Transition from Pediatric to Adult HIV Care for Young Women Living with HIV

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Abstract
Transitioning from pediatric to adult care is a complicated process for youth with chronic illnesses. This study elucidates the unique factors affecting transition preparedness and perception of adult HIV care among a cohort of young women with HIV. Between 2013 and 2015, 48 women with HIV, who had experience with pediatric HIV care, were enrolled in a large Canadian cohort study. Variables were self-reported during peer-administered surveys. Only 60% reported feeling prepared for transition. Having never had contact with child protection services ($P = .049$), never been in foster care ($P = .011$), never been in a group home ($P = .036$), reporting a higher current CD4 count ($P = .033$), and reporting a younger ideal age for transition ($P = .041$) were associated with transition preparedness. Eighty-four percent reported equivalent or better HIV care following transition. Correlates of equivalent/better care following transition included lower personal income ($P = .023$), higher CD4 count ($P = .021$), care by an adult infectious diseases specialist ($P = .002$), and transition preparedness ($P = .005$). Our findings highlight the importance of adequate transition preparation and its effect on perception of care following transition.

Keywords
community-based research, cohort, CHIWOS, women, young women, transition

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While the majority of the people living with HIV have acquired their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood. Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1 Like others their infection as adults, globally, there is an aging cohort of young adults who acquired HIV in childhood.1

How Does Your Research Contribute to the Field?

This article contributes to the field by reporting on transition experience of young women living with HIV, which allows for gender and sex considerations.

What Are Your Research’s Implications toward Theory, Practice, or Policy?

The results of this research have implications for practice related to how transition is managed for young women living with HIV and for considerations related to their sexual and reproductive health.

Methods

Study Design and Population

The Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS) is a national, longitudinal cohort study that was initiated in 2011 to address the lack of knowledge about the health and care of women living with HIV in Canada. CHIWOS has enrolled women in Canada’s most populated provinces, British Columbia, Ontario, and Quebec, which have the largest populations of women living with HIV. CHIWOS employs a community-based research approach and is guided by the frameworks of critical feminism, antioppression, intersectionality, and social justice.

Participants were eligible for the study if they self-identified as a woman (including transgender and gender non-binary
populations), living with HIV, were 16 years or older, and resided in one of the 3 participating provinces. Sampling for the study was nonrandom and purposive.19 Peer research associates (PRA), who were women living with HIV, trained in research practices, administered questionnaires to participants in English or French.

Baseline data from 1422 women living with HIV, recruited between October 2013 to June 2015, were included in this analysis. The current study population included all women enrolled in CHIWOS who completed the baseline questionnaire and self-reported previous or current engagement in pediatric HIV care. Participants with current engagement in pediatric care were included, as their responses were relevant to several of the research measures. Specifically, they were able to respond to transition preparedness, opinions on the importance of knowledge on various topics prior to transition, and for which of those topics they felt they needed more information.

**Ethical Approval and Informed Consent**

Primary ethical approval for this study was provided by the Research Ethics Boards of Simon Fraser University (British Columbia; H12-03326), Women’s College Hospital (Ontario; # 2011-0024-E), and McGill University Health Centre (Quebec; 2012-953 11-102). Written informed consent was obtained from participants confirming their willingness to complete the PRA-administered questionnaire. All participants were given CA$50 to cover costs associated with study participation for each study visit.

**Measures**

**Transition preparedness.** Self-reported transition preparedness was captured by a single question in CHIWOS survey: “Overall, do you feel like your pediatric HIV care program prepared you enough for the change to adult HIV care?” This categorical variable had 4 potential responses: yes, no, not sure, and prefer not to answer. For univariate analyses of preparedness for transition, this outcome was dichotomized to “prepared” versus “not prepared/not sure.”

**Perception of adult care.** Participants were asked a question to enhance our understanding of how they perceive their care following transition, specifically in terms of how it compared to pediatric HIV care. This outcome of interest was ordinal and was defined as “adult HIV care after transition” being better, same, or worse than their pediatric HIV care. For univariate analyses of perception of adult HIV care, the outcome was dichotomized to “better/same” versus “worse.”

**Transition outcomes.** Participants were asked about their actual age at transition, opinions on the ideal age to transition, satisfaction with location of adult provider, opinion on the importance of knowledge on various topics prior to transition, and which of those topics participants felt they needed more information on. Correlates of interest included sociodemographic and clinical variables.

**Statistical Analysis**

Outcomes and baseline characteristics of the study population were summarized using medians and interquartile ranges (IQRs) for continuous variables and frequencies and proportions for categorical variables. Associations between primary outcomes and covariates were tested using $\chi^2$ test or Fisher exact test for categorical variables and Wilcoxon rank for continuous variables. We also compared the transition experience between provinces using $\chi^2$ test for categorical variables and Kruskal-Wallis test for continuous variables. Univariate logistic regression was used to assess unadjusted odds ratios of the associations between preparedness for adult HIV care and covariates. SAS version 9.4 (SAS, Cary, North Carolina) was used for all analyses.

**Results**

**Participants**

A total of 48 young women living with HIV met the inclusion criteria for the current analysis. Four of the participants remained in pediatric HIV care at the time of data collection, while the majority had transitioned to adult care before baseline data were collected. The median age of the sample was 23 years (IQR = 20-25). Comprehensive demographic characteristics of the cohort are presented in Table 1.

**Preparedness for Transition**

Sixty percent (n = 29) of CHIWOS participants who had pediatric care experience reported feeling prepared for their transition to adult care. Nineteen (40%) reported that they were unsure or unprepared for transition. Significantly correlated variables with being prepared for transition were having never been involved with child protection services ($P = .049$), including having never been in foster care ($P = .011$) and never lived in a group home ($P = .036$), reporting a higher (>500) current CD4 count ($P = .033$), and reporting a younger ideal age at transition ($P = .041$). The complete univariate logistic regression model for correlates of feeling prepared for adult HIV care is presented in Table 2.

**Perception of Adult HIV Care**

Of the 44 participants already in adult HIV care, 37 (84%) reported their adult HIV care was equivalent or better than their pediatric care. Significant correlates of reporting equivalent or better adult HIV care, when compared to pediatric HIV care, included lower personal income ($P = .023$), higher CD4 count ($P = .021$), being cared for by an adult infectious diseases specialist ($P = .002$), and having reported feeling
Table 1. Demographic Characteristics of Study Participants Who Reported Previous or Current Engagement in Pediatric HIV Care.a

| Characteristics                     | Values          |
|-------------------------------------|-----------------|
| Age, years                          |                 |
| ≤19                                 | 9 (19%)         |
| 20–24                               | 23 (48%)        |
| ≥25                                 | 16 (33%)        |
| Ethnic background                   |                 |
| African, Caribbean, black           | 19 (40%)        |
| White/Caucasian                     | 19 (40%)        |
| Indigenous                          | 6 (13%)         |
| Other ethnicities                   | 4 (8%)          |
| Born in Canada                      | 30 (63%)        |
| Province of residence               |                 |
| British Columbia                    | 8 (17%)         |
| Ontario                             | 30 (63%)        |
| Quebec                              | 10 (21%)        |
| Marital status                      |                 |
| Single/separated/divorced/widowed   | 32 (67%)        |
| Married/common-law/in a relationship| 16 (33%)        |
| Annual household gross income       |                 |
| <20K                                | 26 (62%)        |
| 20–40K                              | 10 (24%)        |
| >40K                                | 6 (14%)         |
| Age at HIV diagnosis                |                 |
| ≤9 years old                        | 31 (76%)        |
| ≥10 years old                       | 10 (24%)        |
| HIV risk factors                    |                 |
| Perinatal exposure                  | 38 (81%)        |
| Blood transfusion/medical procedure | 5 (11%)         |
| Other                               | 4 (8%)          |
| Recent CD4 countb                   |                 |
| >500                                | 25 (69%)        |
| 200–500                             | 9 (25%)         |
| <200                                | 2 (6%)          |
| Recent viral loadb                  |                 |
| Undetectable                        | 42 (88%)        |
| Detectable                          | 6 (13%)         |
| Time since transition, years        |                 |
| ≤3                                  | 8 (21%)         |
| 4–7                                 | 21 (54%)        |
| ≥8                                  | 10 (26%)        |
| Previous consensual sex             |                 |
| (n = 47)                            | 40 (85%)        |
| Age of sexual debutc                |                 |
| (n = 38)                            | 17 (44–16-18)   |
| Contraceptive use in the last 6 months| 23 (48%)    |
| Discussed reproductive goals with HCP (n = 46) | 17 (35%) |
| Comfortable discussing reproductive goals with HCP (n = 44) | 24 (50%) |
| Previous mental health diagnosis    | 15 (31%)        |
| Ever in foster care                 | 17 (35%)        |
| Adopted                             | 3 (6%)          |

Abbreviation: HCP, health-care provider.  
*aVariables summarized using full sample of 48 unless otherwise specified. For variables where n < 48, the remainder of responses were “don’t know” or “prefer not to answer.” Continuous variables are summarized with medians and interquartile range; categorical variables are summarized with n (%).  
*bRecent CD4 count (cells/mm³) and viral load (log₁₀ copies/mL) refers to self-reported values closest to the time of the survey.  
*cWomen who have previously had consensual sex.

Transition Outcomes

Age at transition. The median age of transition for women already in adult care was 18 years (IQR = 16–18). The median reported ideal age of transition was 18 years (IQR = 17–18). Participants who felt prepared reported the ideal age for transition was 18 years (IQR = 17–18), compared to 19 years (IQR = 18–20) for participants who were unsure or felt unprepared (P = .007). The actual age of transition was not significantly associated with feeling prepared.

Gaps in knowledge prior to transition. Table 4 presents the participants’ responses when asked which topics were important to feel comfortable with or to have information on. They were also asked to report those topics they felt they needed more information on prior to transition. Seventy-three percent of participants reported needing more information on 3 or more topics that they classified as very important. A vast majority of participants noted practical information on posttransition care (eg, filling prescriptions, being comfortable with HIV medications, knowing where to seek care when ill) and HIV knowledge (eg, HIV disease transmission, safer sex, and disclosure) as being very important. The most highly ranked information needs likewise focused on these 2 areas of practicalities (same as above, but also understanding differences between pediatric and adult care, and familiarity with community supports) and HIV knowledge. In addition, understanding rights to confidentiality, respect, and quality of care was highly ranked as being both important and required information.

Location of adult care provider. Of the women in adult care, 31 (65%) received care at a different site than their pediatric care and 40 (83%) reported being happy with their adult health-care provider’s (HCP) location. These were not significantly associated with feeling prepared for transition or perception of adult HIV care following transition.

Engagement in care. Forty-seven (98%) participants had received HIV care within the past year, and of those, 30 (64%) participants reported attending their HIV care clinic 2 to 5 times in the past year. Forty-one (85%) participants were taking ART. However, of those, only 16 (39%) reported >95% adherence. Self-reported CD4 count and viral load are presented in Table 1. Of 27 women who endorsed having on-site mental health services at their HIV care clinic, 10 (37%) had accessed them. Overall, only 17 (35%) participants had discussed their reproductive goals with their HCP, and 24 (50%) participants reported feeling comfortable discussing them. This finding is contextualized by 13 (27%) women reporting having previously been pregnant, 8 (17%) women reporting having previously delivered a child, and 18 (38%) indicated they intended to become pregnant in the future.
Table 2. Univariate Logistic Regression of Feeling Prepared for Adult HIV Care.\(^a\)

| Characteristics\(^b\)                                      | OR  | 95% CI       | \(P\) Value |
|------------------------------------------------------------|-----|--------------|-------------|
| Age, years                                                 |     |              | .204        |
| \(\leq19\)                                                 | Ref |              |             |
| 20-24                                                      | 0.16| 0.02-1.52    |             |
| \(\geq25\)                                                 | 0.13| 0.01-1.24    |             |
| Ethnic background                                           |     |              | .286        |
| White/Caucasian Ref                                        |     |              |             |
| African, Caribbean, black/other                            | 1.66| 0.47-5.93    |             |
| Indigenous                                                 | 0.36| 0.05-2.50    |             |
| Born in Canada                                             | 0.95| 0.29-3.16    | .939        |
| Province of residence                                      |     |              | .200        |
| British Columbia Ref                                       |     |              |             |
| Ontario                                                    | 3.89| 0.76-19.85   |             |
| Quebec                                                     | 1.67| 0.25-11.07   |             |
| Marital status                                             |     |              | .835        |
| Single/separated/divorced/widowed                          | Ref |              |             |
| Married/common-law/in a relationship                       | 1.14| 0.33-3.92    |             |
| Annual household gross income (n = 42)                    |     |              | .923        |
| <20K                                                       | Ref |              |             |
| 20-40K                                                     | 1.1 | 0.25-4.86    |             |
| >40K                                                       | 0.73| 0.12-4.35    |             |
| Age at HIV diagnosis (n = 41)                              |     |              | .416        |
| \(\leq9\) years old                                        | Ref |              |             |
| \(\geq10\) years old                                       | 0.55| 0.13-2.32    |             |
| HIV risk factors (n = 47)                                  |     |              | .921        |
| Perinatal exposure                                          | Ref |              |             |
| Blood transfusion/medical procedure                        | 0.98| 0.15-6.57    |             |
| Other                                                      | 0.65| 0.08-5.14    |             |
| Recent CD4 count\(^c\)                                     |     |              | .033        |
| \(>500\)                                                   | Ref |              |             |
| 200-500                                                    | 0.09| 0.01-0.56    |             |
| \(<200\)                                                   | 0.32| 0.02-5.85    |             |
| Recent viral load\(^c\)                                    |     |              | .166        |
| Undetectable                                               | Ref |              |             |
| Detectable                                                 | 0.28| 0.05-1.7     |             |
| Time since transition, years (n = 39)                      |     |              | .865        |
| \(\leq3\)                                                  | Ref |              |             |
| \(\geq8\)                                                  | 0.6 | 0.09-3.99    |             |
| Previous consensual sex (n = 47)                           | 2.22| 0.44-11.32   | .336        |
| Age of sexual debut (n = 38)                               | 0.97| 0.63-1.49    | .890        |
| Contraceptive use in the last 6 months                     | 0.74| 0.22-2.46    | .627        |
| Discussed reproductive goals with HCP (n = 46)             | 0.87| 0.26-2.97    | .828        |
| Comfortable discussing reproductive goals with HCP (n = 44) | 1.8 | 0.52-6.2     | .352        |
| Previous mental health diagnosis                           | 0.65| 0.19-2.25    | .500        |
| No contact with child protection services in early life     | 3.67| 1.01-13.34   | .049        |
| Never in foster care                                       | 5.27| 1.47-18.94   | .011        |
| Never lived in a group home                                | 5.06| 1.11-23.01   | .036        |
| Reported younger ideal age for transition                  | 0.45| 0.21-0.97    | .041        |
| Perception of adult HIV care\(^d\)                        |     |              | .084        |
| Better                                                    | Ref |              |             |
| Same                                                      | 1.63| 0.42-6.36    |             |
| Worse                                                     | 0.11| 0.01-1.20    |             |

Abbreviation: CI, confidence interval; HCP, health-care provider; OR, odds ratio.

\(^a\)\(N = 48\).

\(^b\)Reported for the 44 women who had transitioned to adult HIV care. Otherwise, where \(n < 48\), the remainder of responses were “don’t know” or “prefer not to answer” and account for the remainder of responses where totals are <100%.

\(^c\)Self-reported values of undetectable viral loads may have been measured on different platforms across the country, but at the time of the study, all should have been at least <50 copies/mL.

\(^d\)10 (21%) and 9 (19%) women answered “no” and “not sure,” respectively, when asked if they felt their pediatric HIV care program was preparing them for adult HIV care.
While the overall results must be generalized with caution, given the high rates of engagement in care reported by study participants (98%), there are interesting considerations for clinicians who are providing care before and after transition to young women living with HIV. The results of this study found moderate self-reported rates of preparedness for transition. The finding that only 60% of participants felt prepared for transition is somewhat disappointing given that coordinated, systematic, and comprehensive transition programs have been suggested to better support youth living with HIV for almost a decade. The finding related to engagement with child protection services in one form or another might have predictive value when providers are trying to screen those who may struggle with transition preparation. Given that we do not have CD4 count data before or at the time of transition for the entire cohort, the predictive value of this correlate is limited and should be used with caution. The finding that women who reported a younger ideal age of transition were also more likely to feel prepared for transition is unsurprising. It is logical that those who reported being eager to transition younger would feel this way due to a personal sense of preparation for the transition.

Social factors, such as no experience with child protection services, foster care services, nor living in a group home, as well as the clinical variable of a relatively preserved CD4 count and the personal preference for a younger ideal age of transition were associated with transition preparedness. The finding related to engagement with child protection services in one form or another might have predictive value when providers are trying to screen those who may struggle with transition preparation. Given that we do not have CD4 count data before or at the time of transition for the entire cohort, the predictive value of this correlate is limited and should be used with caution. The finding that women who reported a younger ideal age of transition were also more likely to feel prepared for transition is unsurprising. It is logical that those who reported being eager to transition younger would feel this way due to a personal sense of preparation for the transition.

The finding that women who had no experience with child protection service, or lived in foster care, or in a group home were more likely to feel prepared for transition reminds us that there are critical contextual issues impacting transition preparedness, some of which we as clinicians may actually have limited ability to mitigate. As others have reported, it appears that complex social circumstances will impede

| Characteristics                              | n    | Better/Same, n = 37 | Worse, n = 7 | P Value |
|----------------------------------------------|------|---------------------|--------------|---------|
| Born in Canada                               |      |                     |              |         |
| Yes                                          | 29   | 24 (83%)            | 5 (17%)      | 1.000   |
| No                                           | 15   | 13 (87%)            | 2 (13%)      |         |
| Personal gross income                        |      |                     |              |         |
| <$20000                                      | 31   | 29 (94%)            | 2 (6%)       | .023    |
| $20 000-$40 000                              | 9    | 5 (56%)             | 4 (44%)      |         |
| >$40 000                                     | 3    | 3 (100%)            | 0 (0%)       |         |
| Ever in foster care                          |      |                     |              |         |
| Yes                                          | 17   | 14 (82%)            | 3 (18%)      | 1.00    |
| No                                           | 29   | 23 (85%)            | 4 (15%)      |         |
| Mental health condition ever                 |      |                     |              |         |
| Yes                                          | 15   | 13 (87%)            | 2 (13%)      | 1.00    |
| No                                           | 29   | 24 (83%)            | 5 (17%)      |         |
| Age at HIV diagnosis                         |      |                     |              | .613    |
| ≤9 years old                                 | 29   | 25 (86%)            | 4 (14%)      |         |
| ≥10 years old                                | 9    | 7 (78%)             | 2 (22%)      |         |
| Most recent CD4, cells/mm³                   |      |                     |              | .021    |
| <200                                         | 2    | 1 (50%)             | 1 (50%)      |         |
| 200-500                                      | 9    | 7 (78%)             | 2 (22%)      |         |
| >500                                         | 21   | 21 (100%)           | 0 (0%)       |         |
| Most recent HIV viral load                   |      |                     |              | .238    |
| Undetectable (<50/mL)                        | 38   | 33 (87%)            | 5 (13%)      |         |
| Detectable (>50/mL)                          | 6    | 4 (67%)             | 2 (33%)      |         |
| Primary adult HIV care provider               |      |                     |              | .002    |
| Family physician/general practitioner         | 4    | 2 (50%)             | 2 (50%)      |         |
| Infectious disease specialist                | 36   | 33 (92%)            | 3 (8%)       |         |
| Other specialist                             | 2    | 0 (0%)              | 2 (100%)     |         |
| Pediatric HIV care prepared for adult care   |      |                     |              | .005    |
| Yes                                          | 25   | 24 (96%)            | 1 (4%)       |         |
| No                                           | 10   | 5 (50%)             | 5 (50%)      |         |
| Not Sure                                     | 9    | 8 (89%)             | 1 (11%)      |         |

*a n = 44. Reported for the 44 women who had transitioned to adult HIV care; 4 women were still in pediatric care and are not included. Where n < 44, the remainder of responses were “don’t know” or “prefer not to answer” and account for the remainder of responses where totals are <100%. Recent CD4 count (in cells/mm³) and viral load (log10 copies/mL) refer to self-reported values closest to the time of the survey. bSelf-reported values of undetectable viral loads may have been measured on different platforms across the country, but at the time of the study, all should have been at least <50 copies/mL.

Discussion

While the overall results must be generalized with caution, given the high rates of engagement in care reported by study participants (98%), there are interesting considerations for clinicians who are providing care before and after transition to young women living with HIV. The results of this study found moderate self-reported rates of preparedness for transition. The finding that only 60% of participants felt prepared for transition is somewhat disappointing given that coordinated, systematic, and comprehensive transition programs have been suggested to better support youth living with HIV for almost a decade. The finding suggests an ongoing need for further transition planning at the pediatric level. This finding is also highly relevant for adult HIV care providers who must be equipped for young women who may not feel fully prepared for the transition. Social factors, such as no experience with child protection services, foster care services, nor living in a group home, as well as the clinical variable of a relatively preserved CD4 count and the personal preference for a younger ideal age of transition were associated with transition preparedness. The finding related to engagement with child protection services in one form or another might have predictive value when providers are trying to screen those who may struggle with transition preparation. Given that we do not have CD4 count data before or at the time of transition for the entire cohort, the predictive value of this correlate is limited and should be used with caution. The finding that women who reported a younger ideal age of transition were also more likely to feel prepared for transition is unsurprising. It is logical that those who reported being eager to transition younger would feel this way due to a personal sense of preparation for the transition.

The finding that women who had no experience with child protection service, or lived in foster care, or in a group home were more likely to feel prepared for transition reminds us that there are critical contextual issues impacting transition preparedness, some of which we as clinicians may actually have limited ability to mitigate. As others have reported, it appears that complex social circumstances will impede
transition and affect personal perception of disease. While we did not detect that a previous mental health diagnosis predicted preparedness for transition or perception of quality of care, the transition literature and our finding of differential experiences among women with a history of foster care emphasize the importance of mental health care and support.4,20,21,22

The finding that women who felt prepared for transition reported a statistically significantly younger ideal age to transition than those who felt unprepared. The actual age was only 1 year older (18 versus 19), which may have less significance clinically than the statistical results suggest. However, it may point to the need for delayed transition for young women at higher risk of struggling with transition, such as those who have had involvement with child protection services. At a minimum, the finding lends further credibility to the well-documented suggestion that adolescents should play an integral role in deciding when and where they transition to adult care.23-26 Further, our findings and those from a Quebec study27 highlight the importance of studying the unique experience of women living with HIV in Canada, as other studies have reported a much older ideal age for transition.14,22,25 This could be related to the influence of local norms, as older age of transition may be commonplace in the United States and England but exceptional in Canada. The need for young adult clinics and flexibility in the age of transition has not yet been widely accepted, although our findings suggest this may be beneficial to ensure greater preparation.

In contrast to a previous report,28 we found that a higher CD4 count was associated with transition preparedness. This finding may suggest that poorer immunologic control could be a predictor of young female patients prone to poorer transition or that transition preparedness is associated with improved clinical outcomes following transition, as evidenced by higher CD4 counts. Given the nature of the data collection, it is not possible to ascertain if this finding is predictive or an outcome of transition preparedness but is worth exploring further. As only 60% of participants overall felt prepared for transition, greater attention to this patient group is warranted, as it implies the need for more individualized and focused preparation in general. We suggest consideration of individualized needs of young women is an essential aspect of transition planning.

Despite only finding moderate rates of transition preparedness, the cohort reported high rates of equivalent or better HIV care posttransition with their adult HIV care providers when asked to compare it to their care in pediatric care. Not surprisingly, preparedness for transition predicted a positive perception of adult HIV care. This may likely be the result of being prepared for the differences between the 2 care environments. Similarly, it was not surprising that we found those with higher current CD4 counts were more likely to report equivalent/better adult HIV care.

Within the sample, we did find additional correlates of interest when reporting equivalent/better adult HIV care that we feel contribute new insight into the literature and may be as a result of our sex-/gender-based analysis. First, we found that 78% of the 37 women who reported better or equivalent care had an income of <$20 000, Canada’s poverty line. This finding is different than previous work, which has well-documented that financial and health insurance challenges are barriers to a successful transition.20,26,28,29 This may reflect the availability of social assistance and supported access to care for very low-income individuals in Canada. Low-income individuals can access care and medication more readily through compassionate services, while middle-income individuals may still have limited resources but may not qualified for compassionate assistance, perhaps causing issues with access to medications for this population. Further, young women living with HIV in Canada who work, albeit with low wages, may have difficulty making time for doctor appointments, an experience that youth

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### Table 4. Participant Responses to Questions about Importance and Their Need for Information on Transition-Related Topics.a

| Topic or Issue                                      | Reported Very Important | Reported Need for Information | Reported Very Important and Need for Information |
|----------------------------------------------------|-------------------------|-------------------------------|-----------------------------------------------|
| Understanding differences of adult and pediatric care | 35 (73%)                | 28 (58%)                      | 22 (46%)                                      |
| Being comfortable attending appointments alone      | 41 (85%)                | 20 (42%)                      | 20 (42%)                                      |
| Being comfortable scheduling your own appointments  | 37 (77%)                | 18 (38%)                      | 16 (33%)                                      |
| Understanding how prescriptions and pharmacies work | 44 (92%)                | 28 (58%)                      | 27 (56%)                                      |
| Being comfortable with your HIV medication          | 46 (96%)                | 25 (52%)                      | 25 (52%)                                      |
| Understanding HIV disease and how it is transmitted | 47 (98%)                | 23 (48%)                      | 22 (46%)                                      |
| Knowing where to seek help when sick               | 46 (96%)                | 29 (60%)                      | 28 (58%)                                      |
| Understanding birth control options and accessing them | 39 (81%)                | 27 (56%)                      | 24 (50%)                                      |
| Knowing available fertility and pregnancy planning services | 33 (69%)                | 29 (60%)                      | 25 (52%)                                      |
| Education on safer sex methods                      | 45 (94%)                | 24 (50%)                      | 23 (48%)                                      |
| Understanding issues around HIV disclosure          | 42 (88%)                | 30 (63%)                      | 26 (54%)                                      |
| Being familiar with community supports (ASOs)       | 34 (71%)                | 32 (67%)                      | 25 (52%)                                      |
| Understanding rights to confidentiality/respect/quality care | 44 (92%)                | 32 (67%)                      | 32 (67%)                                      |
| Understanding your right to participate in research or not | 39 (81%)                | 26 (54%)                      | 22 (46%)                                      |

Abbreviation: ASOs, AIDS service community-based organization.

aN = 48.
may not be prepared for that may impact their perceptions of adult HIV care.

Further, women receiving HIV care from an infectious disease specialist were significantly more likely to report better or equivalent care posttransition than those receiving care from a general practitioner or another specialist. This may reflect the specialized skills and knowledge physicians need to care for young women with HIV. It might also reflect the time constraints experienced by primary care providers who need to address other non-HIV-related aspects of the patient’s health. This may be particularly true given that women are generally more likely to seek comprehensive medical care as compared to their male peers, leaving even less time for a general practitioner to address HIV-related care needs. This finding should be interpreted with caution as only 6 participants received adult HIV care from a physician who was not an infectious disease specialist.

The transition outcome findings also yield some insights for clinical care. Adherence to cART is a timely issue, both for the health of the person living with HIV and also in the context of the mounting U=U movement. Eighty-five percent of women were taking ART at the time of the survey. However, of those, only 39% of women in our cohort reported >95% adherence, supporting previous reports of youth living with HIV since childhood having adherence challenges and facing ongoing challenges with independent management of their HIV following transition. Given lower adherence rates continued to be reported among women with HIV in general, the current findings suggest there is ongoing work to be done in this area of clinical HIV care.

Three-quarters (73%) of women felt they had insufficient information on 3 or more transition-related topics that they considered very important. As knowledge deficits have been well-documented as a barrier to successful transition, it is imperative to prioritize these topics and individualize transition preparation using tools to ensure optimal preparedness. Previous reports demonstrate adolescents commonly need assistance understanding HIV disease, medications, disclosure, and where to seek help when they are sick. Likewise, numerous women in our study reported needing information on the differences between adult and pediatric care, prescriptions and pharmacies, and HIV disclosure.

The relatively low proportion (50%) of women who reported feeling comfortable discussing their reproductive goals with their HCPs is a particular concern for younger women, as reproductive decision-making and planning are critical at this stage in life. Compared to an analysis of the overall CHIWOS sample, where 57.5% of participants with reproductive potential were comfortable discussing reproductive goals with their HCP, this subgroup of younger women were slightly less comfortable. This gap in care may be a barrier to successful engagement in care at a time in life when these discussions are highly relevant. Although we did not look specifically at communication with adult providers, this finding is likely reflective of communication struggles that have previously been described in the literature. The low number of women who had discussed their reproductive goals with their adult HIV provider should serve as a reminder of the importance of being sensitive toward individual reproductive and sexual concerns. Eighty-three percent of our participants previously had consensual sex and 48% used contraception in the last 6 months, which are findings similar to a Quebec study and suggest that, in general, this group is sexually active. Youth living with HIV’s need for support navigating their reproductive and sexuality concerns has been well described. This group of women placed importance on issues such as understanding contraceptive options and knowing available fertility and pregnancy planning services among other topics. Advancing the sexual and reproductive health rights of young women in the context of HIV is a global priority. These results are a call to action for providers to normalize nonbiased discussions about sexual and reproductive health with their young female clients.

Our findings have important implications for both pediatric and adult HCPs caring for young women living with HIV during their transition from pediatric to adult HIV care. We suggest that overall the findings support individualize transition planning to ensure youth have comprehensive information about topics of importance to them and clinical support where they most need it. Additionally, transition procedures should permit flexibility around the move to adult care, allowing for transition experiences that are best suited to the individual woman’s needs based on social and clinical realities of each woman.

Limitations

Recruitment biases must be considered when interpreting the findings, as the sample is not random and only includes participants from British Columbia, Ontario, and Quebec. In addition, the strategy of recruiting women through service hubs such as clinics and community-based organizations may have led to underrepresentation of women not engaged in care, which is an important consideration when describing the success of transition to adult care. As such, conclusions from this study about the wider population of young women living with HIV in Canada must be interpreted with caution. The small sample size may have also decreased the statistical power to detect differences. Due to self-report, there was potential for social desirability bias. Attempts to minimize this and other forms of reporting bias included PRA training, community input into survey development, providing definitions for terms used in the survey, piloting the survey prior to utilization, and the option for the participant to complete sections of the survey of sensitive nature without the interviewer. Self-reports of undetectable viral load were shown to have high validity when compared to laboratory assessments.

Conclusions

This analysis provides new data on the experience of transition from pediatric to adult HIV care for young women living with
HIV in Canada. Our findings highlight the importance of transition preparedness and the potential need for increased support for patients with poor childhood family supports and lower CD4 counts. The findings also provide insight into clinical and social variables that may be predictive of perception of adult HIV care. While the findings are consistent with several previously published papers about HIV and adolescent transition, certain unique findings suggest that the transition experiences of young women require unique considerations. The need to advance HIV transition preparedness models and to address the population’s specific needs and challenges in order to improve health outcomes of young women living with HIV remains evident.

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