did not mention that they would like to receive more support. The four participants also mentioned that the care they are currently receiving was either “good” or “fine”.

The collective participant responses for each interview question are summarized in Table 3. Key words or phrases were chosen to highlight the main themes. The common themes outlined from the participant quotes are visually depicted in Figure 1.

Table 3: Summary of participant responses and quotes (n=4)

Questions	**Participant Responses (n=4)**
Age of Disclosure	16 (25%) Does not remember (25%) 7-9 years old (50%)
Disclosure Process	Told by doctor at hospital (50%) In home country, but does not remember (25%) Told by parent (25%)
Feelings at the time of Disclosure	“At the time, I didn’t really know what it was” (25%) “Surprised, but okay” (25%) “Don’t really think about it” (50%)
Likes about Disclosure	"Good way to let me know why I'm taking medicine" (25%) “Good doctors and supports” (25%) “I haven't really thought much about it" (50%)
Concerns about Disclosure	"If I miss taking my medicine, I worry about it" "Worried about getting sick" (25%) Reported no concerns (75%)
Questions about condition after Disclosure	Reported no questions about condition (100%)
Desired Supports	Reported no other supports desired (100%)
Effect on Life	“Afraid to go closer to them" "I do not like to hurt myself with something pokey" (25%) Reported no effect on life (75%)
Current care	“Fine” “Good” (100%)

Figure 1: Word cloud that represents the common themes described from participant quotes *(Larger sized words were said or described more frequently than smaller sized words)*

4. Discussion

The collective information gathered from the interviews shows that many of the participants do not accurately recall their disclosure process. There were mixed feelings regarding the disclosure process as some were surprised or did not completely understand the implications of HIV. There were a range of reasons why the participants liked or disliked their disclosure process. The responses varied from liking that they now had a purpose for taking medicine to disliking the fact that they had HIV. The diversity of responses may imply the unique context of each individual.

Moreover, the oldest participant appeared to have more reflective responses to the questions. For example, this older participant explained how HIV affected their life, while the three younger participants expressed that HIV had no effect on their life at the present time. These younger participants also expressed indifference to their condition as they do not dwell on their disclosure experience. This may suggest that older adolescents have more insight into their condition. This may further reinforce the idea that disclosure is an ongoing process as children age and develop more insight. Different levels of awareness about the implications of HIV may indicate the factors that can be most therapeutic during an HIV disclosure process. These factors may change over the course of the ongoing disclosure process. Furthermore, the comparison of these results to the WHO and AAP guidelines determines if the current disclosure guidelines were being met.

4.1 Age

Both the WHO and AAP guidelines state that an optimal time for disclosure is when the child is school-aged. The WHO defines school-aged as 6-12 years of age. This appears to have been the age that provided the optimal time for disclosure with these participants. It is unclear if the one participant that had their HIV status disclosed in their teenage years had any barriers affecting their disclosure. The participant may not have been aware of these barriers, but their caregiver or health care provider may have chosen to delay their disclosure. Environmental factors such as the time of immigration or access to services could have also played a role. With the limited data and only one perspective shown, it is difficult to conclude the exact barriers in this case.

4.2 Caregiver Versus Health Care Provider Disclosure

Half of the participants had their status disclosed by a health care provider. Both guidelines state that the person who discloses to the child should depend on the child and their situation. The decision to disclose to the child is an individualized process that considers the child’s well-being and caregiver relationship (25,26). Based on the participant responses, neither health care provider nor caregiver was the preferred person to disclose their HIV status. In the AAP guidelines, the caregiver can be offered a choice for the method of disclosure. These choices can include the health care assisted or family assisted disclosure (25). One option includes the caregiver disclosing in a controlled setting with the assistance of knowledgeable health care providers. It is unclear if this was the case with the participants.

In the WHO's literature review, there are no comparative studies that demonstrate the best person or team to disclose to a child his or her HIV status (26). Before the disclosure process begins, it may be beneficial to have discussions regarding the needs of the caregiver and an explanation of the responsibilities of the health care providers. This discussion can guide the disclosure process to ensure the optimal approach.

4.3 Psychosocial Effects and Supports

Concerns about getting sick or fears of accidentally infecting others appeared to be a theme in the participant's responses. However, the participants did not mention any additional supports that they would have wanted at the time of the interview. This may suggest that these participants have sufficient support networks in place. Nevertheless, with the concerns mentioned, it is important to provide adequate information about HIV during the disclosure process. Stigma is a large barrier to disclosure and accessing supports (6), so creating a welcoming and non-judgmental environment may allow more children and adolescents be open about their concerns. Adequate supports should come from multiple sources, both on a personal (e.g., family and peers) and institutional (e.g., schools) level (26). Effective interventions recommended by the WHO include providing information, sessions for skill building, counselling, and testimonials from people living with HIV (26). Children who have had their HIV status disclosed may need help coping with potential reactions from others. Education and support should aim to teach specific skills to address various forms of stigma (26). With the concerns that arose in the interviews and the emphasis placed on teaching coping skills from both the WHO and AAP, a review of current local supports would assist in identifying gaps within the disclosure process. The disclosure process may be negatively affected if there are no proper supports in place.

4.4 Further Recommendations for Disclosure

Caregivers and health care providers of children and adolescents perinatally infected with HIV should have ongoing discussions about the disclosure process. The child's age, readiness, caregiver relationship, and available supports should be considered when making the decision to disclose. Discussions can be made as early as when the child enters grade school and should continue as they transition into their adult years. Supports should emphasize education about the condition and coping skills. Age-appropriate anticipatory awareness regarding different forms of stigma may also be beneficial to address difficult situations. Supports networks should be adaptable as the child develops more insight into their condition.

4.5 Relevance to Physician Assistant (PA) Profession

Health care providers of HIV-infected children and adolescents can include Physician Assistants. As part of the health care team, PAs may be the ones required to disclose an HIV-positive status to the child. PAs can also facilitate the discussion between the child's caregiver and the health care team to ensure that ongoing communication is occurring before, during, and after the disclosure. Understanding the factors that optimize this disclosure process can allow PAs to be empathetic and supportive throughout this period of change.

4.6 Limitations

The biggest limitation of this project is the small sample size. Due to the specificity of the population, the participant pool was initially small. However, the inability to include Indigenous participants removes a large group in Manitoba with a different set of needs. Therefore, the results of this project cannot be extrapolated to a more general population of children and adolescents born with HIV.

Another limitation is the recall bias in the interview process. Some participants did not accurately remember what was said to them when their HIV status was disclosed. Most participants generally recalled who performed the disclosure and where they were told but had minimal details. This made it difficult to pinpoint specific factors that helped or hindered the process. Some may have also refrained from sharing further information as they may not have wanted to remember or rarely think about their HIV disclosure. Future studies should consider performing interviews by a familiar adult to allow participants to be more open and willing to share their experiences and including Likert scales to mitigate recall bias.

Additionally, the list of questions asked during the interview limited the amount of information that the participants provided. These questions were created to gather a general sense of an individual's experience. However, having specific questions limits the depth of knowledge that could be achieved with a more informal, unstructured interview. Adhering to a script of questions may have prevented participants from sharing other important aspects of their disclosure process. This lack of context may have also led to possible misinterpretation of the quotes and generation of themes. The disclosure process is unique for every individual and can be difficult to capture in a short interview.

4.7 Future Research

Interviews with Indigenous children would provide a better understanding of the needs of a significant portion of children living with HIV in Manitoba. Demographic data should be collected for the perinatally infected HIV children and adolescents in Manitoba to inform the focus of future research in the development of disclosure guidelines. Research on the perspective of the parents as well as health care providers would provide a more holistic picture of the entire disclosure process. Their perspectives would highlight their thought processes in choosing when and how to disclose to the child. Health care provider training in HIV disclosure may also be considered. Provider training can include aspects of communication techniques, management of family dynamics, and education on stigma and confidentiality. Another avenue of research can include adults who have transitioned from pediatric care to determine additional barriers they may have in their adult life. Those who have transitioned into adult care may also provide valuable insights given their maturity and experience.

Conclusion

As a result of this study, a general foundation for HIV disclosure guidelines specific to a Manitoban population may be generated. The disclosure process of this population follows some aspects of the disclosure guidelines outlined by the WHO and AAP, such as the chosen age of disclosure. With the limited data, it is difficult to determine exact factors and barriers that contributed to the disclosure process. The demographic data may not be representative of the general pediatric HIV population, but this information may inform the focus of future research. It is important to note that this study cannot be extrapolated to a larger population but can hopefully be used to facilitate other research in hopes of developing new guidelines and protocols.

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Appendix A: COVID-19 Restrictions

COVID- 19 Provincial Response Level: Critical (Red) Restrictions (In effect on November 20, 2020 at 12:01 a.m.). Updated public health orders go into effect December 11 at 11:59 p.m. and will continue to restrict gatherings at private residences and allow critical retailers to only sell essential items.
The new orders will be in effect province-wide and include:

- A person who resides in a private residence must not permit a person who does not reside in that residence to enter the property or residence. There are some exceptions for those who live alone and for childcare, healthcare, property maintenance and emergencies.
- Gatherings in indoor or outdoor public places are limited to five persons for some specific purposes like weddings, funerals and physically distanced outdoor activities. The fundamentals should still be practiced in these situations, including mask wearing and frequent handwashing.
- Retail businesses must sell only essential items, ensure compliance with capacity limits and implement measures to ensure physical distancing.
- Retailers can continue to sell essential or non-essential items online, by telephone or by remote means for delivery or pick-up.
- Travel to and from northern Manitoba is restricted and non-essential travel is discouraged.
- Other critical services can operate as set out under the public health orders.
- All personal service businesses, including hair salons, barbers and sites offering manicures, pedicures and other esthetic services, must close.
- Gyms and fitness centres must close.
- Religious and cultural gatherings must close or be provided virtually.
- Drive-in events are restricted to household members only, and people must stay in their vehicle.
- Restaurants must close to the public and may be open for delivery, drive-thru or takeout only.
- All recreational activities, sports facilities, casinos, museums, galleries, libraries, movie theatres and concert halls must close.

Taken from Government of Manitoba (2020). *Pandemic response system.* Retrieved on December 16, 2020 from https://www.gov.mb.ca/covid19/restartmb/prs/index.html

Appendix B: Interview Questions

Demographic Questions

1. What ethnicity do you identify as?
2. Are you or your family immigrants or refugees to Canada? If so, how old were you when you entered the country?
3. Were you ever involved in the foster care system?

Questions

1. How old were you when you found out about your HIV status?
2. How did you find out? Who told you?
3. How did you feel about it at the time? (e.g., felt differently, same, etc.)
4. What did you appreciate about the process of how you found out (e.g., what did you like about it?)
5. Were you concerned about anything when you found out about your status? Did you talk to anyone about it?
6. Was there anything you wanted to know about your condition when you found out?
7. What supports (e.g., counselling, information on condition, etc.) do you wish you had?
8. Do you think finding out about your HIV status has had any effect on your life? If so, what specifically?
9. How do you feel about the care you are receiving now?
10. Is there anything else you would like to add?