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

Victoria Logan Kennedy, MN, BScN[1], Kaitlyn Luisa Mellor, MD[1,2], Jason Brophy, MD, MSc[3], Ari Bitnun, MD, MSc[4], Ariane Alimenti, MD[5], Fatima Kakkar, MD[6,7], Carmen Helen Logie, MSW, PhD[1,8], Kath Webster, BA[9], Karène Proulx-Boucher, MA[10], Erin Ding, MSc[11], Shahab Jabbari, MSc[11], Angela Kaida, MSc, PhD[9], Alexandra de Pokomandy, MD, MSc[10,12], and Mona Loutfy, MD, MPH[1,2]; on behalf of the CHIWOS Research Team

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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[1] Women's College Research Institute, Women's College Hospital, Toronto, Ontario, Canada
[2] Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada
[3] Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada
[4] Department of Pediatrics, The Hospital for Sick Children, University of Toronto, Toronto, Ontario, Canada
[5] British Columbia Women's Hospital and Health Centre, Vancouver, British Columbia, Canada
[6] Faculté de médecine, Université de Montréal, Montreal, Quebec, Canada
[7] Centre Hospitalier Universitaire Sainte-Justine, Montreal, Quebec, Canada
[8] Factor-Inwentash Faculty of Social Work, University of Toronto, Toronto, Ontario Canada
[9] Faculty of Health Sciences, Simon Fraser University, Burnaby, British Columbia, Canada
[10] Chronic Viral Illness Service, McGill University Health Centre, Montreal, Quebec, Canada
[11] British Columbia Centre for Excellence in HIV/AIDS, Vancouver, British Columbia, Canada
[12] Department of Family Medicine, McGill University, Montreal, Quebec, Canada

Corresponding Author:
Mona Loutfy, Women's College Research Institute, Women's College Hospital, 76 Grenville Street, Toronto, Ontario, Canada M5S 1B2.
Email: mona.loutfy@wchospital.ca

What Do We Already Know about This topic?

It is well reported that transition from pediatric to adult care is a challenging experience for youth living with many chronic illnesses, including HIV, resulting in poor clinical outcomes in early adulthood.

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.

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.[1] Like others living with HIV, they now have the potential for long, healthy lives. However, research and clinical observations suggest that children living with HIV are facing challenges as they age into adulthood. These challenges range from typical age-associated experiences that may be complicated by HIV to the more complex medical realities of being an adult living with HIV.[2-4]

This bridging between being a pediatric patient to a consumer of adult health services is called transition. Transition research has garnered growing attention in recent years across various congenital and chronic diseases that affect children. Simply put, transition researchers have found that transition is hard. It is often associated with increased morbidity, mortality, high rates of loss to follow-up, and nonretention in care, even among those who were highly engaged as pediatric patients.[5-9] Transition studies in youth living with HIV have found that inadequate preparation for transition can result in loss to follow-up and combination antiretroviral therapy (cART) nonadherence. This in term precipitates negative health outcomes, including HIV viral resistance, immunologic dysfunction, increased likelihood of secondary HIV transmission, and, in some cases, premature death.[10-12] A well-planned and coordinated transition process, combined with strong support,[13,14] can contribute to youth living with HIV successfully assuming adult roles, independently managing their HIV, and optimizing their health and well-being.[11]

In Canada, hospital-based, multidisciplinary medical teams almost exclusively manage pediatric HIV, with pediatric infectious disease specialists leading the medical management of HIV. The medical teams also include nurses, social workers, developmental psychologists, neurodevelopmental experts, and other pediatric providers. This care occurs in family-centered environments, is flexible, and responsive to the family's needs. While pediatric HIV care in Canada is fairly homogenous, adult care environments can range from similar hospital-based, multidisciplinary teams led by adult infectious diseases specialists to community-based care by general practitioners with expertise in HIV, community-based infectious diseases specialists and other integrated care settings (such as Oak Tree Clinic in Vancouver which provides both adult and pediatric care in one clinic). There is heterogeneity in the types of services available, the nature of care provided, and the level of support in each setting.

While pediatric HIV remains rare in Canada, the Canadian pediatric HIV cohort is maturing. As of 2012, there were 202 youth living with HIV in Canada who had transitioned to adult care and another 269 still in pediatric care, of whom half were expected to transition between 2013 and 2017.[15] Despite growing literature on pediatric HIV transition, little work has focused on sex- and gender-based factors that may intersect with transition success.

Given that adult women living with HIV have sex- and gender-based care needs, it is reasonable to suggest that transition may also require tailoring for women and girls. We know that for many young women, the period of late adolescences and young adulthood is a critical time of social vulnerability and biological changes. Because many young women living with HIV already face structural barriers to achieving optimal health,[16] it is imperative that researchers begin to examine correlates and hopefully predictors of a successful transition to adult HIV care. Using a subset of participants from a large Canadian cohort study of women living with HIV, we aimed to explore factors (1) affecting the transition preparedness of young women who acquired HIV in childhood and (2) impacting young women's perspectives on the quality of their adult HIV care providers. We also collected information on participants' age at transition, opinions on the ideal age to transition, important topics to be discussed prior to transition, and satisfaction with location of adult provider.

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.[17] CHIWOS employs a community-based research approach and is guided by the frameworks of critical feminism, antioppression, intersectionality, and social justice.[18]

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 χ^2 test or Fisher exact test for categorical variables and Wilcoxon rank for continuous variables. We also compared the transition experience between provinces using χ^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	
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 (n = 42)	
<20K	26 (62%)
20-40K	10 (24%)
>40K	6 (14%)
Age at HIV diagnosis (n = 41)	
≤9 years old	31 (76%)
≥10 years old	10 (24%)
HIV risk factors (n = 47)	
Perinatal exposure	38 (81%)
Blood transfusion/medical procedure	5 (11%)
Other	4 (8%)
Recent CD4 count[b] (n = 36)	
>500	25 (69%)
200-500	9 (25%)
<200	2 (6%)
Recent viral load[b]	
Undetectable	42 (88%)
Detectable	6 (13%)
Time since transition, years (n = 39)	
≤3	8 (21%)
4-7	21 (54%)
≥8	10 (26%)
Previous consensual sex (n = 47)	40 (85%)
Age of sexual debut[c] (n = 38)	17 (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.

[a] Variables 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 (%).

[b] Recent CD4$^+$ count (cells/mm^3) and viral load ($\log_{10}$ copies/mL) refers to self-reported values closest to the time of the survey.

[c] Women who have previously had consensual sex.

prepared for transition ($P = .005$). All factors associated with perception of adult HIV care since transitioning are presented in Table 3.

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
≤19	Ref		
20-24	0.16	0.02-1.52	
≥25	0.13	0.01-1.24	
Ethnic background			
White/Caucasian	Ref		.286
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
≤9 years old	Ref		
≥10 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]			
>500	Ref		.033
200-500	0.09	0.01-0.56	
<200	0.32	0.02-5.85	
Recent viral load[c]			
Undetectable	Ref		.166
Detectable	0.28	0.05-1.7	
Time since transition, years (n = 39)			
≤3	Ref		.865
4-7	0.8	0.15-4.26	
≥8	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]			
Better	Ref		.084
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.

Table 3. Univariate Analyses of Covariates of Perception of Adult HIV Care.[a]

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				
≤9 years old	29	25 (86%)	4 (14%)	.613
≥10 years old	9	7 (78%)	2 (22%)	
Most recent CD4, cells/mm^3				
<200	2	1 (50%)	1 (50%)	.021
200-500	9	7 (78%)	2 (22%)	
>500	21	21 (100%)	0 (0%)	
Most recent HIV viral load				
Undetectable (<50/mL[b])	38	33 (87%)	5 (13%)	.238
Detectable (>50/mL)	6	4 (67%)	2 (33%)	
Primary adult HIV care provider				
Family physician/general practitioner	4	2 (50%)	2 (50%)	.002
Infectious disease specialist	36	33 (92%)	3 (8%)	
Other specialist	2	0 (0%)	2 (100%)	
Pediatric HIV care prepared for adult care				
Yes	25	24 (96%)	1 (4%)	.005
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/mm^3) and viral load ($\log_{10}$ copies/mL) refer to self-reported values closest to the time of the survey.

[b] 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.

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.[20] 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,[4,13,14,21,22] it appears that complex social circumstances will impede

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.

[a] N = 48.

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 study[27] 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 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,[30,31] 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[4,22,27] and facing ongoing challenges with independent management of their HIV following transition.[4,10] Given lower adherence rates continued to be reported among women with HIV in general,[32] 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,[4,14,25,28,33] it is imperative to prioritize these topics and individualize transition preparation using tools to ensure optimal preparedness.[22,25] Previous reports demonstrate adolescents commonly need assistance understanding HIV disease, medications, disclosure, and where to seek help when they are sick.[14,28,34,35] 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,[33] 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.[25,26,29] 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[27] 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.[26,27,36,37] 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.[38] 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.[39]

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 supports 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.

Authors' Note

CHIWOS Research Team: *British Columbia:* Aranka Anema (University of British Columbia), Denise Becker (Positive Living Society of British Columbia), Lori Brotto (University of British Columbia), Allison Carter (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Claudette Cardinal (Simon Fraser University), Guillaume Colley (British Columbia Centre for Excellence in HIV/AIDS), Erin Ding (British Columbia Centre for Excellence), Janice Duddy (Pacific AIDS Network), Nada Gataric (British Columbia Centre for Excellence in HIV/AIDS), Robert S. Hogg (British Columbia Centre for Excellence in HIV/AIDS and Simon Fraser University), Terry Howard (Positive Living Society of British Columbia), Shahab Jabbari (British Columbia Centre for Excellence), Evin Jones (Pacific AIDS Network), Mary Kestler (Oak Tree Clinic, BC Women's Hospital and Health Centre), Andrea Langlois (Pacific AIDS Network), Viviane Lima (British Columbia Centre for Excellence in HIV/AIDS), Elisa Lloyd-Smith (Providence Health Care), Melissa Medjuck (Positive Women's Network), Cari Miller (Simon Fraser University), Deborah Money (Women's Health Research Institute), Valerie Nicholson (Simon Fraser University), Gina Ogilvie (British Columbia Centre for Disease Control), Sophie Patterson (Simon Fraser University), Neora Pick (Oak Tree Clinic, BC Women's Hospital and Health Centre), Eric Roth (University of Victoria), Kate Salters (Simon Fraser University), Margarite Sanchez (ViVA, Positive Living Society of British Columbia), Jacquie Sas (CIHR Canadian HIV Trials Network), Paul Sereda (British Columbia Centre for Excellence in HIV/AIDS), Marcie Summers (Positive Women's Network), Christina Tom (Simon Fraser University, BC), Clara Wang (British Columbia Centre for Excellence), Kath Webster (Simon Fraser University), Wendy Zhang (British Columbia Centre for Excellence in HIV/AIDS). *Ontario:* Rahma Abdul-Noor (Women's College Research Institute), Jonathan Angel (Ottawa Hospital Research Institute), Fatimatou Barry (Women's College Research Institute), Greta Bauer (University of Western Ontario), Kerrigan Beaver (Women's College Research Institute), Anita Benoit (Women's College Research Institute), Breklyn Bertozzi (Women's College Research Institute), Sheila Borton (Women's College Research Institute), Tammy Bourque (Women's College Research Institute), Jason Brophy (Children's Hospital of Eastern Ontario), Ann Burchell (Ontario HIV Treatment Network), Allison Carlson (Women's College Research Institute), Lynne Cioppa (Women's College Research Institute), Jeffrey Cohen (Windsor Regional Hospital), Tracey Conway (Women's College Research Institute), Curtis Cooper (Ottawa Hospital Research Institute), Jasmine Cotnam (Women's College Research Institute), Janette Cousineau (Women's College Research Institute), Marisol Desbiens (Women's College Research Institute), Annette Fraleigh (Women's College Research Institute), Brenda Gagnier (Women's College Research Institute), Claudine Gasingirwa (Women's College Research Institute), Saara Greene (McMaster University), Trevor Hart (Ryerson University), Shazia Islam (Women's College Research Institute), Charu Kaushic (McMaster University), Logan Kennedy (Women's College Research Institute), Desiree Kerr (Women's College Research Institute), Gladys Kwaramba (Women's College Research Institute), Lynne Leonard (University of Ottawa), Johanna Lewis (Women's College Research Institute), Carmen Logie (University of Toronto), Shari Margolese (Women's College Research Institute), Marvelous Muchenje (Women's Health in Women's Hands), Mary (Muthoni) Ndung'u (Women's College Research Institute), Kelly O'Brien (University of Toronto), Charlene Ouellette (Women's College Research Institute), Jeff Powis (Toronto East General Hospital), Corinna Quan (Windsor Regional Hospital), Janet Raboud (Ontario HIV Treatment Network), Anita Rachlis (Sunnybrook Health Science Centre), Edward Ralph (St. Joseph's Health Care), Sean Rourke (Ontario HIV Treatment Network), Sergio Rueda (Ontario HIV Treatment Network), Roger Sandre (Haven Clinic), Fiona Smaill (McMaster University), Stephanie Smith (Women's College Research Institute), Tsitsi Tigere (Women's College Research Institute), Wangari Tharao (Women's Health in Women's Hands), Sharon Walmsley (Toronto General Research Institute), Wendy Wobeser (Kingston University), Jessica Yee (Native Youth Sexual Health Network), Mark Yudin (St-Michael's Hospital). *Quebec:* Dada Mamvula Bakombo (McGill University Health Centre), Jean-Guy Baril (Université de Montréal), Marc Boucher (CHU Ste-Justine), Isabelle Boucoiran (CHU Ste-Justine), Nora Butler Burke (University Concordia), Pierrette Clément (McGill University Health Center), José Côté (Centre Hospitalier de L'Université de Montréal), Janice Dayle, (McGill University Health Centre), Danièle Dubuc, (McGill University Health Centre), Mylène Fernet (Université du Québec à Montréal), Marilou Gagnon (University of Ottawa), Danielle Groleau (McGill University), Aurélie Hot (COCQ-SIDA), Maxime Kiboyogo (McGill University Health Centre), Marina Klein (McGill University Health Centre), Gary Lacasse (Canadian AIDS Society), Valérie Lamarre (CHU Ste-Justine), Carrie Martin (Native Women's Shelter of Montreal), Lyne Massie, (Université de Québec à Montréal), Brigitte Ménard, (McGill University Health Centre), Ken Monteith (COCQ-SIDA), Nadia O'Brien (McGill University), Joanne Otis (Université du Québec à Montréal), Doris Peltier (Canadian Aboriginal AIDS Network), Alie Pierre, (McGill University Health Centre), Karène Proulx-Boucher (McGill University Health Centre), Danielle Rouleau (Centre Hospitalier de l'Université de Montréal), Geneviève Rouleau (Centre Hospitalier de l'Université de Montréal), Édénia Savoie (McGill University Health Centre), Cécile Tremblay (Centre Hospitalier de l'Université de Montréal), Benoit Trottier (Clinique l'Actuel), Sylvie Trottier (Centre Hospitalier Universitaire de Québec), Christos Tsoukas (McGill University Health Centre). *Other Canadian provinces or international jurisdictions:* Jacqueline Gahagan *(Dalhousie University)*, Catherine Hankins *(University of Amsterdam)*, Renee Masching (*Canadian Aboriginal AIDS Network)*, Susanna Ogunnaike-Cooke (*Public Health Agency of Canada)*. All other CHIWOS Research Team Members wish to remain anonymous.

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ORCID iD

Victoria Logan Kennedy https://orcid.org/0000-0002-7478-8596

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