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Experiences and resultant care gaps among women with HIV in Canada: Concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Findings

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Keywords:	HIV & AIDS < INFECTIOUS DISEASES, Health Equity, Patient-Centered Care, QUALITATIVE RESEARCH

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Experiences and resultant care gaps among women with HIV in Canada: Concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Findings

Abstract

Objectives: The community-based, longitudinal, Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), explored the experiences of women living with HIV in Canada over the past decade. CHIWOS' high impact publications document significant gaps in the provision of health care to women living with HIV. We used concept mapping to analyse and present a summary of CHIWOS findings on women's experiences navigating these gaps.

Design: Concept mapping procedures were performed in two steps. First, two reviewers (AY and PM) independently reviewed CHIWOS manuscripts and conference abstracts written before 1 August 2019 to identify main themes and generate individual concept maps. Next, the preliminary results were presented to national experts, including women living with HIV, to consolidate findings into an overall visual summarizing the experiences and care gaps of women living with HIV in CHIWOS.

Setting: British Columbia, Ontario and Quebec, Canada.

Participants: Healthcare professionals who care for people living with HIV, researchers, and cis-gender and transgender women living with HIV.

Results: Overall, a total of 59 peer-reviewed articles and conference abstracts met the inclusion criteria. Using concept mapping, themes were generated and structured through online meetings. In total, six concept maps were co-developed: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women's health. Two summary diagrams were created, one for all women and one specific to trans

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women. Resilience, social support, positive healthy actions, and women-centred HIV care were highlighted as strengths leading to well-being for women with HIV.

Conclusions: Concept mapping resulted in a composite summary of 59 peer-reviewed CHIWOS papers. This activity will allow for priority setting of positive actions for optimizing care and well-being for women with HIV.

Keywords: HIV, women's health, healthcare systems, care gaps, concept mapping

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Strengths and limitations of this study (Article Summary)

- The study comprehensively summarizes the health experiences of women with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) and identifies potential gaps in their care.
- A diverse group of women living with HIV experts across Canada took part in this study to provide feedback on the concept maps which used results from 59 peer-reviewed publications by, with and for women living with HIV.
- The process of concept mapping and reviewing visualizations with key informants occurred from June 2019 to March 2021, hence no later data could be included in the summarization of key CHIWOS publication findings.
- This is the first study to explore a composite of the findings from CHIWOS manuscripts and conference abstracts using the methodology of collaborative concept mapping.

Background

Recent studies have found that women living with HIV experience unique health and social needs that differ from those of men living with HIV and limit their access to treatment and care services.[1-3] The historical lack of research focusing on the realities of women living with HIV is potentially detrimental to the health of women.[4,5] These circumstances led to the development and implementation of the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) – the largest community-based study in Canada exploring the experiences and priorities of a diverse,

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national cohort of women living with HIV in British Columbia (BC), Ontario (ON), and Quebec (QC) from 2011-2021.

CHIWOS was initiated in 2011 through a qualitative phase, which informed the creation of an in-depth survey.[1,2] The study's objectives were to examine women's access to women-centred HIV care and the impact of corresponding patterns of use on health outcomes.[2] CHIWOS was guided by principles of equitable involvement of those affected *by* the research *in* the research process by establishing community-academic partnerships and shared decision-making throughout the study.[6,7] This research approach, reflecting community-based research (CBR) approaches, was enacted in part through the involvement of women living with HIV as trained community researchers in each stage of the research.[2,8,9] CHIWOS was created by, with, and for women living with HIV in collaboration with academic researchers, clinicians, and community partners to investigate women's mental, sexual and reproductive health care priorities, and need for a women-centred HIV care model.[1,2,10] Cohort data collection was launched in 2013 in three Canadian provinces (BC, ON, QC). Survey data were collected at three-time points, 18 months apart, from August 2013 to September 2018. A complete description of CHIWOS can be found at www.chiwos.ca. CHIWOS remains the largest longitudinal study of women with HIV in Canada, successfully enrolling a diverse cohort of 1,422 women with HIV (356 from BC [25%], 713 from ON [50%], and 353 from QC [25%]).[1,2]

As of August 2019, our team, including women living with HIV, produced 116 publications (53 articles and 60 conference abstracts) using CHIWOS data. This academic content explores dozens of specific topics related to the experiences of women living with HIV, including psychosocial determinants, clinical, mental, sexual,

reproductive health outcomes, access to, and quality of healthcare that characterize women's health gaps and needs and that can be used to inform programming and policy in Canada. In an effort to better understand the main topics and gaps of CHIWOS manuscripts and conference abstracts, this study applied a form of concept mapping used in education, as according to Novak and Gowin (1984).[11] The goal of this methodology was to visualize concepts of CHIWOS findings in a hierarchical fashion, with the most inclusive and general concepts at the top of the map, and specific concepts arranged hierarchically below to represent the inter-related relationships in each publication included. We sought to apply these findings towards the creation of a summary diagram to summarize the health experiences and gaps of women living with HIV enrolled in CHIWOS. An added benefit of using concept mapping in this study is that the simplistic visualizations allow for increased accessibility of the CHIWOS findings to those outside of academia, including community members and knowledge users. Our goal was to use these findings to characterize women living with HIV's healthcare needs and gaps to inform policy and programming in Canada.

Methods

Concept mapping is a graphical methodology used to organize and present knowledge. Since its conception by Novak (1974)[12], it has been adapted in education as a learning tool to capture expert knowledge and in qualitative research to present findings and analyse themes.[13,14] This methodology was chosen to illustrate the key themes from the CHIWOS publications, including both manuscripts and conference abstracts, and their relation to each other in order to demonstrate the experiences and related gaps in care women living with HIV face in Canada. Understanding the intersectional complexity

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of the data, a social-ecological perspective was applied to further understand the interplay between multi-level factors of women living with HIV, their community, and society.[15-17]

For this study, the concept mapping process from Novak (1998)[18] was used to encompass five steps:

Step 1: Conduct a thematic analysis on CHIWOS publications and summarize key findings

All CHIWOS publications (including manuscripts and conference abstracts) published, under review, or near publication submission before 1 August 2019 were examined alongside inclusion criteria developed by the core concept team (including AY, MK, ML, and PM). To be included for review, publications were to 1) include national quantitative CHIWOS questionnaire data, and/or 2) be published, under review or near submission in a peer-reviewed journal. Publications that included qualitative CHIWOS data, utilized only provincial data, were process or methods pieces, or were in-press were excluded. Figure 1 shows the selection process. A total of 116 CHIWOS publications (including articles and conference abstracts) were reviewed of which 57 were excluded. This resulted in 59 eligible publications that met the inclusion criteria (summarized in Table 1). Eligible publications were grouped together by theme and discussed further in step 3.

[insert Figure 1 here]

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Table 1: Summary of Included CHIWOS Publications

Concept Map Theme	Manuscript Citation (n=44)	Abstract Citation (n=15)
Quality of life	n=4	
	Logie, Wang et al. 2018 Carter, Loutfy et al. 2018 Kteily-Hawa, Andany et al. 2019 Kteily-Hawa, Warren et al. 2019	
HIV care	n=8	n=4
	Kennedy, Mellor et al. 2020 Kerkerian, Kestler et al. 2018 Kronfli, Lacombe-Duncan et al. 2017 Kronfli, Lacombe-Duncan et al. 2017 Logie, Wang et al. 2018 Loutfy, de Pokomandy et al. 2017 O'Brien, Godard-Sebillotte et al. 2019 Shokoohi, Bauer et al. 2019	Conway, Gormley et al. 2019 Kaida, Conway et al. 2019 Loutfy, de Pokomandy et al. 2015 Puskas, Pick et al. 2018
Psychosocial & mental health	n=14	n=4
	Carter, Roth et al. 2018 Churchill. 2018 Gormley, Nicholson al. 2021 Heer, Kaida et al. 2022 Jaworsky, Logie et al. 2018 Logie, Lacombe-Duncan et al. 2018 Logie, Marcus et al. 2019 Logie, Wang et al. 2018 Logie, Williams et al. 2019 Patterson, Nicholson et al. 2020 Shokoohi, Bauer et al. 2018 Shokoohi, Bauer, Kaida et al. 2019 Shokoohi, Bauer et al. 2019 Wagner, Jaworsky et al. 2018	Kaida, Nicholson et al. 2019 Logie, Wang et al. 2019 Parry, Lee et al. 2019 Underhill, Wu et al. 2018
Sexual health	n=8	n=2
	Carter, Greene et al. 2018 Carter, Greene, Money et al. 2018 Carter, Greene et al. 2019 Carter, Patterson et al. 2020 de Pokomandy, Burchell et al. 2019 Kaida, Carter et al. 2015	Salters, Loutfy et al. 2015 Underhill, Kennedy et al. 2017

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	Logie, Kaida et al. 2020 Patterson, Carter et al. 2017	
Reproductive health	n=6	n=4
	Andany, Kaida et al. 2020 Fortin-Hughes, Proulx-Boucher et al. 2019 Kaida, Patterson et al. 2017 Salters, Loutfy et al. 2017 Skeritt L, de Pokomandy et al. 2021 Valiaveetil, Loutfy et al. 2019	Boucoiran, Kaida et al. 2019 Kaida, Gormley et al. 2019 Kaida, Money et al. 2017 Siou, Salters et al. 2016
Trans women living with HIV	n=4	n=1
	Lacombe-Duncan, Bauer et al. 2019 Lacombe-Duncan, Newman et al. 2017 Lacombe-Duncan, Warren et al. 2021 Logie, Lacombe-Duncan et al. 2018	Lacombe-Duncan, Persad et al. 2017

See Supplementary 1 for included publications citations.

From the 59 included manuscripts and conference abstracts, we began by identifying the major findings of each that answered the guiding question: what are the experiences among women living with HIV who participated in CHIWOS regarding their psychosocial determinants, clinical, mental, sexual and reproductive health outcomes and access to and quality of healthcare that characterize their healthcare gaps and needs and that can be used to inform policy and programming in Canada? We then used the coding step of a thematic analysis[19] to code the findings into their simplest form (e.g., lower food security is associated with increased substance use). As a last step, we listed the concepts and linking words within each code (e.g., concepts = lower food security, substance use; linking words = is associated with).[19] This process was repeated for each manuscript and conference abstract.

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Step 2: Individual concept mapping of CHIWOS manuscripts and abstracts

The concepts and linking words from Step 1 were used to guide the design of 59 individual concept maps, each visually summarizing the key findings of one manuscript or conference abstract. Figure 2 is an example of one of the individual concepts we created from the CHIWOS findings.

[insert Figure 2 here]

Within each map, concepts were listed in hierarchical order with the most overarching general concepts at the top and the most specific concepts at the bottom.[11] Using an online software, CMAPTools[20], concepts were designated by boxes and lines were drawn from one concept to another with the linking words placed in between. An arrowhead guided the direction of the relationship between the two concepts. We adapted the concept map process by adding in extra features that better visually represent the CHIWOS findings. For example, arrowheads pointed towards outcomes of CHIWOS findings. Bi-directional arrows were used when a relationship was present between two outcomes. Solid lines represented a positive association between concepts while dotted lines represented a negative association between concepts. Concepts that recurred in two or more individual concept maps were considered critical findings and were designated by a blue shaded concept box.

AY and PM independently reviewed each concept map to ensure all major findings were represented and summarized into the visual. If there was a discrepancy, a third reviewer (ML) was consulted to make the final decision.

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Step 3: Compilation of individual concept maps into composite concept maps

AY, PM, and ML grouped the maps with main concepts with similar themes together. Six major themes were identified: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women living with HIV.

The individual concept maps that fell under each major theme were compiled together to create a composite concept map. AY and PM drew cross-links between concepts that had relationships but were on different domains of the composite concept map.[14] This process was repeated for each theme and six composite concept maps were developed.

Step 4: Internal development team review and brainstorming of overarching visualization

An internal team (including AY, MK, ML, and PM) meeting was held in August 2019 to review all six composite concept maps. The goal was to ensure all key findings were represented on the maps with good readability. The guiding question was referred to when deciding to remove or add concepts to the map.

The team was asked to brainstorm ideas to design a compilation visual representing the findings of the six composite maps that answered our guiding research question. A preliminary sketch was formed which is now referred to as the summary diagram.

Step 5: External expert team review and validation

The first author of each included CHIWOS manuscript and conference abstract (herein referred to as lead investigators), and all CHIWOS community researchers were identified as potential key participants in this study and were approached for recruitment from October 2019 to November 2020. A total of six CHIWOS lead investigators

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representing different disciplines, and 26 community researchers from each of the three provinces were invited to participate in the study by email. A total of 29 meetings were held with groups of participants and took place both in-person and virtually.

For orientation, introductory slides explaining the concept mapping methodology and its application to CHIWOS findings were shown to the group. Each of the six composite concept maps were then presented. Lead investigators were asked to ensure that all major CHIWOS findings were accurate and present, and community researchers were asked to ensure that the experiences of women living with HIV were accurately represented. All participants were asked to provide input on the readability, clarity, and inclusivity of language. Next, the summary diagram was presented and participants were asked to ensure that all key components from the composite concept maps were included in the summary diagram, in addition to providing feedback on design features including colour, layout, and display of content. All participant feedback was documented and the feedback between different focus groups were compared. All suggestions and changes were reviewed by AY and PM through revisiting the manuscript and abstracts and addressing the guiding research question. Updated composite theme maps and the summary diagrams were presented at a follow-up meeting and consensus was reached by discussion.

The study was assessed to not require ethical approval by a human research ethics committee by the research team because the Ethical Principles for Medical Research Involving Human Subjects did not apply. Instead, participants, all of whom had been previously engaged as CHIWOS team members, were recruited on a volunteer basis. We

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obtained informed consent from all participants. Community partners were compensated for their involvement in this project.

Results

A total of 18 individuals participated in this study including six lead investigators (BC: n=1; ON: n=3; QC: n=2), and 12 community researchers (BC: n=5; ON: n=7). All participants identified as women (cis-gender and transgender). There was diverse representation across age, race, ethnicity, and gender identity demographic categories.

Composite Concept Maps

Overall, six composite maps were created (see Supplemental Figures 1-6).

We developed composite map 1 (see Supplemental Figure 1) from four manuscripts focused on the topic of quality of life. Notable findings in this concept map include bi-directional association of physical and mental health quality of life, and the association of experiences of women-centred HIV care with higher resilience and in turn higher quality of life. This map illustrates the influence socioeconomic status, experiences of stigma, sexual orientation, substance use, social support, and relationship status have on mental and physical health-related quality of life.

From eight manuscripts and four conference abstracts, map 2 (see Supplemental Figure 2) was created to illustrate findings related to HIV care. This map demonstrates associations between several aspects of HIV care including viral suppression, use of combination antiretroviral therapy (cART), care access and attrition. Notable findings include the effect social and peer support have on increasing access to HIV care and the effect of racial discrimination on care attrition. Violence in adulthood was found to reduce cART use and adherence, leading to reduced viral suppression. On the other hand,

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peer leadership involvement was associated with higher awareness of cART prevention benefits.

Map 3 (see Supplemental Figure 3) demonstrates the connections between various facets of psychosocial and mental health and represents data from 14 manuscripts and four abstracts. Indigenous heritage was associated with higher violence in adulthood as well as lower housing security and income. Food security was associated with higher substance use. This map emphasizes the impact of intersectional stigma on all aspects of mental health, which are associated with clinical measures like cART initiation.

The most complex of the six visuals is map 4 (see Supplemental Figure 4) which explores sexual health experiences of women enrolled in CHIWOS. This map represented data from eight manuscripts and two abstracts. Its findings were organized into social and medical aspects of sexual health sub-categories. A main finding was the association of higher depression and violence in adulthood with lower pleasure and satisfaction in relationships. Higher HIV-related stigma was also associated with higher sexual inactivity in the past six months, which was a recurring theme to emerge in the included publications.

The fifth map (see Supplemental Figure 5) showed CHIWOS findings related to reproductive health. The production of this map as separate from sexual health was intentional to illustrate that for many women, sexual health goes beyond reproductive health desires or lack thereof. This map drew on data from six manuscripts and four abstracts, and includes sub-categories of menstruation, pregnancy, contraceptive use, and early menopause. Findings showed low use of a narrow range of contraceptive methods, with sexual orientation, previous pregnancies, and age influencing contraceptive choice.

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Service provider counselling on choices for feeding practices, infant feeding support and free formula programs were associated with positive infant feeding experiences for women.

The final map titled trans women concept map (see Supplemental Figure 6) included topics from all five of the other concept maps from the exclusive perspective of trans women in CHIWOS, with data drawn from four manuscripts and one abstract that solely analyzed trans women's data. This map shows trans women's experiences of gender discrimination and transphobia, which influence barriers to gender affirming and general HIV care, with HIV-related stigma playing a significant role in this association. Higher sexual relationship power was associated with lower depression/PTSD symptoms. Higher social support was associated with resilience, which trans women experienced higher levels of than cis women in CHIWOS.

Summary Diagrams

Community partners engaged in arts-based design of the two summary diagrams. It was important to the community partners that the visuals were rooted in the stories and experiences of CHIWOS participants, and its elements were accessible, empowering, holistic, authentic, and inclusive. These were the words community partners used in our meetings together while co-developing the figures.

From the six composite concept maps, two summary diagrams were created (see Figures 3 and 4), one for all women and one for trans women in collaboration with the three CHIWOS lead investigators and 26 community researchers who participated in the study. A total of 29 meetings were held to create these visuals. These diagrams provide a summary of the key insights, barriers, and supports that affect the health and well-being

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of women living with HIV involved in CHIWOS. From the 59 publications and six composite concept maps, it was found that a socio-ecologic model was appropriate to show how individual, societal, and structural factors affect women's health and well-being.[11-13] As a result, the diagram was created in the shape of concentric circles. At the centre of both visuals is a speaking bubble highlighting the stories that women who participated in CHIWOS shared and was named by the team's Indigenous Elder (VN): "Honouring Their Voices." The inner circle of both figures highlights the aspects that are important to women's quality of life: HIV health, general health including physical, health, sexual and reproductive health, mental health, violence and trauma, substance use, culture and spirituality, and resilience. Surrounding quality of life are social factors that combine to affect the health of individuals and their communities, such as housing stability, food security, income, and social isolation. The outer circle consists of the structural factors that affect health including HIV-related stigma, and gender and racial discrimination. Intersecting these layers of the women's health experiences are the important ways women are addressing barriers in their lives, including social support, accessing, or calling to action the need for women-centred HIV care (WCHC), and positive healthy actions.

[insert Figure 3 here]

Through consultations with trans women on the composite maps, the second summary diagram (see Figure 4) was created to reflect the most important and recurring findings of the concept mapping exercise as they relate to the experiences of trans women with HIV involved in CHIWOS. The main difference from Figure 3 is the addition of gender affirmation in the inner circle in reference to trans women's experiences.

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Community researchers define gender affirmation whereby an individual receives the affirmation they desire from those around them, including social recognition and/or medical access to hormone therapy and gender-affirming surgeries.

[insert Figure 4 here]

These figures show that there are both commonalities and differences in the experiences of women living with HIV; however, resilience was present among all CHIWOS participants.

With meeting facilitation support from The Public Studio, an activist design studio in Toronto (https://thepublicstudio.ca/), we identified that community partners wanted a sun to be a theme of the visuals that radiates energetically from the centre of the diagram and a strength-based title as the "Wheel of Resilience and Support." It was important to the community partners that the visuals serve as an invitation to translate the stories of CHIWOS participants into action.

Discussion

The six composite concept maps and two summary diagrams encapsulate the work conducted by the CHIWOS team over the past decade. They culminated into a mosaic of information that illustrate the health experiences of women living with HIV in Canada. The socio-ecologic model applied to the summary diagrams well describe these experiences. [11-13]

A recurring theme in the concept maps and summary diagrams was the lack of receipt of comprehensive WCHC,[28] including lack of discussion of reproductive goals, and decreased access to care like gender affirmation. This finding suggests providers must improve knowledge through accessing clinical guidelines related to women living

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3 with HIV such as the Canadian HIV Pregnancy Planning Guidelines, the Guidelines for
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5 the Use of Antiretroviral Agents in Adults and Adolescents with HIV, and the British
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8 Columbia Guidelines for the Care of HIV Positive Pregnant Women & Interventions to
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10 Reduce Perinatal Transmission, and trans women living with HIV like the Sherbourne's
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12 Guidelines for Gender-Affirming Primary Care.[21-23,30] The concept maps also
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15 demonstrate the negative effects of low socioeconomic status and stigma and
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17 discrimination on women's self-reported resilience. This could impact the ability to self-
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19 advocate in healthcare settings, further affecting quality of care received. This finding has
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22 important implications to how clinicians and service providers approach care
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24 relationships and the importance of practicing from a person-centred lens.
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26 The creation of separate concept maps for cis and trans women shows the
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29 important similarities and differences between cis and trans women's experiences. Our
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31 findings show many similarities in the health experiences of cis and trans women living
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33 with HIV in CHIWOS were shared.[25] This is important for providers who often assume
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36 providing care to trans women living with HIV requires a unique skillset and approach.[26]
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38 The key differences in the summary diagrams were gender affirmation at the individual
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40 level, as well as trans care knowledge and training at the structural level. Obtaining
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43 training in trans health and gender affirmation is a manageable goal that providers can
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45 achieve to deliver more competent care to trans women living with HIV.[27]
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47 A main strength of this study is the richness of CHIWOS dataset analyses
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50 conducted over the last 10 years. This study included a large number of publications from
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52 diverse authors and perspectives, focused on several different topics and subsets of the
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54 CHIWOS participant population. This increased the reliability of the findings and
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ensured a full picture of the CHIWOS population's experiences was represented in the concept maps. Further strengthening this representation was the iterative and community-based nature of the concept mapping process itself. The process was entirely driven by a diverse group of community members who amended the maps and diagrams through several rounds of consultations, which ensured their accuracy.

In addition to the many strengths, there were some limitations of this study. Although efforts were made to engage lead investigators and community researchers from all provinces included in the CHIWOS study, only individuals from Ontario and British Columbia participated in the focus group discussions. However, six manuscripts with the first author from Quebec were included in production of concept maps. Another limitation of the study was the exclusion of qualitative manuscripts which hold rich data. A reason for this decision was the challenges in the consistency of scoring schemes needed for concept mapping, which has been highlighted in the literature.[24,28] Additionally, we recognize that given the unique perspectives of Indigenous women living with HIV, that the creation of an Indigenous-specific summary diagram would have strengthened our study. We did not create this diagram due to the lack of quantitative publications specifically focused on Indigenous women who participated in CHIWOS at the time of concept mapping analysis. In keeping with the First Nations principles of ownership, control, access and possession (OCAP)[29], the ownership of CHIWOS data from Indigenous women was transferred to Indigenous partners in through ceremony in 2017.[31] From the inception of CHIWOS, Indigenous women have prioritized community-based knowledge translation activities, including several fireside chats, gatherings and posters to share Indigenous CHIWOS findings with community over

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3 more traditional methods of academic knowledge translation outputs, such as manuscript or abstract production.[32] However, since the concept mapping interviews were held, the CHIWOS-PAW (Positive Aboriginal Women) team of Indigenous leaders published a manuscript on findings from the CHIWOS-PAW sub-study using arts-based research methods, Indigenous teachings and Ceremony, and Sharing Circles to gather Indigenous women's perspectives and experiences of their health and healthcare.[33] Another manuscript examining findings from the Indigenous women who participated in CHIWOS is forthcoming, led by Indigenous scholars.

Recently, other CHIWOS investigators used mapping techniques to examine the experiences of women living with HIV in accessing care. Skerritt et al.[34] used Fuzzy Cognitive Mapping, a participatory research method, to identify factors influencing satisfaction with HIV care in order to understand women's engagement in the HIV care cascade. Several similarities exist between our approaches to mapping. For instance, Skerritt et al.'s concept map #2 (HIV Care Concept Map) shows the relationships among access to care, comprehensive care, and feelings of stigma.[34] Our study is unique as it includes concept maps related to quality of life, psychosocial and mental health, sexual health, reproductive health, and trans women with HIV, and also provides the perspectives from women in Ontario in addition to those in Quebec and British Columbia. Both studies provide valuable visual insights into women's experiences and complement each other.

Further, the results of the concept maps identified the need for policy options and interventions to address women's health gaps and needs. The two summary diagrams demonstrate the need for prioritization of social support, leadership, and capacity-

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building for women living with HIV across all system levels. They highlight the importance of addressing intersecting social determinants of health to improve health outcomes for women living with HIV. The next steps for policy advocacy are the co-development of a national WCHC[35] strategy that ensures equitable access to care including gender affirmation, and resource creation and education to increase knowledge about the health care gaps women living with HIV experience in Canada.

Conclusion

We developed a unifying summary of the health experience of women living with HIV in Canada by applying concept mapping to 59 CHIWOS publications. The produced visuals can be used to inform policy and programming by providing easy to understand evidence on gaps related to the social determinants of health including housing, food security, and income, in addition to structural barriers such as multiple areas of discrimination. Importantly, these visuals promote strength-based approaches to women living with HIV's health and wellbeing such as increasing access to WCHC care and self-care through positive healthy actions in a way that is accessible to all audiences. The results of this study should guide future research and care priorities for women living with HIV in Canada.

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Contributions

AY, PM, MK and ML contributed to the study conception and design. AY, PM, MK, and BG contributed to the preparation, participant recruitment, and publication screening process. AY, PM, MK, and ML participated in the development of concept maps and summary diagrams. PM, JK, and ML wrote the first draft of the manuscript. PF, YP, NO, BG, BB, SS, MN, AF, BG, CC, KW, MS, AL, CL, AP, AK, and ML provided feedback and edits on all the visuals and versions of the manuscripts. All authors have read and agreed to the published version of the manuscript.

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Competing Interests: None declared.

Patient Consent: Obtained

Patient and public involvement: Patients and/or the public were involved in the design, conduct, or dissemination plans of this research. Refer to the Methods for further details.

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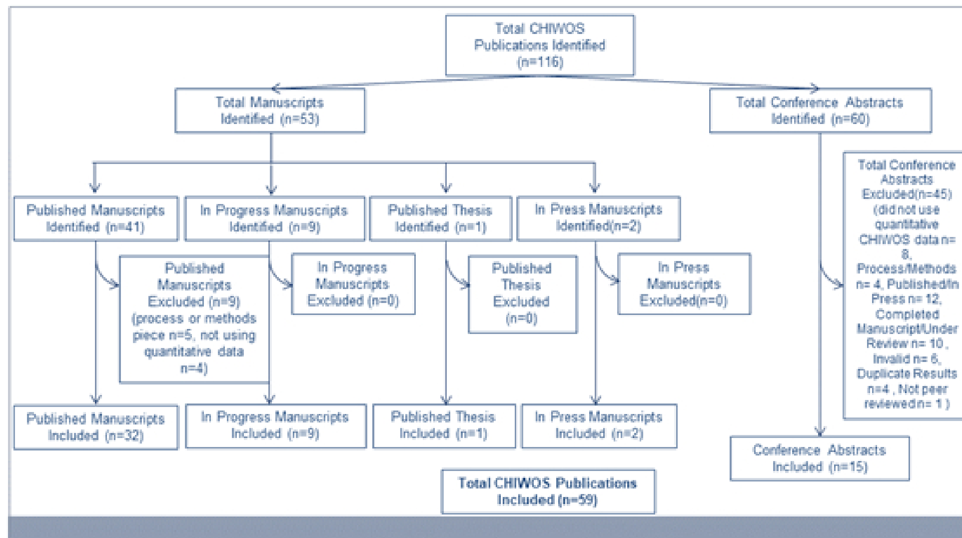

Figure 1: Applying the Eligibility Criteria to the CHIWOS Publications

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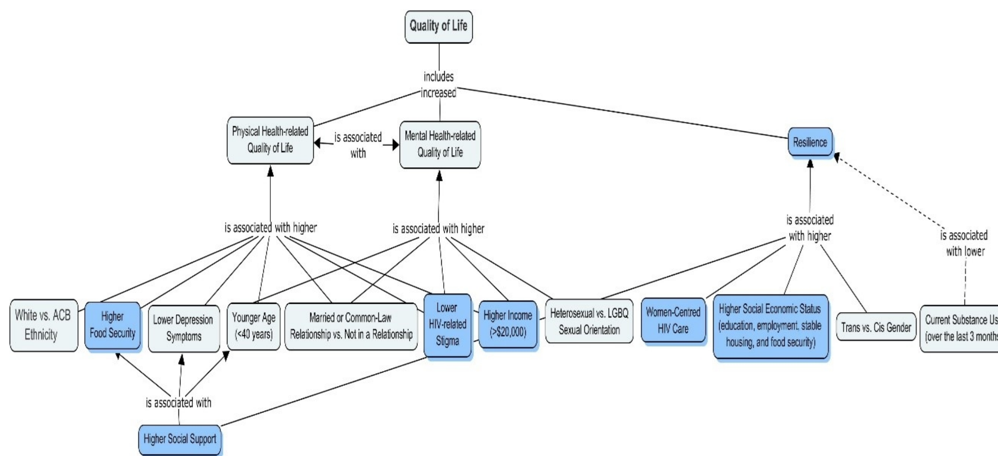

Figure 2: Quality of Life Concept Map

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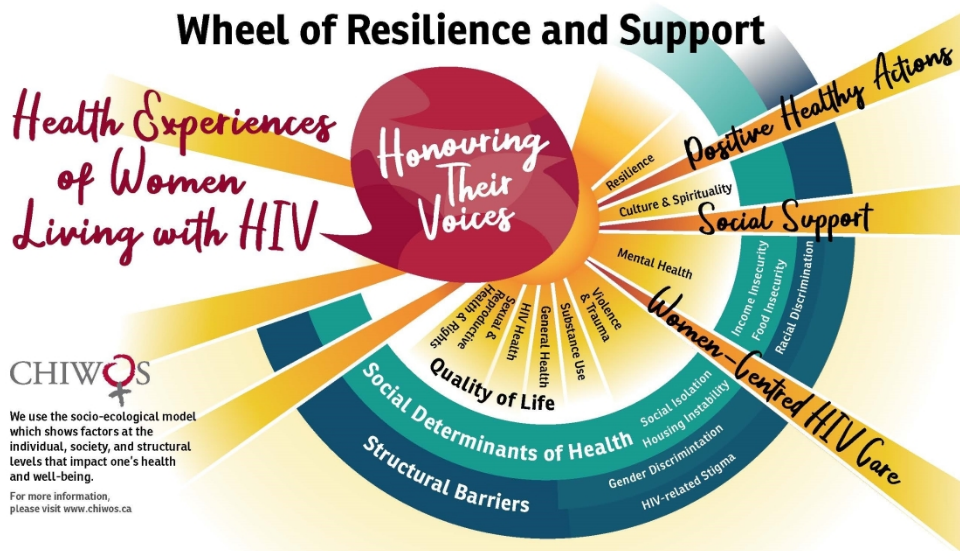

Figure 3: CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

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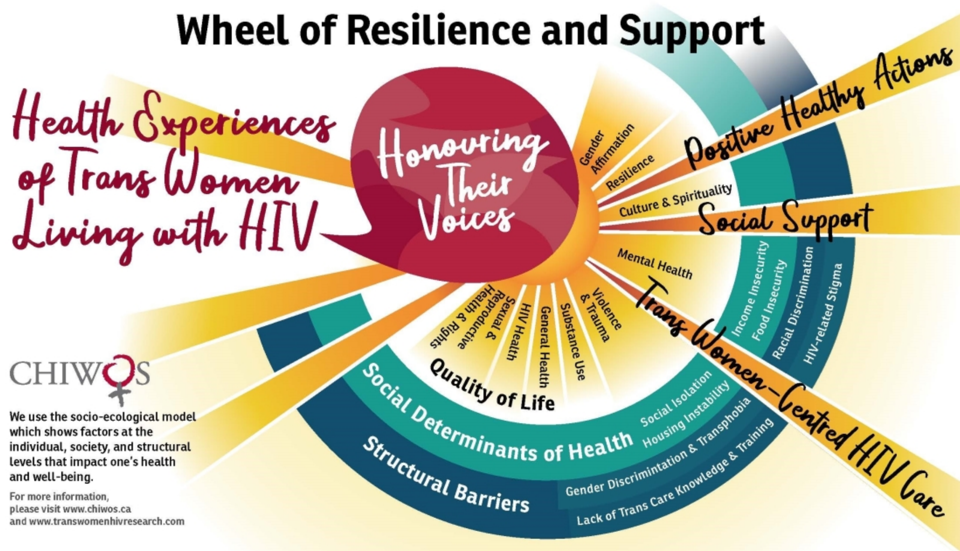

Figure 4: CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

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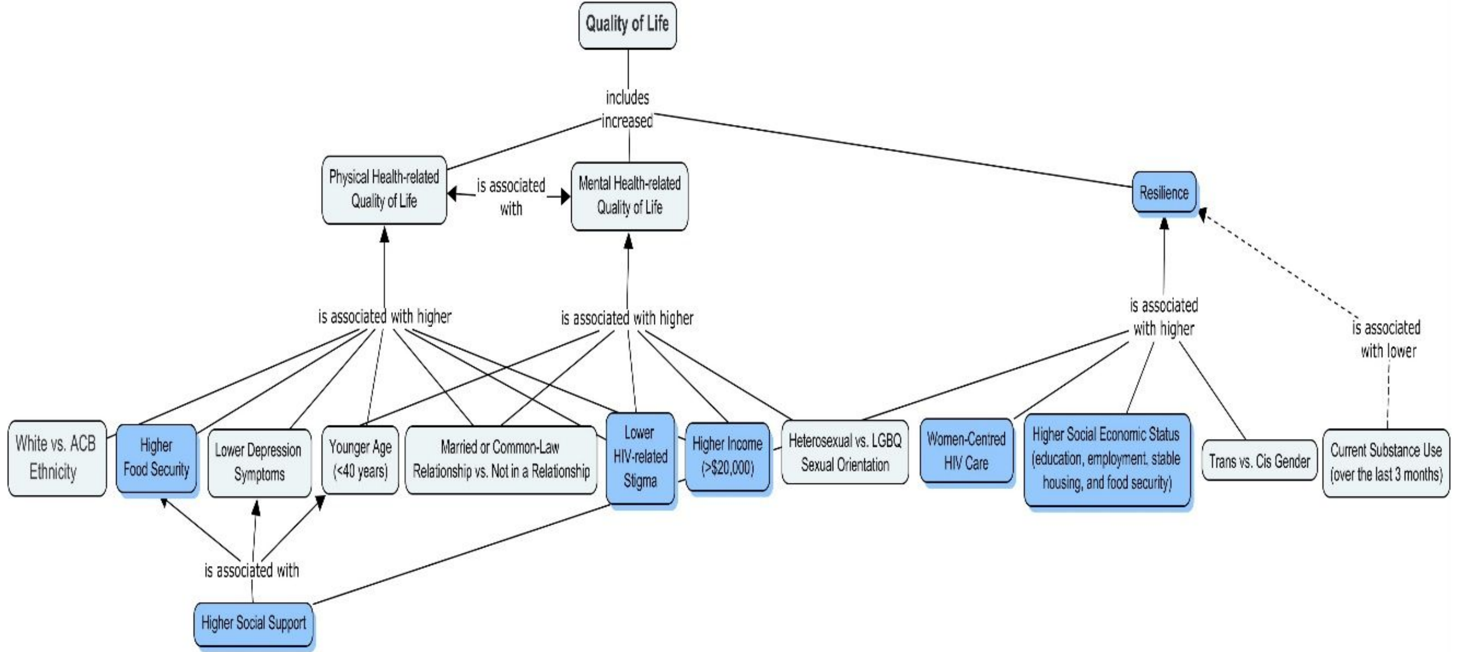
Supplementary Figures

Supplemental Figure 1: Quality of Life Concept Map



Our definition of Quality of Life (QOL) extends beyond one's physical and mental health status. It is expanded to also include QOL's relationship with resilience and overall wellbeing. QOL was measured using the SF-12 scale.

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5 **Supplemental Figure 2:** HIV Care Concept Map
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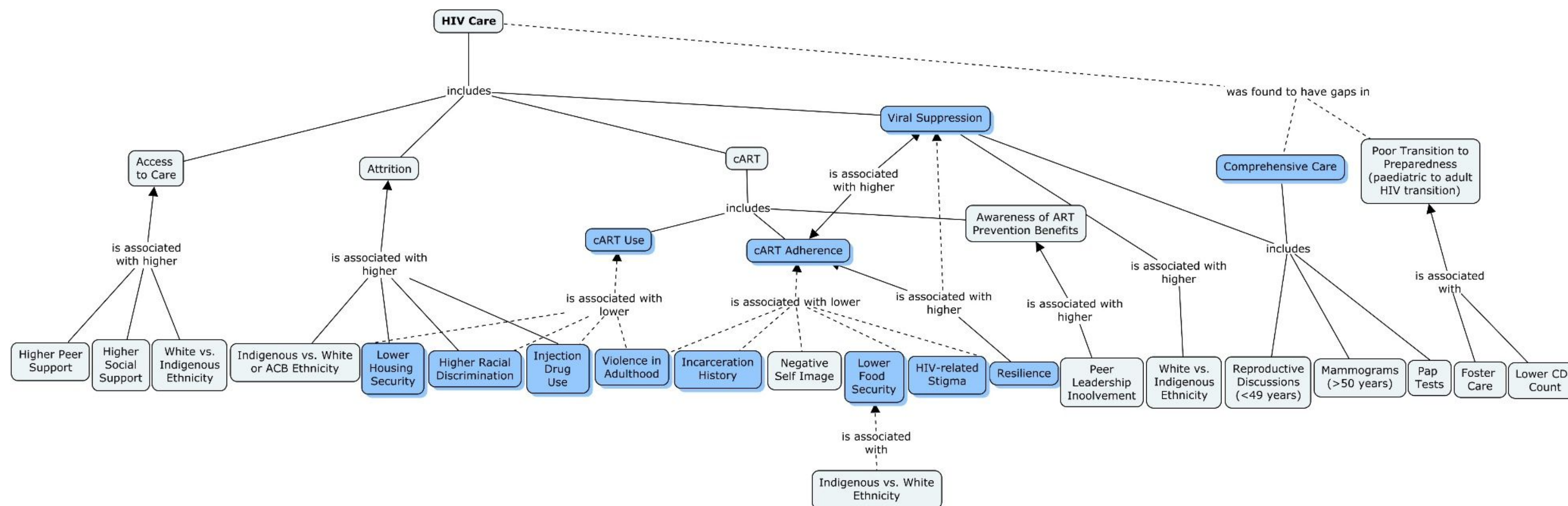

25 Attrition refers to reduction in the % at each stage of the HIV care cascade. These stages are: 1) access to care, 2) cART use, 3) cART
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27 adherence, and 4) viral suppression.
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29 Comprehensive care is defined by four indicators: Pap test, viral load suppression, reproductive discussions, and mammograms.
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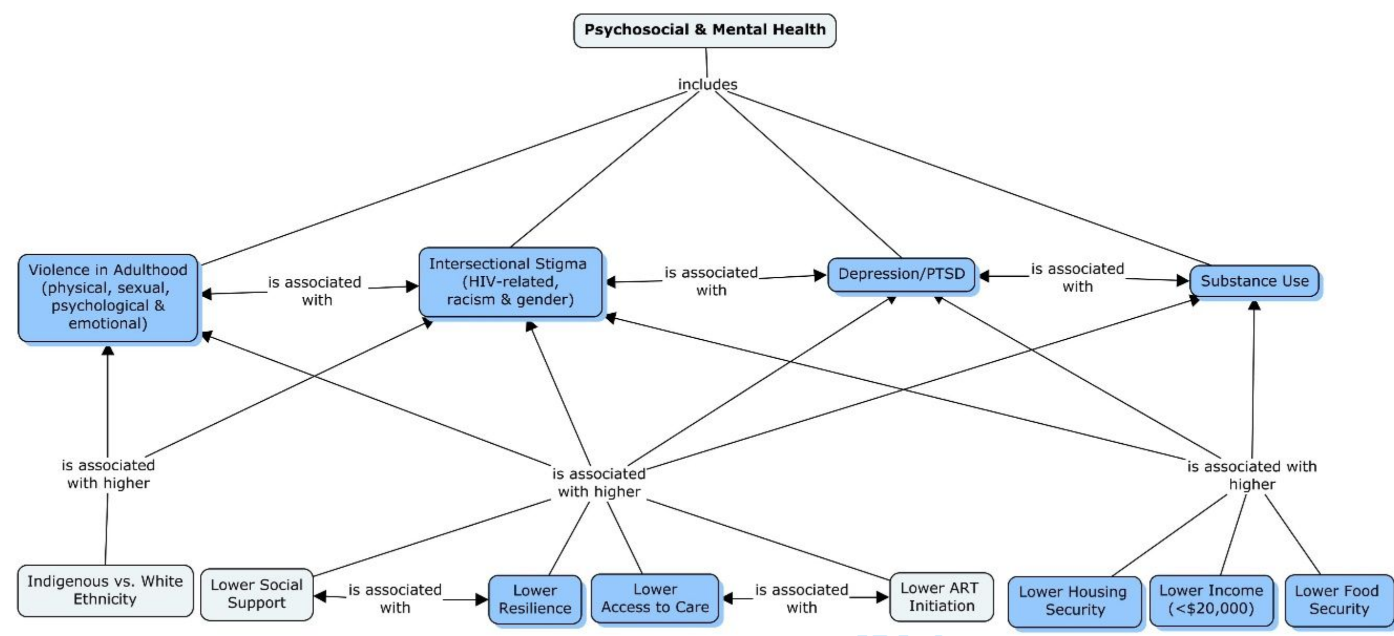
Supplemental Figure 3: Psychosocial and Mental Health Concept Map



Intersectional stigma, violence, depression/PTSD, and substance use are associated with each other. Also, access to care was measured using the Barriers to Access to Care 12-item scale.

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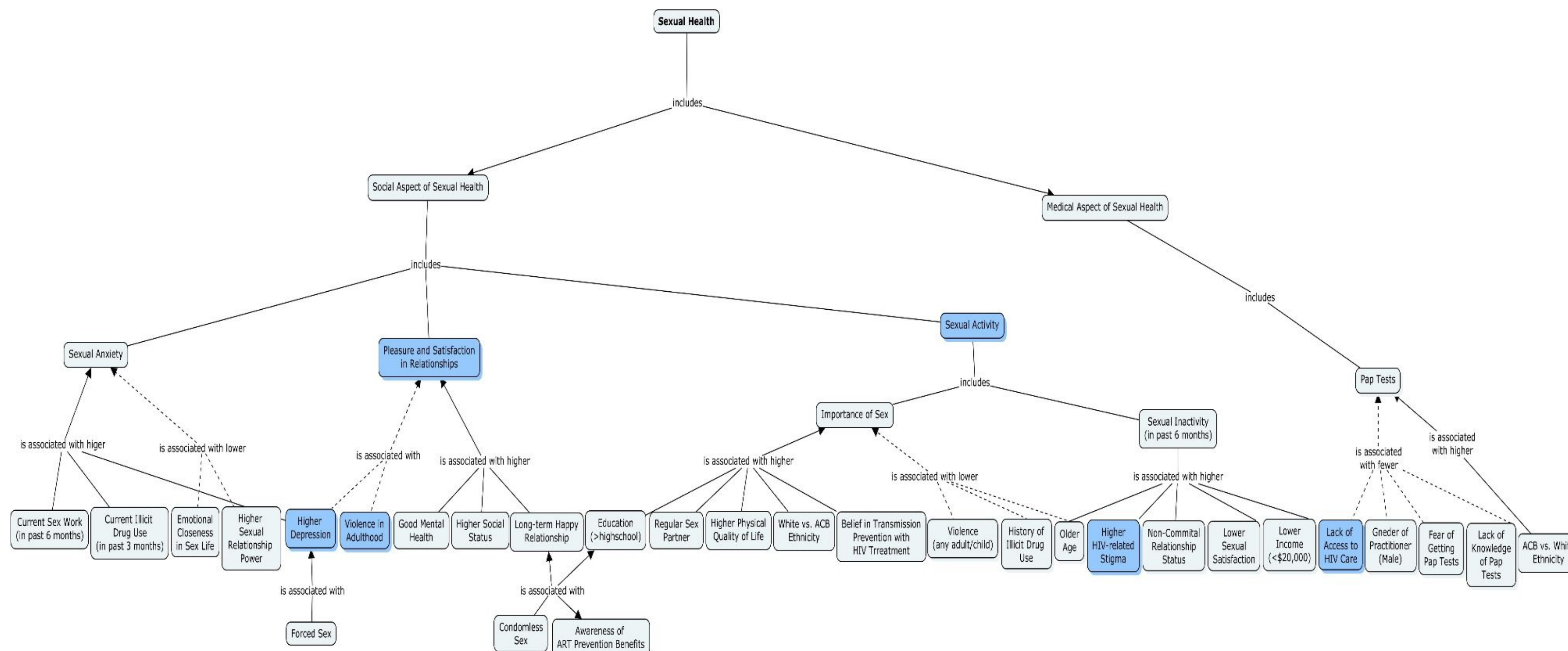
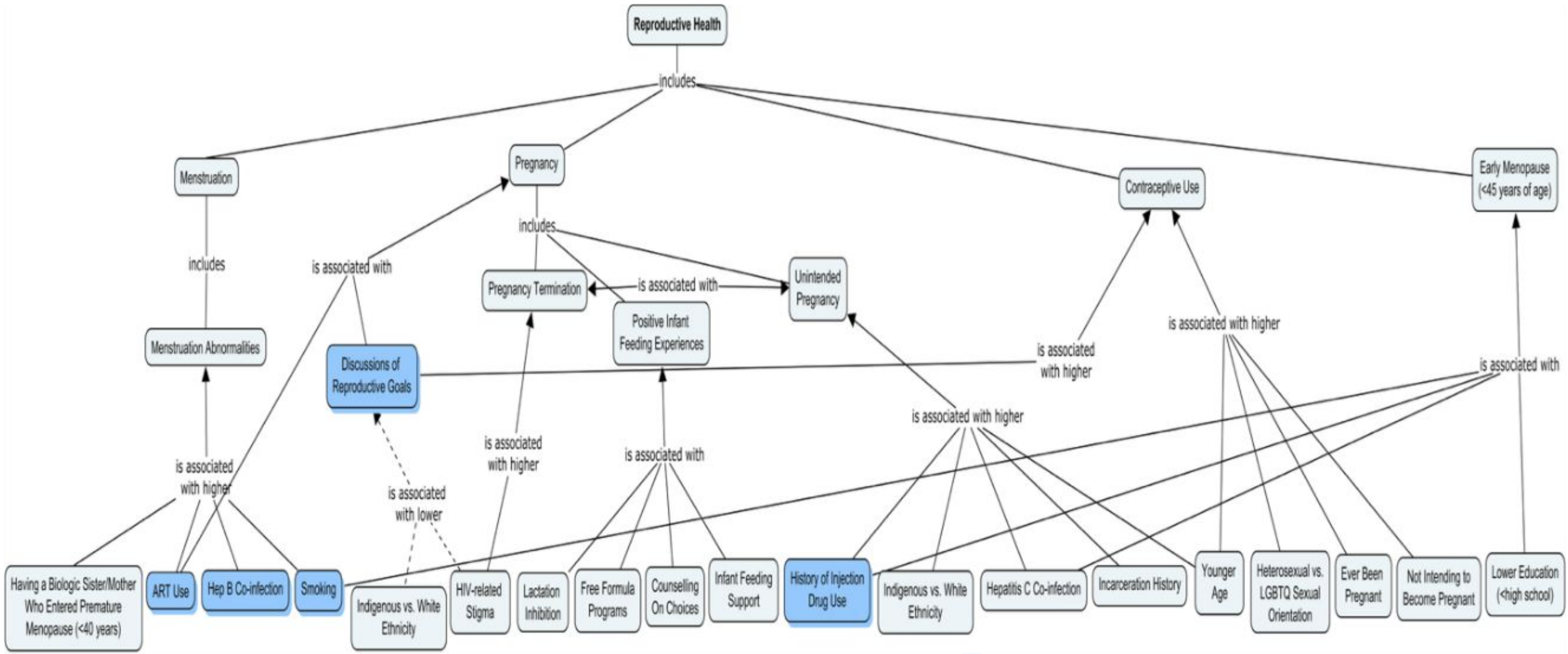
Supplemental Figure 4: Sexual Health Concept Map



There are various medical aspects of sexual health, including the experiences and management of sexually transmitted infections; however, CHIWOS has not yet analyzed data on them.

Sexual activity was defined as consensual sex (oral or penetrative) in the past six months based on the questionnaire used; but it is understood to represent much more including sexual desire, sexual needs, sexual being, and more.

Supplemental Figure 5: Reproductive Health Concept Map



CHIWOS findings showed a narrow range of contraceptive methods used.

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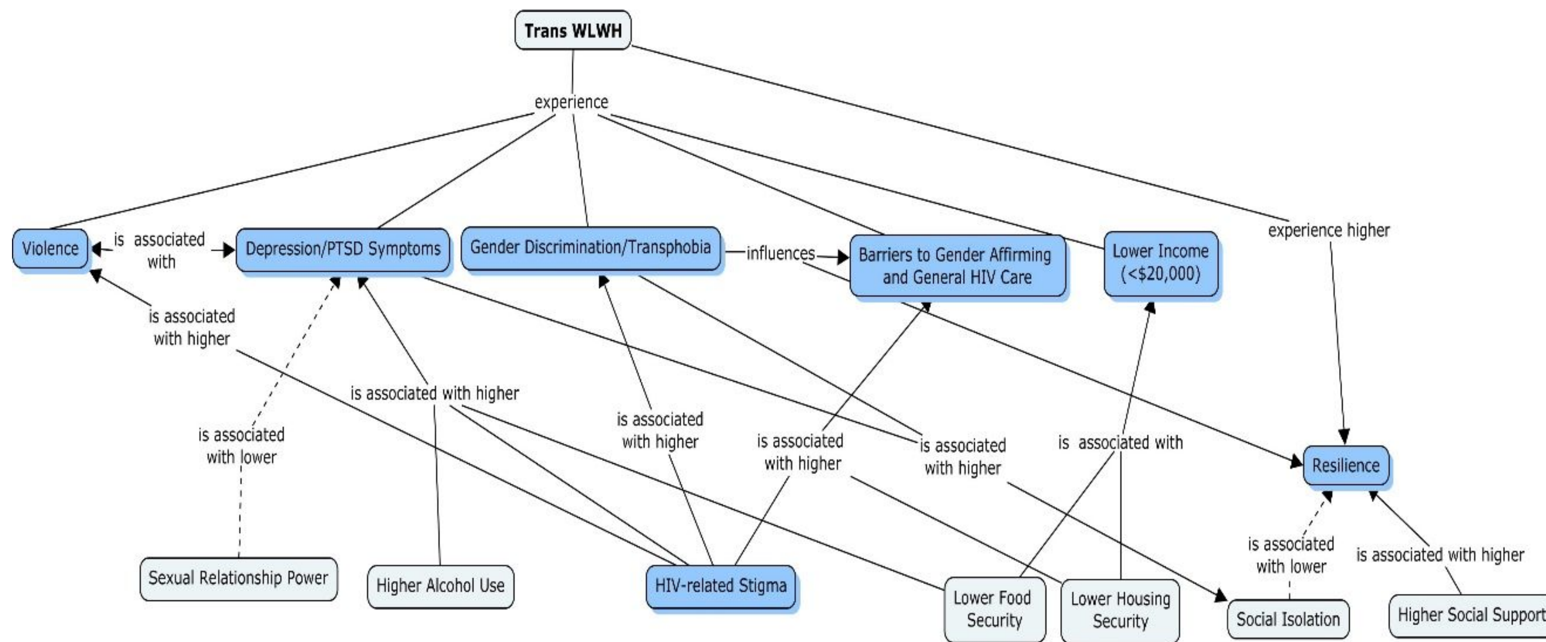
Supplemental Figure 6: Trans WLWHIV Concept Map



Social isolation is the absence of social and economic supports (i.e., lower income, housing, and food services) which are barriers to ongoing engagement in HIV care. These variables are in comparison to cis-gender women.

BMJ Open

Experiences and resultant care gaps among women with HIV in Canada: Concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Findings

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	Care, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Experiences and resultant care gaps among women with HIV in Canada: Concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Findings

Abstract

Objectives: The community-based, longitudinal, Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) explored the experiences of women with HIV in Canada over the past decade. CHIWOS' high impact publications document significant gaps in the provision of health care to women with HIV. We used concept mapping to analyse and present a summary of CHIWOS findings on women's experiences navigating these gaps.

Design: Concept mapping procedures were performed in two steps between June 2019 and March 2021. First, two reviewers (AY and PM) independently reviewed CHIWOS manuscripts and conference abstracts written before 1 August 2019 to identify main themes and generate individual concept maps. Next, the preliminary results were presented to national experts, including women with HIV, to consolidate findings into visuals summarizing the experiences and care gaps of women with HIV in CHIWOS.

Setting: British Columbia, Ontario and Quebec, Canada.

Participants: A total of 18 individual CHIWOS team members participated in this study including six lead investigators of CHIWOS and 12 community researchers.

Results: Overall, a total of 60 peer-reviewed manuscripts and conference abstracts met the inclusion criteria. Using concept mapping, themes were generated and structured through online meetings. In total, six concept maps were co-developed: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women's health. Two summary diagrams were created encompassing the concept map

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themes, one for all women and one specific to trans women with HIV. Through our analysis, resilience, social support, positive healthy actions, and women-centred HIV care were highlighted as strengths leading to well-being for women with HIV.

Conclusions: Concept mapping resulted in a composite summary of 60 peer-reviewed CHIWOS publications. This activity allows for priority setting to optimize care and well-being for women with HIV.

Keywords: HIV, women's health, healthcare systems, care gaps, concept mapping

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Strengths and limitations of this study

- The study comprehensively summarizes the health experiences of women with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) and identifies potential gaps in their care.
- A diverse group of women and HIV experts across Canada took part in this study to provide feedback on the concept maps which used results from 60 peer-reviewed publications by, with and for women with HIV.
- Between June 2019 and March 2021, the process of concept mapping and reviewing visualizations with key informants took place. No new publications developed after the cut-off date of August 1, 2019 could be included in this analysis. However, manuscripts under review or near publication were included and have all since been published.
- Although efforts were made to engage team members from all provinces included in the CHIWOS study, only community researchers from Ontario and British

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Columbia agreed to take part in this study, though academic researchers from Quebec participated.

Introduction

Recent studies have found that women with HIV experience unique health and social needs that differ from those of men with HIV and limit their access to treatment and care services (1-3). The historical lack of research focusing on the realities of women with HIV may be detrimental to their health (4,5). These circumstances led to the development and implementation of the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) – the largest community-based study in Canada exploring the experiences and priorities of a diverse, national cohort of women with HIV in British Columbia (BC), Ontario (ON), and Quebec (QC) from 2013-2018.

CHIWOS was initiated in 2011 through a qualitative phase, which informed the creation of an in-depth survey (1,2). The study's objectives were to examine women's access to women-centred HIV care and the impact of corresponding usage patterns on health outcomes (2). CHIWOS was guided by principles of equitable involvement of those affected *by* the research *in* the research process by establishing community-academic partnerships and shared decision-making throughout the study (6,7). This research approach, reflecting community-based research (CBR) values, was enacted in part through the involvement of women with HIV as trained community researchers to conduct research activities in each stage of the project (2,8,9). CHIWOS was created by, with, and for women with HIV in collaboration with academic researchers, clinicians, and community partners to investigate women's mental, sexual and reproductive health care priorities, and need for a women-centred HIV care model (1,2,10). Cohort data

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3 collection was launched in 2013 and collected at three time points, 18 months apart,
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6 from August 2013 to September 2018. A complete description of CHIWOS can be found
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8 at www.chiwos.ca. As of publication acceptance, CHIWOS remains the largest
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10 longitudinal study of women with HIV in Canada, successfully enrolling a diverse cohort
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13 of 1,422 women with HIV (356 from BC [25%], 713 from ON [50%], and 353 from QC
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15 [25%]) (1,2).
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17 As of August 2019, a total of 113 publications (53 manuscripts and 60 conference
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20 abstracts) had been written using CHIWOS data. This academic content explores dozens
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22 of specific topics related to the experiences of women with HIV, including psychosocial
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24 determinants, clinical, mental, sexual, and reproductive health outcomes, as well as
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27 access to, and quality of healthcare that characterize women's health gaps and needs and
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29 that can be used to inform programming and policy in Canada. In an effort to better
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31 understand the main topics and gaps of CHIWOS manuscripts and conference abstracts,
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34 this study applied Novak and Gowin's (1984) concept mapping methodology (11). The
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36 goal of this methodology was to visualize concepts of CHIWOS findings in a hierarchical
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38 fashion, with the most inclusive and general concepts at the top of the map, and specific
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41 concepts arranged hierarchically below to represent the inter-related relationships in each
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43 publication included. We sought to apply these findings towards the creation of a
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45 summary diagram to summarize the health experiences and gaps of women with HIV
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47 enrolled in CHIWOS. An added benefit of using concept mapping in this study is that the
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50 simplistic visualizations allowed for increased accessibility of the CHIWOS findings to
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52 those outside of academia, including some community members and knowledge users,
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54 which enabled shared decision-making to inform the final product. Our goal was to use
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these findings to characterize women with HIV's healthcare needs and gaps to inform policy and programming in Canada.

Methods

Concept mapping is a graphical methodology used to organize and present knowledge. Since its conception by Novak (1974) (12), it has been adapted in qualitative research to present findings and analyze themes (13,14). This methodology was chosen to illustrate the key themes from the CHIWOS publications, including both manuscripts and conference abstracts, and their relation to each other in order to demonstrate the experiences and related gaps in care women with HIV face in Canada. We used a social-ecological perspective to understand the interplay between multi-level factors impacting women with HIV, their community, and society (15-17).

For this study, the concept mapping process from Novak (1998) (18) was used and encompassed five steps:

Step 1: Conduct a thematic analysis on CHIWOS publications and summarize key findings

All CHIWOS publications (including manuscripts and conference abstracts) published, under review, or near publication submission before 1 August 2019 were examined alongside inclusion criteria developed by the core concept team (including AY, MK, ML, and PM). To be included for review, manuscripts were to 1) include national quantitative CHIWOS questionnaire data, and 2) be published, under review or near submission in a peer-reviewed journal (manuscripts) or be presented at a HIV-related conference (abstracts) by the exclusion date.

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Manuscripts that did not use quantitative CHIWOS data or were process or methods pieces were excluded. For conference abstracts, those which had been published or submitted as manuscripts, showed duplicate results to other abstracts, or were not peer-reviewed prior to conference presentation were excluded. Figure 1 shows the selection process. A total of 113 CHIWOS publications (including manuscripts and conference abstracts) were reviewed, of which 53 were excluded. This resulted in 60 eligible publications that met the inclusion criteria (summarized in Table 1). Eligible publications were grouped together by their overarching theme (discussed further in step 3).

[insert Figure 1 here]

Table 1: Summary of Included CHIWOS Publications

Concept Map Theme	Manuscripts (n=44)	Conference Abstracts (n=16)
Quality of life	n=4	
	(a) Logie, Wang et al. 2018 Carter, Loutfy et al. 2018 Kteily-Hawa, Andany et al. 2019 Kteily-Hawa, Warren et al. 2019	
HIV care	n=8	n=4
	Kennedy, Mellor et al. 2020 Kerkerian, Kestler et al. 2018 (a) Kronfli, Lacombe-Duncan et al. 2017 (b) Kronfli, Lacombe-Duncan et al. 2017 (b) Logie, Wang et al. 2018 Loutfy, de Pokomandy et al. 2017 O'Brien, Godard-Sebillotte et al. 2019 (a) Shokoohi, Bauer et al. 2019	Conway, Gormley et al. 2019 Kaida, Conway et al. 2019 Loutfy, de Pokomandy et al. 2015 Puskas, Pick et al. 2018
Psychosocial & mental health	n=14	n=5
	Carter, Roth et al. 2018 Churchill. 2018 Gormley, Nicholson al. 2021 Heer, Kaida et al. 2022	Kaida, Nicholson et al. 2019 (a) Logie, Wang et al. 2019 (b) Logie, Wang et al. 2019

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	Jaworsky, Logie et al. 2018 (a) Logie, Lacombe-Duncan et al. 2018 Logie, Marcus et al. 2019 (c) Logie, Wang et al. 2018 Logie, Williams et al. 2019 Patterson, Nicholson et al. 2020 Shokoohi, Bauer et al. 2018 (b) Shokoohi, Bauer, et al. 2019 (c) Shokoohi, Bauer et al. 2019 Wagner, Jaworsky et al. 2018	Parry, Lee et al. 2019 Underhill, Wu et al. 2018
Sexual health	n=8	n=2
	(a) Carter, Greene et al. 2018 (b) Carter, Greene, et al. 2018 Carter, Greene et al. 2019 Carter, Patterson et al. 2020 de Pokomandy, Burchell et al. 2019 Kaida, Carter et al. 2015 Logie, Kaida et al. 2020 Patterson, Carter et al. 2017	Salters, Loutfy et al. 2015 Underhill, Kennedy et al. 2017
Reproductive health	n=6	n=4
	Andany, Kaida et al. 2020 Fortin-Hughes, Proulx-Boucher et al. 2019 Kaida, Patterson et al. 2017 Salters, Loutfy et al. 2017 Skeritt L, de Pokomandy et al. 2021 Valiaveetil, Loutfy et al. 2019	Boucoiran, Kaida et al. 2019 Kaida, Gormley et al. 2019 Kaida, Money et al. 2017 Siou, Salters et al. 2016
Trans women with HIV	n=4	n=1
	Lacombe-Duncan, Bauer et al. 2019 Lacombe-Duncan, Newman et al. 2017 Lacombe-Duncan, Warren et al. 2021 (b) Logie, Lacombe-Duncan et al. 2018	Lacombe-Duncan, Persad et al. 2017

See Supplementary Material for full citations.

From the 60 included manuscripts and conference abstracts, we began by identifying the major findings of each that answered the guiding question: what

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characterizes the healthcare gaps and needs of CHIWOS participants? We examined publications to identify themes related to gaps in care, as well as explicit findings related to healthcare access and quality. We then used the coding step of a thematic analysis (19) to code the findings into their simplest form (e.g., lower food security is associated with increased substance use). As a last step, we listed the concepts and linking words within each code (e.g., concepts = lower food security, substance use; linking words = is associated with) (19). This process was repeated for each manuscript and conference abstract. In our efforts to mitigate theme overrepresentation, we opted to include an abstract only when a corresponding manuscript was not available. However, given the inherent intersectionality of the data, there may be instances where subsets of the data were presented in multiple publications. A thorough exploration of such cases is provided in the discussion section for clarity and transparency.

Step 2: Individual concept mapping of CHIWOS manuscripts and abstracts

The concepts and linking words from Step 1 were used to guide the design of 60 individual concept maps, each visually summarizing the key findings of one manuscript or conference abstract. Figure 2 is an example of one of the individual concept maps we created from the CHIWOS findings.

[insert Figure 2 here]

Within each map, concepts were listed in hierarchical order with the most overarching general concepts at the top and the most specific concepts at the bottom (11). Using an online software, CMAPTools (20), concepts were designated by boxes and lines were drawn from one concept to another with the linking words placed in between. We adapted the concept map process by adding in extra features that better visually represent

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the CHIWOS findings. For example, arrowheads pointed towards outcomes of CHIWOS findings. Bi-directional arrows were used when a relationship was present between two outcomes. Solid lines represented a positive association between concepts while dotted lines represented a negative association between concepts. Concepts that recurred in two or more individual concept maps were considered critical findings and were designated by a blue shaded concept box.

AY and PM independently reviewed each concept map to ensure all major findings were represented and summarized into the visual. If there was a discrepancy, a third reviewer (ML) was consulted to make the final decision.

Step 3: Compilation of individual concept maps into composite concept maps

AY, PM, and ML grouped the maps with main concepts and similar themes together. Six major themes were identified: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women with HIV.

The individual concept maps that fell under each major theme were compiled together to create a composite concept map. AY and PM drew cross-links between concepts that had relationships but were on different domains of the composite concept map (14). This process was repeated for each theme and six composite concept maps were developed.

Step 4: Internal development team review and brainstorming of overarching visualization

An internal team (including AY, MK, ML, and PM) meeting was held in August 2019 to review all six composite concept maps. The goal was to ensure all key findings were represented on the maps with good readability. The guiding question was referred to when deciding to remove or add concepts to the map. The team then brainstormed ideas

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to design a compilation visual representing the findings of the six composite maps that answered our guiding research question. A preliminary sketch was formed which is now referred to as the summary diagram.

Step 5: External expert team review and validation

The first author of each included CHIWOS manuscript and conference abstract (herein referred to as lead investigators), and all CHIWOS community researchers were identified as potential key participants in this study and were approached for recruitment from October 2019 to November 2020. Over 30 CHIWOS academic and community team members from all three provinces were invited to participate in the study by email. A total of 29 meetings were held with groups of participants and took place both in-person and virtually.

For orientation, introductory slides explaining the concept mapping methodology and its application to CHIWOS findings were shown to the group. Each of the six composite concept maps were then presented. Lead investigators were asked to ensure that all major CHIWOS findings were accurate and present, and community researchers were asked to ensure that the experiences of women with HIV were accurately represented. All participants were asked to provide input on the readability, clarity, and inclusivity of language. Next, the summary diagram was presented, and participants were asked to ensure that all key components from the composite concept maps were included in the summary diagram, in addition to providing feedback on design features including colour, layout, and display of content. All participant feedback was documented and the feedback between different focus groups were compared. All suggestions and changes were reviewed by AY and PM through revisiting the manuscript and abstracts and

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addressing the guiding research question. Updated composite theme maps and the summary diagrams were presented at a follow-up meeting and consensus was reached by discussion.

Ethics Approval

The study was assessed by the research ethics board at Women's College Hospital to not require ethical approval by a human research ethics committee because the Ethical Principles for Medical Research Involving Human Subjects did not apply. Instead, participants, all of whom had been previously engaged as CHIWOS research team members participated as research consultants to the concept process on a volunteer basis. We obtained informed consent from all participants.

Patient and Public Involvement

Evidently, women with HIV (community researchers; those previously involved in the CHIWOS project) Their invaluable insights significantly contributed to the thematic analysis and individual concept mapping, offering a nuanced perspective on healthcare gaps and needs. Additionally, their active participation in validating composite concept maps and the summary diagram guaranteed precision and inclusivity in the representation of findings. In recognition of their contributions, all community members involved were appropriately compensated for their time and expertise.

Results

A total of 18 individuals participated in the design and review of the concept maps, including six academic investigators (BC: n=1; ON: n=3; QC: n=2), and 12 community researchers (BC: n=5; ON: n=7). All participants identified as cis or trans women.

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Composite Concept Maps

Overall, six composite maps were created (see Supplementary Figures 1-6).

We developed composite map 1 (see Supplementary Figure 1) from four manuscripts focused on the topic of quality of life. Notable findings in this concept map include bi-directional association of physical and mental health quality of life, and the association of experiences of women-centred HIV care with higher resilience and in turn higher quality of life. This map illustrates the influence socioeconomic status, experiences of stigma, sexual orientation, substance use, social support, and relationship status have on mental and physical health-related quality of life.

From eight manuscripts and four conference abstracts, map 2 (see Supplementary Figure 2) was created to illustrate findings related to HIV care. This map demonstrates associations between several aspects of HIV care including viral suppression, use of combination antiretroviral therapy (cART), care access and attrition. Notable findings include the effect having social and peer support have on increasing access to HIV care and the effect of racial discrimination on care attrition. Experiencing violence in adulthood was found to reduce cART use and adherence, leading to reduced viral suppression. On the other hand, peer leadership involvement was associated with higher awareness of cART prevention benefits.

Map 3 (see Supplementary Figure 3) demonstrates the connections between various facets of psychosocial and mental health and represents data from 14 manuscripts and five abstracts. Indigenous heritage was associated with experiencing higher violence in adulthood as well as lower housing security and income. Lower food security was associated with higher substance use. This map emphasizes the negative impact of

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intersectional stigma on all aspects of mental health, which are associated with clinical measures like a lack of cART initiation.

The most complex of the six visuals is map 4 (see Supplementary Figure 4) which explores sexual health experiences of women enrolled in CHIWOS. This map represented data from eight manuscripts and two abstracts. Its findings were organized into social and medical aspects of sexual health sub-categories. A main finding was the association of higher depression and experienced violence in adulthood with lower pleasure and satisfaction in relationships. Higher HIV-related stigma was also associated with higher sexual inactivity in the past six months, which was a recurring theme in the included publications.

The fifth map (see Supplementary Figure 5) showed CHIWOS findings related to reproductive health. The production of this map as separate from sexual health was intentional to illustrate that for many women, sexual health goes beyond reproductive health desires or lack thereof. This map drew on data from six manuscripts and four abstracts, and includes sub-categories of menstruation, pregnancy, contraceptive use, and early menopause. Findings showed low use of a narrow range of contraceptive methods, with sexual orientation, previous pregnancies, and age influencing contraceptive choice. Service provider counselling on choices for infant feeding practices, support and free formula programs were associated with positive infant feeding experiences for women.

The final map titled Trans Women Concept Map (see Supplementary Figure 6) included topics from all five of the other concept maps but from the exclusive perspective of trans women in CHIWOS, with data drawn from four manuscripts and one abstract that solely analysed trans women's data. This map shows trans women's experiences of

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gender discrimination and transphobia, which influence barriers to gender affirming and general HIV care, with HIV-related stigma playing a significant role in this association. Higher sexual relationship power was associated with lower depression and post-traumatic stress disorder symptoms. Higher social support was associated with resilience, which trans women experienced higher levels of than cis women in CHIWOS.

Summary Diagrams

From the six composite concept maps, two summary diagrams were created (see Figures 3 and 4), one for all women and one for trans women specifically. These diagrams provide a summary of the key insights, barriers, and supports that affect the health and well-being of women with HIV involved in CHIWOS. Through actively participating in the arts-based design process of the two summary diagrams, community researchers played a vital role in shaping both the overall themes presented and the final visual of the diagrams. They insisted on grounding the diagrams in the stories and experiences of CHIWOS participants, highlighting the importance of making them accessible, empowering, holistic, authentic, and inclusive - these specific terms were consistently used by community researchers during our collaborative meetings as we worked together on developing the diagrams. The meaningful engagement of community researchers (who collected the CHIWOS data) ensured women with HIV were represented and involved in shared decision-making between community and academic team members in the creation of these diagrams.

We utilized a socio-ecologic model in developing the summary diagrams to show how the individual, societal, and structural factors present in the concept maps intersect to affect women's health and well-being (11-13). To visually represent this intersection,

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the diagram was created in the shape of concentric circles. At the centre of both visuals is a speaking bubble highlighting the stories that women who participated in CHIWOS shared and was named by the community researchers: "Honouring Their Voices." The inner circle of both figures highlights the aspects that are important to women's quality of life: HIV health, general health including physical, health, sexual and reproductive health, mental health, violence and trauma, substance use, culture and spirituality, and resilience. Surrounding quality of life are social factors that combine to affect the health of individuals and their communities, such as housing stability, food security, income, and social isolation. The outer circle consists of the structural factors that affect health including HIV-related stigma, and gender and racial discrimination. Intersecting these layers of the women's health experiences are the important ways women are addressing barriers in their lives, including through social support, accessing, or calling to action the need for women-centred HIV care, and positive healthy actions.

[insert Figure 3 here]

Through consultations with a trans women advocate and CHIWOS team member, the second summary diagram (see Figure 4) was created to reflect the most important and recurring findings of the concept mapping exercise as they relate to the experiences of trans women with HIV involved in CHIWOS. The main difference from Figure 3 is the addition of gender affirmation in the inner circle in reference to trans women's experiences. Community researchers define gender affirmation whereby an individual receives the affirmation they desire with respect to their gender identity and expression from those around them, including social recognition and/or medical access to care such as hormone therapy and gender-affirming surgeries.

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[insert Figure 4 here]

Together, the concept maps show that there are both commonalities and differences in the experiences of women with HIV; however, resilience was present among all CHIWOS participants.

Through facilitated discussions with The Public Studio, an activist design studio in Toronto (https://thepublicstudio.ca/), we identified that community partners wanted: 1) a sun to be a theme of the visuals that radiates energetically from the centre of the diagram and 2) a strength-based title such as the "Wheel of Resilience and Support." It was important to the community partners that the visuals served as an invitation to translate the stories of CHIWOS participants into action.

Discussion

The six composite concept maps and two summary diagrams show a decade of work done by the CHIWOS team, providing a dynamic mosaic of information representative of the intricacies of women's experiences (11-13). The co-creation of concept maps, distinct from traditional systematic reviews, offers an innovative and valuable approach to understanding the health experiences of women with HIV, providing novel insights that extend beyond individual publications for a more comprehensive and nuanced understanding of the multifaceted experiences of women who participated in CHIWOS. The integration of cross-cutting themes like women-centred HIV care and the importance of positive healthy actions in the summary diagram visually emphasizes the most crucial issues for future research, thus contributing to the advancement of policy and programming for women with HIV in Canada.

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A main strength of this study is the richness of CHIWOS dataset analyses conducted over the last 10 years. This study included publications from diverse authors and perspectives and focused on different topics and subsets of the CHIWOS participant population. This increased the reliability of the findings and ensured a full picture of the CHIWOS population's experiences was represented in the concept maps. Further strengthening this representation was the iterative and community-based nature of the concept mapping process itself. The process was driven by a diverse group of community members who amended the maps and diagrams through several rounds of consultations, which ensured their accuracy. While we recognize that the inclusion of publications under review or nearing publication may be perceived as a potential limitation due to the absence of peer review, we primarily interpret this as a strength. This decision allowed us to account for the inherent time lag between research analysis and formal publication, ensuring our analysis captures both established and emerging insights in the field. Furthermore, all "in progress" manuscripts included in this analysis have since been published, affirming the validity of our conclusions.

To prevent theme overrepresentation, we carefully examined the content of each conference abstract and publication to ensure duplicate results were not included. Some publications covered similar themes, such as disclosure, pregnancy loss, cervical cancer disparities, women-centred HIV care, help-seeking, the relationship between stigma and other factors, conception in serodiscordant couples, and issues specific to trans women. However, there were nuanced differences with each of these themes. For instance, the conference abstract focused on disclosure specifically addresses disclosure worries as a factor contributing to health outcomes, while the manuscripts explore experienced child

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abuse as a determinant of barriers to disclosure and awareness of the criminalization of disclosure. We find including these nuanced distinctions valuable, as concepts recurring in two or more concept maps were considered critical findings. Our rigorous approach to highlight crucial findings without data overrepresentation is a key strength of this study.

The co-creation of separate concept maps for cis and trans women shows the important similarities and differences between cis and trans women's experiences, and provides a unique perspective not explored in the individual concept maps. Our findings show many similarities in the health experiences of cis and trans women with HIV in CHIWOS were shared (21). This is important for providers who often assume providing care to trans women with HIV requires a unique skillset and approach (22). The key differences in the summary diagrams were gender affirmation at the individual level, as well as trans care knowledge and training at the structural level. Obtaining training in trans health and gender affirmation is a manageable goal that providers can achieve to deliver more competent care to trans women with HIV (23).

There are some limitations of this study . Efforts were made to engage lead investigators and community researchers from all provinces included in the CHIWOS study, but only academic researchers (not community researchers) from Quebec participated in this study. However, six manuscripts were included in production of the concept maps in which the first author was from Quebec and community members were involved in co-authoring these publications. In shaping our study, we intentionally excluded manuscripts exclusively featuring qualitative data; a decision that might be seen as constraining the incorporation of certain insights. This choice was driven by the inherent challenges of equitably integrating qualitative and quantitative data, especially

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given the marked difference in sample sizes between the two types of manuscripts. To mitigate this limitation, we extensively involved community researchers in the concept mapping and summary diagram creation process, ensuring a comprehensive approach.

Recently, fellow CHIWOS investigators also employed mapping techniques to examine the experiences of women with HIV in accessing care. Skerritt et al. (24) used Fuzzy Cognitive Mapping, a participatory research method, to identify factors influencing satisfaction with HIV care and to understand engagement in the HIV care cascade. The Summary Fuzzy Cognitive Map they produced shows the weightings of categories influencing satisfaction of care, with the most significant being feeling safe and supported by healthcare providers, accessible services, and healthcare provider expertise (24). These mirror some of our findings in our concept maps 2 and 6 which show the relationships among access to care, comprehensive care, and feelings of stigma. Both studies offer valuable visual insights into women's experiences, complementing each other and contributing to a comprehensive understanding when interpreted together.

Our study delved into the nuanced experiences of women with HIV through the lens of CHIWOS, examining psychosocial determinants, clinical aspects, mental health, sexual and reproductive health outcomes, and healthcare access and quality gaps to inform policy and programming for women with HIV in Canada. A recurring theme in the concept maps and summary diagrams was the lack of receipt of comprehensive women-centred HIV care (3) including lack of discussion of reproductive goals, and access to care like gender affirmation. This finding suggests providers must improve knowledge through accessing clinical guidelines related to women with HIV such as the Canadian HIV Pregnancy Planning Guidelines, the Guidelines for the Use of

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Antiretroviral Agents in Adults and Adolescents with HIV, the British Columbia Guidelines for the Care of HIV Positive Pregnant Women & Interventions to Reduce Perinatal Transmission, and the Sherbourne's Guidelines for Gender-Affirming Primary Care (25-28). The concept maps also demonstrate the negative effects of low socioeconomic status and stigma and discrimination on women's self-reported resilience. This could impact the ability to self-advocate in healthcare settings, further affecting quality of care received. This finding has important implications to how clinicians and service providers approach care relationships and the importance of practicing from a person-centred lens.

In exploring the intricate layers of women's experiences with HIV, composite maps 2, 3, and 4 show the profound impact stigma has on the lives of women with HIV. Societal stigma surrounding HIV not only amplifies the complexities of managing a chronic health condition, but also significantly contributes to heightened mental and emotional distress. Within this challenging context, resilience emerges as a pivotal force in composite maps 1 and 6. The intricate interplay between resilience and stigma reveals a dynamic process wherein women not only navigate adversity but also actively contribute to dismantling societal prejudices (29). These composites maps contribute to a deeper understanding of the complex relationship between stigma, resilience, and empowerment, which the Wheel of Resilience points to the need for a more supportive environment for women with HIV.

The interconnectedness between mental health and experiences of violence in adulthood further compounds the challenges women with HIV face as seen in composite maps 1-4. Women with HIV often contend with not only the physiological ramifications

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of the virus but also the psychological distress stemming from social stigma and potential encounters with violence. The intersectionality of these factors poses a considerable barrier to accessing mental health support, further exacerbating the mental health disparities women are experiencing within their communities. Addressing the intricate relationship between mental health, stigma, and violence is important to fostering a more comprehensive approach to care for women with HIV, ensuring that interventions are not only medically sound but also attuned to unique health needs of women.

Another notable finding was the significance of positive healthy actions in the health experiences of women with HIV. This theme was evident in several concept maps, including the Quality of Life concept map which illustrated connections between social support and reduced HIV-related stigma, and the HIV Care concept map which demonstrated correlations between peer leadership involvement and increased awareness of ART prevention benefits. This finding has substantial policy implications, suggesting that investment in peer leadership and support programs for women with HIV can yield tangible mental and physical health benefits. Such proactive measures may contribute to a reduced burden on the greater healthcare system.

The next steps for policy advocacy are the co-development of a national women-centred HIV care (30) strategy that ensures equitable access to care including gender affirmation, and resource creation and education to increase knowledge about the health care gaps women with HIV experience in Canada. Since the completion of this study, the field of women-centred HIV care has experienced significant developments, including the publication of a Women-Centred HIV Care Model informed by CHIWOS findings in 2021 (30), the launch of new women-specific HIV studies such as the British Columbia

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CARMA-CHIWOS (BCC3) study (31), and movement towards a National Action Plan to advance the sexual and reproductive health and rights of women with HIV in Canada (32). Aligned with these recent contributions, the findings from this concept mapping study underscore persisting unanswered questions and emphasize crucial future research priorities. One essential research focus that arises from our study is the need to develop and implement comprehensive women-centred HIV care strategies in clinical settings to facilitate translation of women's needs to their care providers, thereby influencing clinical measures of health and well-being. Moreover, our findings, coupled with insights from the broader literature (3,22,33-38) highlight the diversity among women with HIV, reflecting the varied nature of their needs. While the Women-Centred HIV Care Model provides a solid foundation, it is evident that women's priorities and needs vary, often shaped by other aspects of their identity including race and gender identity. Led by members of the respective groups and individuals with lived experience, ongoing efforts are being made to customize and tailor the Women-Centred HIV Care Model for priority populations, including trans women, African, Caribbean, and Black women, as well as Indigenous women. Our findings also highlight the need to investigate the intersection of mental health, stigma, trauma and violence and its impact on the wellbeing of women with HIV, as well as to develop trauma-informed strategies, approaches and programming aimed at addressing these intersecting factors. In summary, future research should concentrate on developing positive and health-oriented actions and programs tailored to women with HIV, incorporating an intersectional perspective. These efforts should not only address the unique needs shaped by diverse aspects of identity, but also

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offer leadership and capacity-building opportunities for peer-led initiatives centered around self-care and wellbeing.

Conclusion

We developed a unifying summary of the health experience of women with HIV in Canada by applying concept mapping to 60 CHIWOS publications. The produced visuals can be used to inform policy and programming by providing easy to understand evidence on gaps related to the social determinants of health including housing, food security, and income, in addition to structural barriers such as multiple areas of discrimination. Importantly, these visuals promote strength-based approaches to women with HIV's health and wellbeing. The results of this study should guide future research and care priorities for women with HIV in Canada, placing a specific emphasis on trauma-informed, peer-led positive healthy actions accessible to women in all their diversity. This includes initiatives aimed at enhancing women-centred HIV care and self-care to comprehensively improve the holistic wellbeing of women with HIV.

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Contributions

AY, PM, MK and ML contributed to the study conception and design. AY, PM, MK, and BG contributed to the preparation, participant recruitment, and publication screening process. AY, PM, MK, and ML participated in the development of concept maps and summary diagrams. PM, JK, and ML wrote the first draft of the manuscript. VN, RG, PF, YP, NO, BG, BB, SS, MN, AF, BG, CC, KW, MS, AL, CL, AP, AK, and ML provided feedback and edits on all the visuals and versions of the manuscripts. All authors have read and agreed to the published version of the manuscript.

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Competing Interests: None declared.

Patient Consent: Obtained

Patient and public involvement: Patients and/or the public were involved in the design, conduct, or dissemination plans of this research. Refer to the Methods for further details.

Data Availability Statement: No additional data available.

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Ethics Approval: The study was assessed by the research ethics board at Women's College Hospital to not require ethical approval by a human research ethics committee because the Ethical Principles for Medical Research Involving Human Subjects did not apply. Refer to the Methods for further details.

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Figure Legend

Figure 1 – Applying the Eligibility Criteria to CHIWOS Publications

Figure 2 - Example of an individual concept map from one publication (Access to Care, Kronfil et al., 2017)

Figure 3 - CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

Figure 4 - CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

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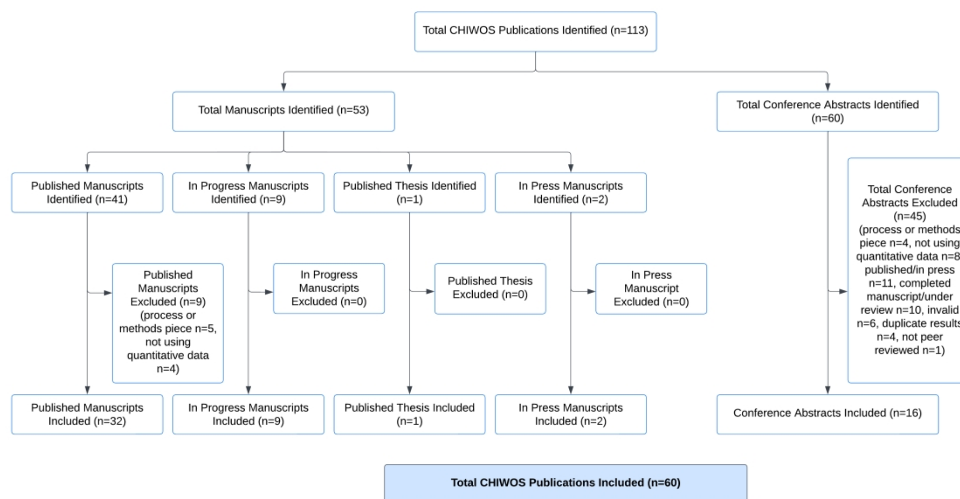

Figure 1: Applying the Eligibility Criteria to CHIWOS Publications

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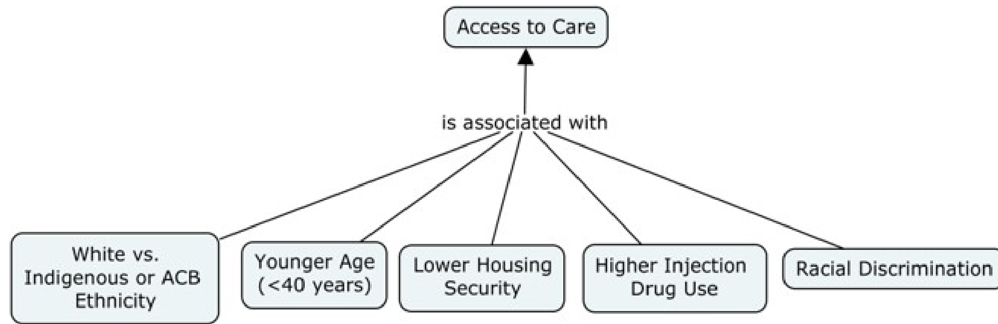

Figure 2: Example of an individual concept map from one publication (Access to Care, Kronfil et al., 2017)

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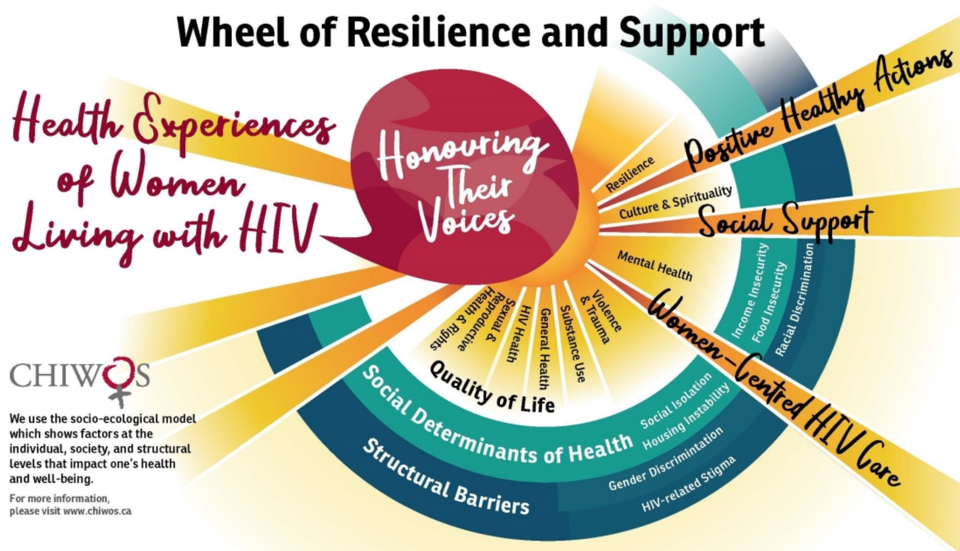

Figure 3: CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

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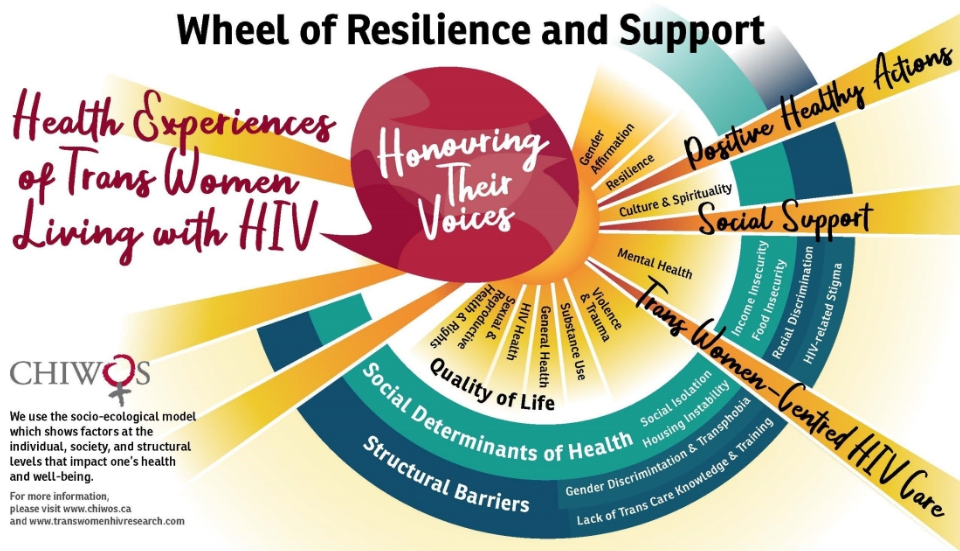

25 Figure 4: CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

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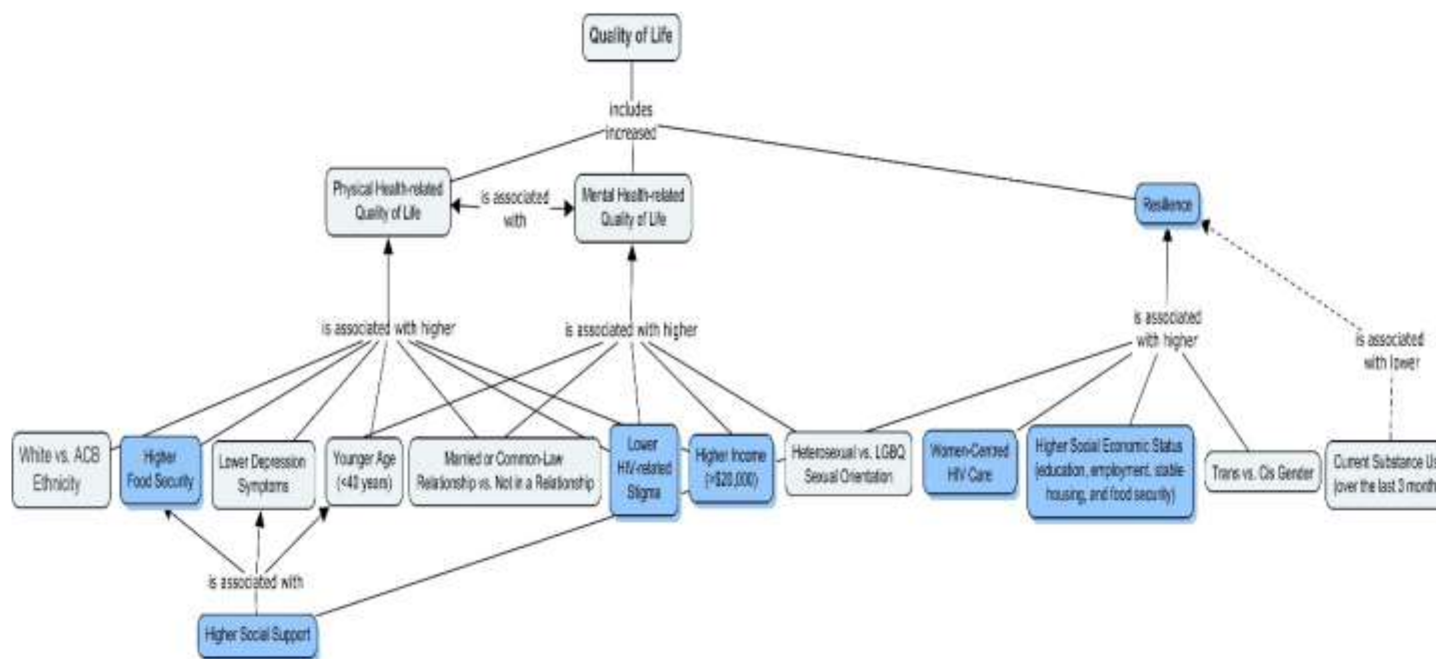
Supplementary Figure 1: Quality of Life Concept Map



Our definition of Quality of Life (QOL) extends beyond one's physical and mental health status. It is expanded to also include QOL's relationship with resilience and overall wellbeing. QOL was measured using the SF-12 scale.

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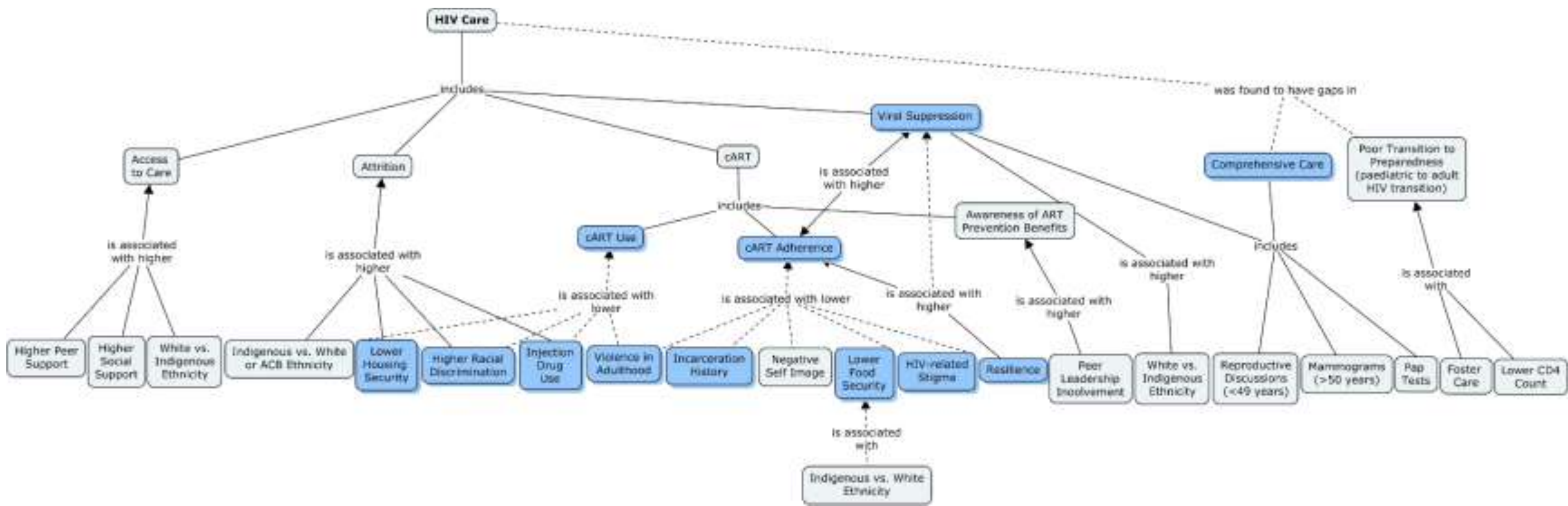
Supplementary Figure 2: HIV Care Concept Map



Attrition refers to reduction in the % at each stage of the HIV care cascade. These stages are: 1) access to care, 2) cART use, 3) cART adherence, and 4) viral suppression.

Comprehensive care is defined by four indicators: Pap test, viral load suppression, reproductive discussions, and mammograms.

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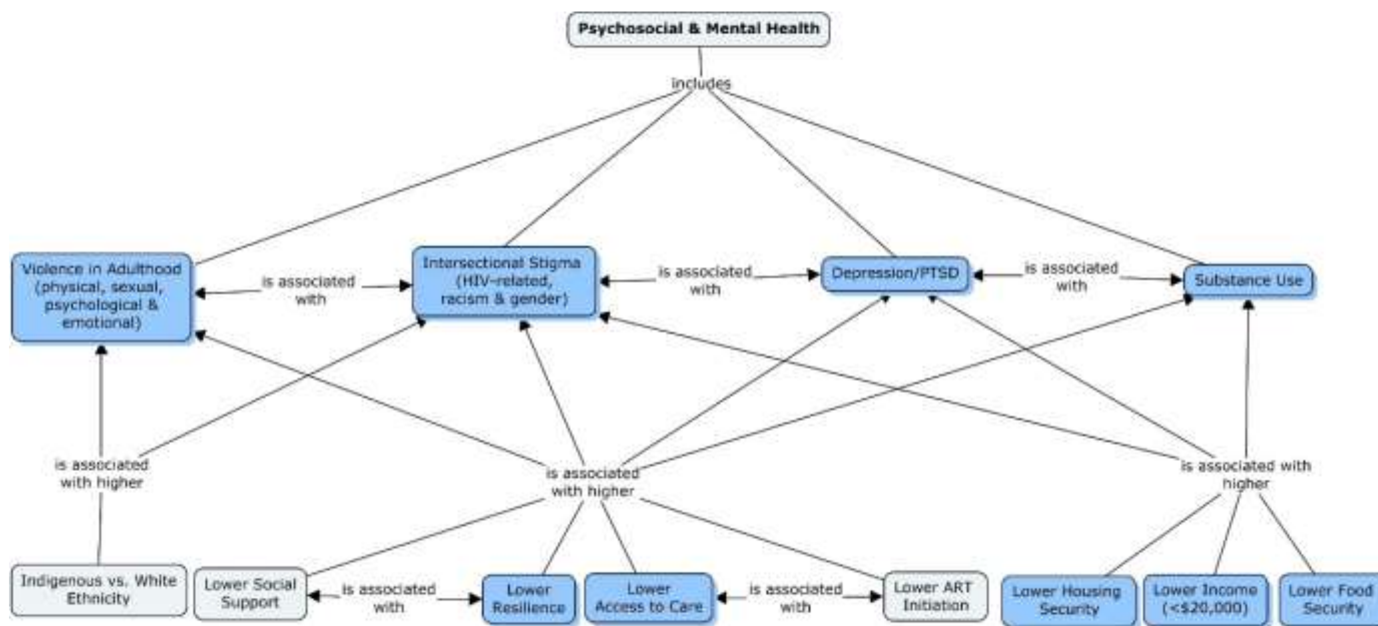
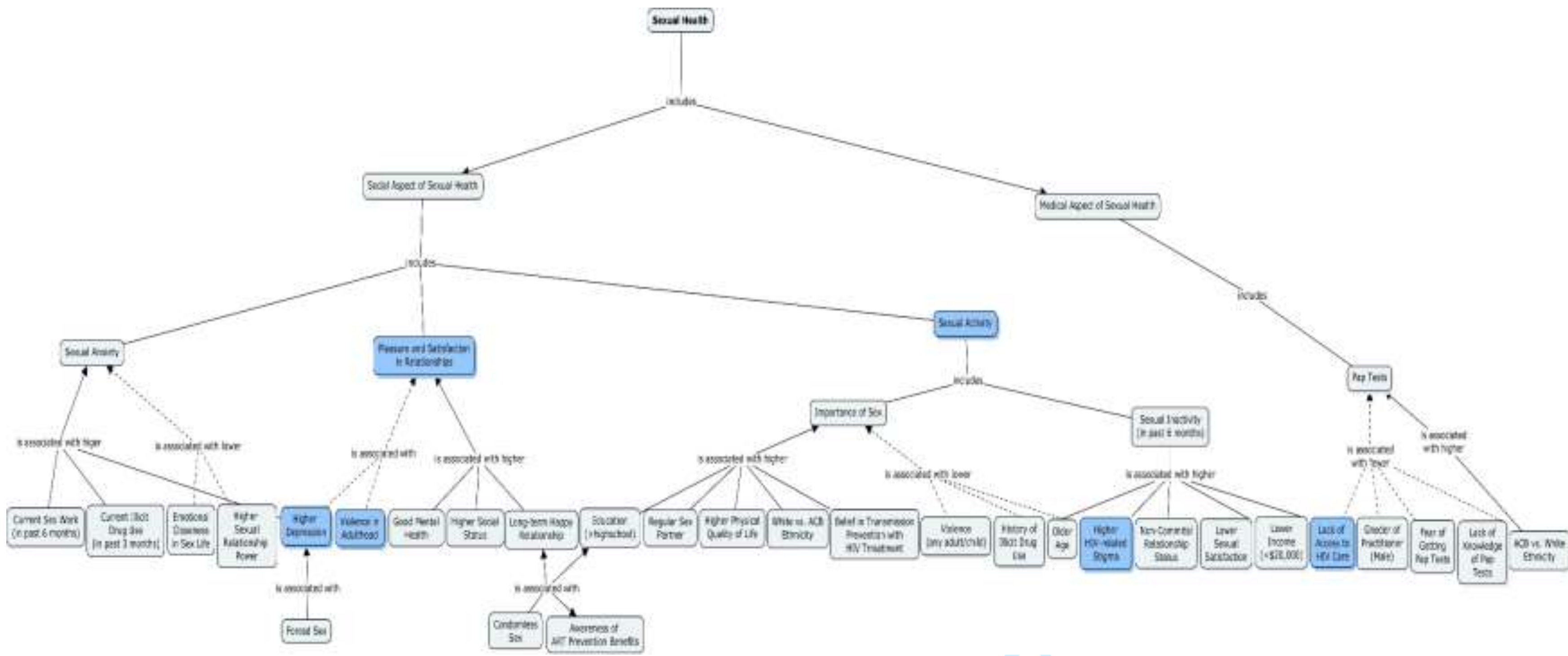
Supplementary Figure 3: Psychosocial and Mental Health Concept Map



Intersectional stigma, violence, depression/PTSD, and substance use are associated with each other. Also, access to care was measured using the Barriers to Access to Care 12-item scale.

Supplementary Figure 4: Sexual Health Concept Map



There are various medical aspects of sexual health, including the experiences and management of sexually transmitted infections; however, CHIWOS has not yet analyzed data on them.

Sexual activity was defined as consensual sex (oral or penetrative) in the past six months based on the questionnaire used; but it is understood to represent much more including sexual desire, sexual needs, sexual being, and more.

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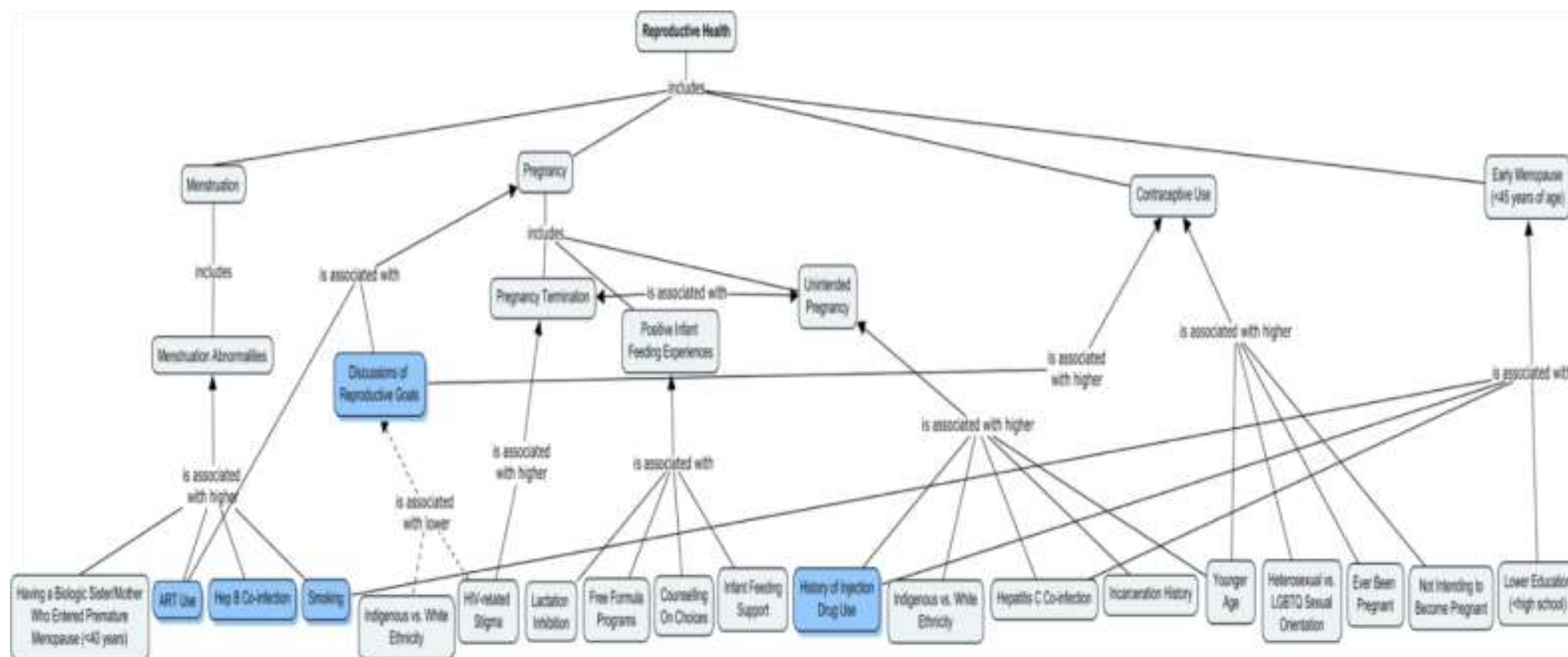
Supplementary Figure 5: Reproductive Health Concept Map



CHIWOS findings showed a narrow range of contraceptive methods used.

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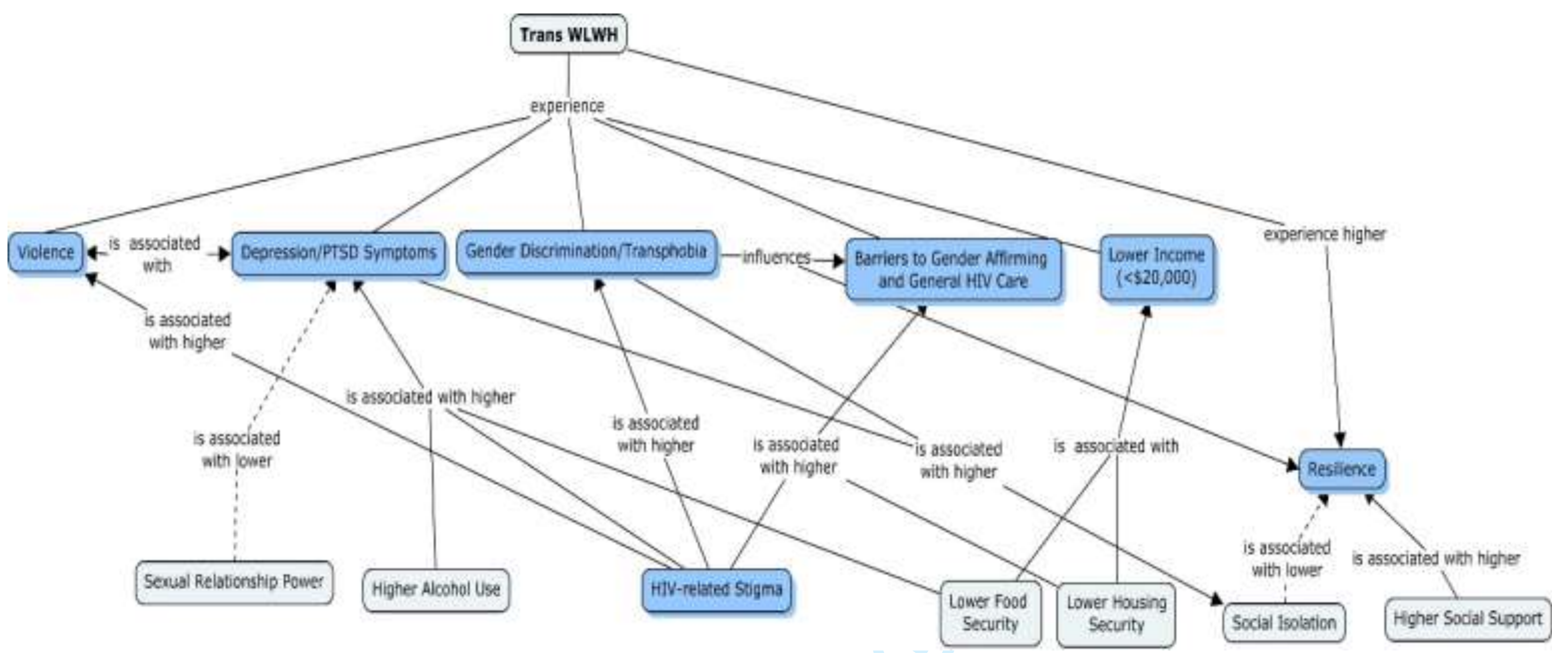
Supplementary Figure 6: Trans WLWHIV Concept Map



Social isolation is the absence of social and economic supports (i.e., lower income, housing, and food services) which are barriers to ongoing engagement in HIV care. These variables are in comparison to cis-gender women.

BMJ Open

Experiences and resultant care gaps among women with HIV in Canada: concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) findings

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Primary Subject Heading:	HIV/AIDS
Secondary Subject Heading:	Health services research, Patient-centred medicine, Sexual health
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, Health Equity, Patient-Centered

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Experiences and resultant care gaps among women with HIV in Canada: concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) findings

Abstract

Objectives: The community-based, longitudinal, Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) explored the experiences of women with HIV in Canada over the past decade. CHIWOS' high impact publications document significant gaps in the provision of health care to women with HIV. We used concept mapping to analyse and present a summary of CHIWOS findings on women's experiences navigating these gaps.

Design: Concept mapping procedures were performed in two steps between June 2019 and March 2021. First, two reviewers (AY and PM) independently reviewed CHIWOS manuscripts and conference abstracts written before 1 August 2019 to identify main themes and generate individual concept maps. Next, the preliminary results were presented to national experts, including women with HIV, to consolidate findings into visuals summarizing the experiences and care gaps of women with HIV in CHIWOS.

Setting: British Columbia, Ontario and Quebec, Canada.

Participants: A total of 18 individual CHIWOS team members participated in this study including six lead investigators of CHIWOS and 12 community researchers.

Results: Overall, a total of 60 peer-reviewed manuscripts and conference abstracts met the inclusion criteria. Using concept mapping, themes were generated and structured through online meetings. In total, six composite concept maps were co-developed: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women's health. Two summary diagrams were created encompassing the concept

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map themes, one for all women and one specific to trans women with HIV. Through our analysis, resilience, social support, positive healthy actions, and women-centred HIV care were highlighted as strengths leading to well-being for women with HIV.

Conclusions: Concept mapping resulted in a composite summary of 60 peer-reviewed CHIWOS publications. This activity allows for priority setting to optimize care and well-being for women with HIV.

Keywords: HIV, women's health, healthcare systems, care gaps, concept mapping

Strengths and limitations of this study

- The study comprehensively summarizes the health experiences of women with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) and identifies potential gaps in their care.
- A diverse group of women and HIV experts across Canada took part in this study to provide feedback on the concept maps which used results from 60 peer-reviewed publications by, with and for women with HIV.
- Between June 2019 and March 2021, the process of concept mapping and reviewing visualizations with key informants occurred, with a cut-off date of August 1, 2019 for new publications; however, manuscripts under review or nearing publication were considered and all have since been published.
- Although efforts were made to engage team members from all provinces included in the CHIWOS study, only community researchers from Ontario and British

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Columbia agreed to take part in this study, though academic researchers from Quebec participated.

INTRODUCTION

Recent studies have found that women with HIV experience unique health and social needs that differ from those of men with HIV and limit their access to treatment and care services (1-3). The historical lack of research focusing on the realities of women with HIV may be detrimental to their health (4,5). These circumstances led to the development and implementation of the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) – the largest community-based study in Canada exploring the experiences and priorities of a diverse, national cohort of women with HIV in British Columbia (BC), Ontario (ON), and Quebec (QC) from 2013-2018.

CHIWOS was initiated in 2011 through a qualitative phase, which informed the creation of an in-depth survey (1,2). The study's objectives were to examine women's access to women-centred HIV care and the impact of corresponding usage patterns on health outcomes (2). CHIWOS was guided by principles of equitable involvement of those affected *by* the research *in* the research process by establishing community-academic partnerships and shared decision-making throughout the study (6,7). This research approach, reflecting community-based research (CBR) values, was enacted in part through the involvement of women with HIV as trained community researchers to conduct research activities in each stage of the project (2,8,9). CHIWOS was created by, with, and for women with HIV in collaboration with academic researchers, clinicians, and community partners to investigate women's mental, sexual and reproductive health

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care priorities, and need for a women-centred HIV care model (1,2,10). Cohort data collection was launched in 2013 and collected at three time points, 18 months apart, from August 2013 to September 2018. A complete description of CHIWOS can be found at www.chiwos.ca. As of publication acceptance, CHIWOS remains the largest longitudinal study of women with HIV in Canada, successfully enrolling a diverse cohort of 1,422 women with HIV (356 from BC [25%], 713 from ON [50%], and 353 from QC [25%]) (1,2).

As of August 2019, a total of 113 publications (53 manuscripts and 60 conference abstracts) had been written using CHIWOS data. This academic content explores dozens of specific topics related to the experiences of women with HIV, including psychosocial determinants, clinical, mental, sexual, and reproductive health outcomes, as well as access to, and quality of healthcare that characterize women's health gaps and needs and that can be used to inform programming and policy in Canada. In an effort to better understand the main topics and gaps of CHIWOS manuscripts and conference abstracts, this study applied Novak and Gowin's (1984) concept mapping methodology (11). The goal of this methodology was to visualize concepts of CHIWOS findings in a hierarchical fashion, with the most inclusive and general concepts at the top of the map, and specific concepts arranged hierarchically below to represent the inter-related relationships in each publication included. We sought to apply these findings towards the creation of a summary diagram to summarize the health experiences and gaps of women with HIV enrolled in CHIWOS. An added benefit of using concept mapping in this study is that the simplistic visualizations allowed for increased accessibility of the CHIWOS findings to those outside of academia, including some community members and knowledge users,

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which enabled shared decision-making to inform the final product. Our goal was to use these findings to characterize women with HIV's healthcare needs and gaps to inform policy and programming in Canada.

METHODS

Concept mapping is a graphical methodology used to organize and present knowledge. Since its conception by Novak (1974) (12), it has been adapted in qualitative research to present findings and analyze themes (13,14). This methodology was chosen to illustrate the key themes from the CHIWOS publications, including both manuscripts and conference abstracts, and their relation to each other in order to demonstrate the experiences and related gaps in care women with HIV face in Canada. We used a social-ecological perspective to understand the interplay between multi-level factors impacting women with HIV, their community, and society (15-17).

For this study, the concept mapping process from Novak (1998) (18) was used and encompassed five steps:

Step 1: Conduct a thematic analysis on CHIWOS publications and summarize key findings

All CHIWOS publications (including manuscripts and conference abstracts) published, under review, or near publication submission before 1 August 2019 were examined alongside inclusion criteria developed by the core concept team (including AY, MK, ML, and PM). To be included for review, manuscripts were to 1) include national quantitative CHIWOS questionnaire data, and 2) be published, under review or near submission in a peer-reviewed journal (manuscripts) or be presented at a HIV-related conference (abstracts) by the exclusion date.

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Manuscripts that did not use quantitative CHIWOS data or were process or methods pieces were excluded. For conference abstracts, those which had been published or submitted as manuscripts, showed duplicate results to other abstracts, or were not peer-reviewed prior to conference presentation were excluded. Figure 1 shows the selection process. The inclusion and exclusion criteria were designed to ensure a comprehensive and representative analysis, encompassing all eligible manuscripts or conference abstracts, thereby mitigating the potential for bias or skew in the publication list. A total of 113 CHIWOS publications (including manuscripts and conference abstracts) were reviewed, of which 53 were excluded. This resulted in 60 eligible publications that met the inclusion criteria (summarized in Table 1). Eligible publications were grouped together by their overarching theme (discussed further in step 3).

Table 1. Summary of included CHIWOS publications

Composite Concept Map Theme	Manuscripts (n=44)	Conference Abstracts (n=16)
Quality of life	n=4	
	(a) Logie, Wang et al. 2018 Carter, Loutfy et al. 2018 Kteily-Hawa, Andany et al. 2019 Kteily-Hawa, Warren et al. 2019	
HIV care	n=8	n=4
	Kennedy, Mellor et al. 2020 Kerkerian, Kestler et al. 2018 (a) Kronfli, Lacombe-Duncan et al. 2017 (b) Kronfli, Lacombe-Duncan et al. 2017 (b) Logie, Wang et al. 2018 Loutfy, de Pokomandy et al. 2017 O'Brien, Godard-Sebillotte et al. 2019 (a) Shokoohi, Bauer et al. 2019	Conway, Gormley et al. 2019 Kaida, Conway et al. 2019 Loutfy, de Pokomandy et al. 2015 Puskas, Pick et al. 2018
Psychosocial & mental health	n=14	n=5

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	Carter, Roth et al. 2018 Churchill. 2018 Gormley, Nicholson al. 2021 Heer, Kaida et al. 2022 Jaworsky, Logie et al. 2018 (a) Logie, Lacombe-Duncan et al. 2018 Logie, Marcus et al. 2019 (c) Logie, Wang et al. 2018 Logie, Williams et al. 2019 Patterson, Nicholson et al. 2020 Shokoohi, Bauer et al. 2018 (b) Shokoohi, Bauer, et al. 2019 (c) Shokoohi, Bauer et al. 2019 Wagner, Jaworsky et al. 2018	Kaida, Nicholson et al. 2019 (a) Logie, Wang et al. 2019 (b) Logie, Wang et al. 2019 Parry, Lee et al. 2019 Underhill, Wu et al. 2018
Sexual health	n=8	n=2
	(a) Carter, Greene et al. 2018 (b) Carter, Greene, et al. 2018 Carter, Greene et al. 2019 Carter, Patterson et al. 2020 de Pokomandy, Burchell et al. 2019 Kaida, Carter et al. 2015 Logie, Kaida et al. 2020 Patterson, Carter et al. 2017	Salters, Loutfy et al. 2015 Underhill, Kennedy et al. 2017
Reproductive health	n=6	n=4
	Andany, Kaida et al. 2020 Fortin-Hughes, Proulx-Boucher et al. 2019 Kaida, Patterson et al. 2017 Salters, Loutfy et al. 2017 Skeritt L, de Pokomandy et al. 2021 Valiaveetil, Loutfy et al. 2019	Boucoiran, Kaida et al. 2019 Kaida, Gormley et al. 2019 Kaida, Money et al. 2017 Siou, Salters et al. 2016
Trans women with HIV	n=4	n=1
	Lacombe-Duncan, Bauer et al. 2019 Lacombe-Duncan, Newman et al. 2017 Lacombe-Duncan, Warren et al. 2021 (b) Logie, Lacombe-Duncan et al. 2018	Lacombe-Duncan, Persad et al. 2017

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From the 60 included manuscripts and conference abstracts, we began by identifying the major findings of each that answered the guiding question: what characterizes the healthcare gaps and needs of CHIWOS participants? We examined publications to identify themes related to gaps in care, as well as explicit findings related to healthcare access and quality. We then used the coding step of a thematic analysis (19) to code the findings into their simplest form (e.g., lower food security is associated with increased substance use). As a last step, we listed the concepts and linking words within each code (e.g., concepts = lower food security, substance use; linking words = is associated with) (19). This process was repeated for each manuscript and conference abstract. In our efforts to mitigate theme overrepresentation, we opted to include an abstract only when a corresponding manuscript was not available. However, given the inherent intersectionality of the data, there may be instances where subsets of the data were presented in multiple publications. A thorough exploration of such cases is provided in the discussion section for clarity and transparency.

Step 2: Individual concept mapping of CHIWOS manuscripts and abstracts

The concepts and linking words from Step 1 were used to guide the design of 60 individual concept maps, each visually summarizing the key findings of one manuscript or conference abstract. Figure 2 is an example of one of the individual concept maps we created from the CHIWOS findings.

Within each map, concepts were listed in hierarchical order with the most overarching general concepts at the top and the most specific concepts at the bottom (11). Using an online software, CMAPTools (20), concepts were designated by boxes and lines were drawn from one concept to another with the linking words placed in between. We

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adapted the concept map process by adding in extra features that better visually represent the CHIWOS findings. For example, arrowheads pointed towards outcomes of CHIWOS findings. Bi-directional arrows were used when a relationship was present between two outcomes. Solid lines represented a positive association between concepts while dotted lines represented a negative association between concepts. Concepts that recurred in two or more individual concept maps were considered critical findings and were designated by a blue shaded concept box.

AY and PM independently reviewed each concept map to ensure all major findings were represented and summarized into the visual. If there was a discrepancy, a third reviewer (ML) was consulted to make the final decision.

Step 3: Compilation of individual concept maps into composite concept maps

AY, PM, and ML grouped the maps with main concepts and similar themes together. Six major themes were identified: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women with HIV.

The individual concept maps that fell under each major theme were compiled together to create a composite concept map. AY and PM drew cross-links between concepts that had relationships but were on different domains of the composite concept map (14). This process was repeated for each theme and six composite concept maps were developed.

Step 4: Internal development team review and brainstorming of overarching visualization

An internal team (including AY, MK, ML, and PM) meeting was held in August 2019 to review all six composite concept maps. The goal was to ensure all key findings were

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represented on the maps with good readability. The guiding question was referred to when deciding to remove or add concepts to the map. The team then brainstormed ideas to design a compilation visual representing the findings of the six composite maps that answered our guiding research question. A preliminary sketch was formed which is now referred to as the summary diagram.

Step 5: External expert team review and validation

The first author of each included CHIWOS manuscript and conference abstract (herein referred to as lead investigators), and all CHIWOS community researchers were identified as potential key participants in this study and were approached for recruitment from October 2019 to November 2020. Over 30 CHIWOS academic and community team members from all three provinces were invited to participate in the study by email, of which 18 agreed to participate. A total of 29 meetings were held with groups of participants and took place both in-person and virtually.

For orientation, introductory slides explaining the concept mapping methodology and its application to CHIWOS findings were shown to the group. Each of the six composite concept maps were then presented. Lead investigators were asked to ensure that all major CHIWOS findings were accurate and present, and community researchers were asked to ensure that the experiences of women with HIV were accurately represented. All participants were asked to provide input on the readability, clarity, and inclusivity of language. Next, the summary diagram was presented, and participants were asked to ensure that all key components from the composite concept maps were included in the summary diagram, in addition to providing feedback on design features including colour, layout, and display of content. All participant feedback was documented and the

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feedback between different focus groups were compared. All suggestions and changes were reviewed by AY and PM through revisiting the manuscript and abstracts and addressing the guiding research question. Updated composite theme maps and the summary diagrams were presented at a follow-up meeting and consensus was reached by discussion.

Ethics approval

The study was assessed by the research ethics board at Women's College Hospital to not require ethical approval by a human research ethics committee because the Ethical Principles for Medical Research Involving Human Subjects did not apply. Instead, participants, all of whom had been previously engaged as CHIWOS research team members participated as research consultants to the concept process on a volunteer basis. We obtained informed consent from all participants in CHIWOS.

Patient and public involvement

Evidently, women with HIV (community researchers; those previously involved in the CHIWOS project) were involved in the study. Their invaluable insights significantly contributed to the thematic analysis and individual concept mapping, offering a nuanced perspective on healthcare gaps and needs. Additionally, their active participation in validating composite concept maps and the summary diagram guaranteed precision and inclusivity in the representation of findings. In recognition of their contributions, all community members involved were appropriately compensated for their time and expertise.

RESULTS

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A total of 18 individuals participated in the design and review of the concept maps, including six academic investigators (BC: n=1; ON: n=3; QC: n=2), and 12 community researchers (BC: n=5; ON: n=7). All participants identified as cis or trans women.

Composite concept maps

Overall, six composite maps were created (see Supplementary Figures 1-6).

We developed composite concept map 1 (see Supplementary Figure 1) from four manuscripts focused on the topic of quality of life. Notable findings in this map include bi-directional association of physical and mental health quality of life, and the association of experiences of women-centred HIV care with higher resilience and in turn higher quality of life. This map illustrates the influence socioeconomic status, experiences of stigma, sexual orientation, substance use, social support, and relationship status have on mental and physical health-related quality of life.

From eight manuscripts and four conference abstracts, composite concept map 2 (see Supplementary Figure 2) was created to illustrate findings related to HIV care. This map demonstrates associations between several aspects of HIV care including viral suppression, use of combination antiretroviral therapy (cART), care access and attrition. Notable findings include the effect having social and peer support have on increasing access to HIV care and the effect of racial discrimination on care attrition. Experiencing violence in adulthood was found to reduce cART use and adherence, leading to reduced viral suppression. On the other hand, peer leadership involvement was associated with higher awareness of cART prevention benefits.

Composite concept map 3 (see Supplementary Figure 3) demonstrates the connections between various facets of psychosocial and mental health and represents data

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3 from 14 manuscripts and five abstracts. Indigenous heritage was associated with
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5 experiencing higher violence in adulthood as well as lower housing security and income.
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7 Lower food security was associated with higher substance use. This map emphasizes the
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9 negative impact of intersectional stigma on all aspects of mental health, which are
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11 associated with clinical measures like a lack of cART initiation.

The most complex of the six visuals is composite concept map 4 (see Supplementary Figure 4) which explores sexual health experiences of women enrolled in CHIWOS. This map represented data from eight manuscripts and two abstracts. Its findings were organized into social and medical aspects of sexual health sub-categories. A main finding was the association of higher depression and experienced violence in adulthood with lower pleasure and satisfaction in relationships. Higher HIV-related stigma was also associated with higher sexual inactivity in the past six months, which was a recurring theme in the included publications.

The fifth composite concept map (see Supplementary Figure 5) showed CHIWOS findings related to reproductive health. The production of this map as separate from sexual health was intentional to illustrate that for many women, sexual health goes beyond reproductive health desires or lack thereof. This map drew on data from six manuscripts and four abstracts, and includes sub-categories of menstruation, pregnancy, contraceptive use, and early menopause. Findings showed low use of a narrow range of contraceptive methods, with sexual orientation, previous pregnancies, and age influencing contraceptive choice. Service provider counselling on choices for infant feeding practices, support and free formula programs were associated with positive infant feeding experiences for women.

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The final map titled Trans Women Concept Map (see Supplementary Figure 6) included topics from all five of the other composite concept maps but from the exclusive perspective of trans women in CHIWOS, with data drawn from four manuscripts and one abstract that solely analysed trans women's data. This map shows trans women's experiences of gender discrimination and transphobia, which influence barriers to gender affirming and general HIV care, with HIV-related stigma playing a significant role in this association. Higher sexual relationship power was associated with lower depression and post-traumatic stress disorder symptoms. Higher social support was associated with resilience, which trans women experienced higher levels of than cis women in CHIWOS.

Summary diagrams

From the six composite concept maps, two summary diagrams were created (see Figures 3 and 4), one for all women and one for trans women specifically. These diagrams provide a summary of the key insights, barriers, and supports that affect the health and well-being of women with HIV involved in CHIWOS. Through actively participating in the arts-based design process of the two summary diagrams, community researchers played a vital role in shaping both the overall themes presented and the final visual of the diagrams. They insisted on grounding the diagrams in the stories and experiences of CHIWOS participants, highlighting the importance of making them accessible, empowering, holistic, authentic, and inclusive - these specific terms were consistently used by community researchers during our collaborative meetings as we worked together on developing the diagrams. The meaningful engagement of community researchers (who collected the CHIWOS data) ensured women with HIV were represented and involved in

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shared decision-making between community and academic team members in the creation of these diagrams.

We utilized a socio-ecologic model in developing the summary diagrams to show how the individual, societal, and structural factors present in the concept maps intersect to affect women's health and well-being (11-13). To visually represent this intersection, the diagram was created in the shape of concentric circles. At the centre of both visuals is a speaking bubble highlighting the stories that women who participated in CHIWOS shared and was named by the community researchers: "Honouring Their Voices." The inner circle of both figures highlights the aspects that are important to women's quality of life: HIV health, general health including physical, health, sexual and reproductive health, mental health, violence and trauma, substance use, culture and spirituality, and resilience. Surrounding quality of life are social factors that combine to affect the health of individuals and their communities, such as housing stability, food security, income, and social isolation. The outer circle consists of the structural factors that affect health including HIV-related stigma, and gender and racial discrimination. Intersecting these layers of the women's health experiences are the important ways women are addressing barriers in their lives, including through social support, accessing, or calling to action the need for women-centred HIV care, and positive healthy actions.

Through consultations with a trans women advocate and CHIWOS team member, the second summary diagram (see Figure 4) was created to reflect the most important and recurring findings of the concept mapping exercise as they relate to the experiences of trans women with HIV involved in CHIWOS. The main difference from Figure 3 is the addition of gender affirmation in the inner circle in reference to trans women's

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experiences. Community researchers define gender affirmation whereby an individual receives the affirmation they desire with respect to their gender identity and expression from those around them, including social recognition and/or medical access to care such as hormone therapy and gender-affirming surgeries.

Together, the composite concept maps show that there are both commonalities and differences in the experiences of women with HIV; however, resilience was present among all CHIWOS participants.

Through facilitated discussions with The Public Studio, an activist design studio in Toronto (https://thepublicstudio.ca/), we identified that community partners wanted: 1) a sun to be a theme of the visuals that radiates energetically from the centre of the diagram and 2) a strength-based title such as the "Wheel of Resilience and Support." It was important to the community partners that the visuals served as an invitation to translate the stories of CHIWOS participants into action.

DISCUSSION

The six composite concept maps and two summary diagrams show a decade of work done by the CHIWOS team, providing a dynamic mosaic of information representative of the intricacies of women's experiences (11-13). The co-creation of concept maps, distinct from traditional systematic reviews, offers an innovative and valuable approach to understanding the health experiences of women with HIV, providing novel insights that extend beyond individual publications for a more comprehensive and nuanced understanding of the multifaceted experiences of women who participated in CHIWOS. The integration of cross-cutting themes like women-centred HIV care and the importance of positive healthy actions in the summary diagram visually emphasizes the most crucial

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issues for future research, thus contributing to the advancement of policy and programming for women with HIV in Canada.

A main strength of this study is the richness of CHIWOS dataset analyses conducted over the last 10 years. This study included publications from diverse authors and perspectives and focused on different topics and subsets of the CHIWOS participant population. This increased the reliability of the findings and ensured a full picture of the CHIWOS population's experiences was represented in the concept maps. Further strengthening this representation was the iterative and community-based nature of the concept mapping process itself. The process was driven by a diverse group of community members who amended the maps and diagrams through several rounds of consultations, which ensured their accuracy. While we recognize that the inclusion of publications under review or nearing publication may be perceived as a potential limitation due to the absence of peer review, we primarily interpret this as a strength. This decision allowed us to account for the inherent time lag between research analysis and formal publication, ensuring our analysis captures both established and emerging insights in the field. Furthermore, all "in progress" manuscripts included in this analysis have since been published, affirming the validity of our conclusions.

To prevent theme overrepresentation, we carefully examined the content of each conference abstract and publication to ensure duplicate results were not included. Some publications covered similar themes, such as disclosure, pregnancy loss, cervical cancer disparities, women-centred HIV care, help-seeking, the relationship between stigma and other factors, conception in serodiscordant couples, and issues specific to trans women. However, there were nuanced differences with each of these themes. For instance, the

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conference abstract focused on disclosure specifically addresses disclosure worries as a factor contributing to health outcomes, while the manuscripts explore experienced child abuse as a determinant of barriers to disclosure and awareness of the criminalization of disclosure. We find including these nuanced distinctions valuable, as concepts recurring in two or more composite concept maps were considered critical findings. Our rigorous approach to highlight crucial findings without data overrepresentation is a key strength of this study.

The co-creation of separate composite concept maps for cis and trans women shows the important similarities and differences between cis and trans women's experiences, and provides a unique perspective not explored in the individual concept maps. Our findings show many similarities in the health experiences of cis and trans women with HIV in CHIWOS were shared (21). This is important for providers who often assume providing care to trans women with HIV requires a unique skillset and approach (22). The key differences in the summary diagrams were gender affirmation at the individual level, as well as trans care knowledge and training at the structural level. Obtaining training in trans health and gender affirmation is a manageable goal that providers can achieve to deliver more competent care to trans women with HIV (23).

There are some limitations of this study . Efforts were made to engage lead investigators and community researchers from all provinces included in the CHIWOS study, but only academic researchers (not community researchers) from Quebec participated in this study. However, six manuscripts were included in production of the composite concept maps in which the first author was from Quebec and community members were involved in co-authoring these publications. In shaping our study, we

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intentionally excluded manuscripts exclusively featuring qualitative data; a decision that might be seen as constraining the incorporation of certain insights. This choice was driven by the inherent challenges of equitably integrating qualitative and quantitative data, especially given the marked difference in sample sizes between the two types of manuscripts. To mitigate this limitation, we extensively involved community researchers in the concept mapping and summary diagram creation process, ensuring a comprehensive approach.

Recently, fellow CHIWOS investigators also employed mapping techniques to examine the experiences of women with HIV in accessing care. Skerritt et al. (24) used Fuzzy Cognitive Mapping, a participatory research method, to identify factors influencing satisfaction with HIV care and to understand engagement in the HIV care cascade. The Summary Fuzzy Cognitive Map they produced shows the weightings of categories influencing satisfaction of care, with the most significant being feeling safe and supported by healthcare providers, accessible services, and healthcare provider expertise (24). These mirror some of our findings in our composite concept maps 2 and 6 which show the relationships among access to care, comprehensive care, and feelings of stigma. Both studies offer valuable visual insights into women's experiences, complementing each other and contributing to a comprehensive understanding when interpreted together.

Our study delved into the nuanced experiences of women with HIV through the lens of CHIWOS, examining psychosocial determinants, clinical aspects, mental health, sexual and reproductive health outcomes, and healthcare access and quality gaps to inform policy and programming for women with HIV in Canada. A recurring theme in

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the composite concept maps and summary diagrams was the lack of receipt of comprehensive women-centred HIV care (3) including lack of discussion of reproductive goals, and access to care like gender affirmation. This finding suggests providers must improve knowledge through accessing clinical guidelines related to women with HIV such as the Canadian HIV Pregnancy Planning Guidelines, the Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV, the British Columbia Guidelines for the Care of HIV Positive Pregnant Women & Interventions to Reduce Perinatal Transmission, and the Sherbourne's Guidelines for Gender-Affirming Primary Care (25-28). The composite concept maps also demonstrate the negative effects of low socioeconomic status and stigma and discrimination on women's self-reported resilience. This could impact the ability to self-advocate in healthcare settings, further affecting quality of care received. This finding has important implications to how clinicians and service providers approach care relationships and the importance of practicing from a person-centred lens.

In exploring the intricate layers of women's experiences with HIV, composite concept maps 2, 3, and 4 show the profound impact stigma has on the lives of women with HIV. Societal stigma surrounding HIV not only amplifies the complexities of managing a chronic health condition, but also significantly contributes to heightened mental and emotional distress. Within this challenging context, resilience emerges as a pivotal force in composite concept maps 1 and 6. The intricate interplay between resilience and stigma reveals a dynamic process wherein women not only navigate adversity but also actively contribute to dismantling societal prejudices (29). These map contribute to a deeper understanding of the complex relationship between stigma,

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resilience, and empowerment, which the Wheel of Resilience points to the need for a more supportive environment for women with HIV.

The interconnectedness between mental health and experiences of violence in adulthood further compounds the challenges women with HIV face, as depicted in composite concept maps 1-4. Women with HIV often contend with not only the physiological ramifications of the virus but also the psychological distress stemming from social stigma and potential encounters with violence. Composite concept map 3 highlights this especially for Indigenous women, who confront heightened violence in adulthood, likely due in part to the impact of historical and systemic factors such as colonialism and anti-Indigenous racism. While this trend was primarily noted among Indigenous women, it is probable that similar dynamics affect other racialized women as well. Composite concept map 2 introduces another dimension by revealing a correlation between experiencing violence in adulthood and a decrease in the utilization and adherence to cART. This clinical impact of violence emphasizes the pressing need for comprehensive trauma healing interventions. Evidently, the convergence of mental health, stigma, and violence presents significant obstacles for women with HIV to access adequate mental health support, worsening existing disparities. It is vital to address this complex relationship to develop a more holistic approach to care for women with HIV, ensuring much-needed interventions are not only medically effective but also tailored to women's unique health and holistic needs.

Another notable finding was the significance of positive healthy actions in the health experiences of women with HIV. This theme was evident in several composite concept maps, including map 1, which illustrated connections between social support and

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reduced HIV-related stigma, and map 2, which demonstrated correlations between peer leadership involvement and increased awareness of ART prevention benefits. This finding has substantial policy implications, suggesting that investment in peer leadership and support programs for women with HIV can yield tangible mental and physical health benefits. Such proactive measures may contribute to a reduced burden on the greater healthcare system.

The next steps for policy advocacy are the co-development of a national women-centred HIV care (30) strategy that ensures equitable access to care including gender affirmation, and resource creation and education to increase knowledge about the health care gaps women with HIV experience in Canada. Since the completion of this study, the field of women-centred HIV care has experienced significant developments, including the publication of a Women-Centred HIV Care Model informed by CHIWOS findings in 2021 (30), the launch of new women-specific HIV studies such as the British Columbia CARMA-CHIWOS (BCC3) study (31), and movement towards a National Action Plan to advance the sexual and reproductive health and rights of women with HIV in Canada (32). Aligned with these recent contributions, the findings from this concept mapping study underscore persisting unanswered questions and emphasize crucial future research priorities. One essential research focus that arises from our study is the need to develop and implement comprehensive women-centred HIV care strategies in clinical settings to facilitate translation of women's needs to their care providers, thereby influencing clinical measures of health and well-being. Moreover, our findings, coupled with insights from the broader literature (3,22,33-38) highlight the diversity among women with HIV, reflecting the varied nature of their needs. While the Women-Centred HIV Care Model

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provides a solid foundation, it is evident that women's priorities and needs vary, often shaped by other aspects of their identity including race and gender identity. Led by members of the respective groups and individuals with lived experience, ongoing efforts are being made to customize and tailor the Women-Centred HIV Care Model for priority populations, including trans women, African, Caribbean, and Black women, as well as Indigenous women. Our findings also highlight the need to investigate the intersection of mental health, stigma, trauma and violence and its impact on the wellbeing of women with HIV, as well as to develop trauma-informed strategies, approaches and programming aimed at addressing these intersecting factors. In summary, future research should concentrate on developing positive and health-oriented actions and programs tailored to women with HIV, incorporating an intersectional perspective. These efforts should not only address the unique needs shaped by diverse aspects of identity, but also offer leadership and capacity-building opportunities for peer-led initiatives centered around self-care and wellbeing.

CONCLUSION

We developed a unifying summary of the health experience of women with HIV in Canada by applying concept mapping to 60 CHIWOS publications. The produced visuals can be used to inform policy and programming by providing easy to understand evidence on gaps related to the social determinants of health including housing, food security, and income, in addition to structural barriers such as multiple areas of discrimination. Importantly, these visuals promote strength-based approaches to women with HIV's health and wellbeing. The results of this study should guide future research and care priorities for women with HIV in Canada, placing a specific emphasis on trauma-

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informed, peer-led positive healthy actions accessible to women in all their diversity. This includes initiatives aimed at enhancing women-centred HIV care and self-care to comprehensively improve the holistic wellbeing of women with HIV.

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Patient and public involvement: Patients and/or the public were involved in the design, conduct, or dissemination plans of this research. Refer to the Methods for further details.

Data availability statement: No additional data available.

Ethics approval and consent to participate: The study was assessed by the research ethics board at Women's College Hospital to not require ethical approval by a human research ethics committee because the Ethical Principles for Medical Research Involving Human Subjects did not apply. We obtained informed consent from all participants in CHIWOS. Refer to the Methods for further details.

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FIGURE TITLES

Figure 1. Applying the Eligibility Criteria to CHIWOS Publications

Figure 2. Example of an individual concept map from one publication (Access to Care, Kronfil et al., 2017)

Figure 3. CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

Figure 4. CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

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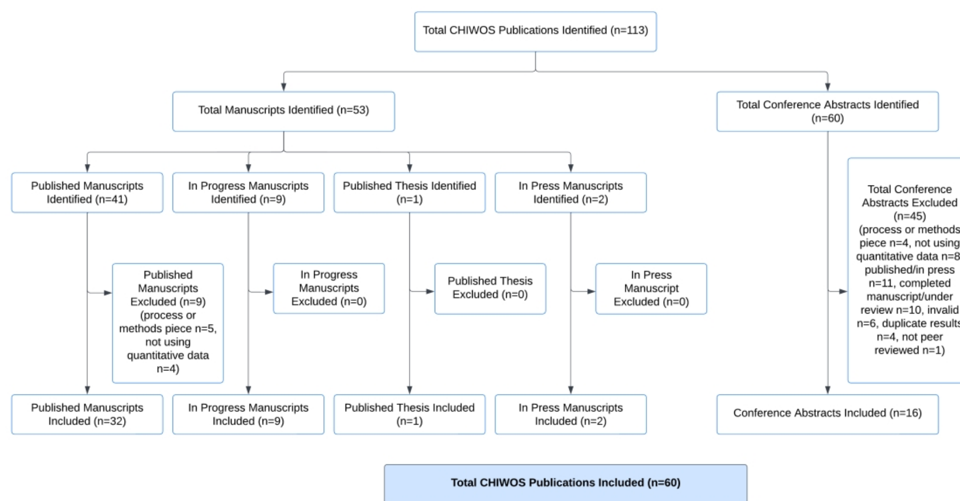

Figure 1: Applying the Eligibility Criteria to CHIWOS Publications

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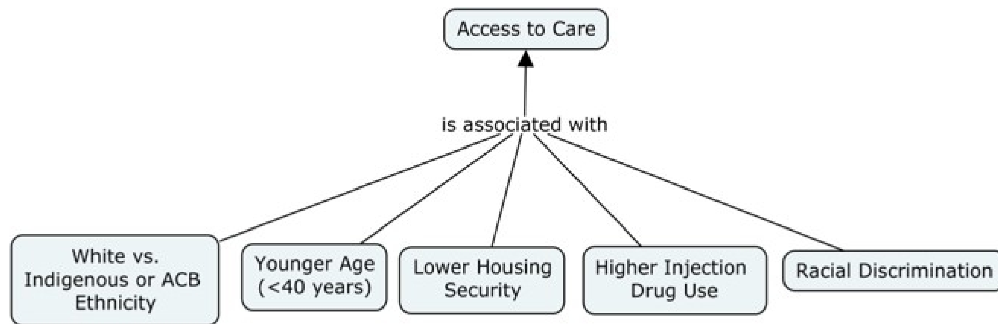

Figure 2: Example of an individual concept map from one publication (Access to Care, Kronfil et al., 2017)

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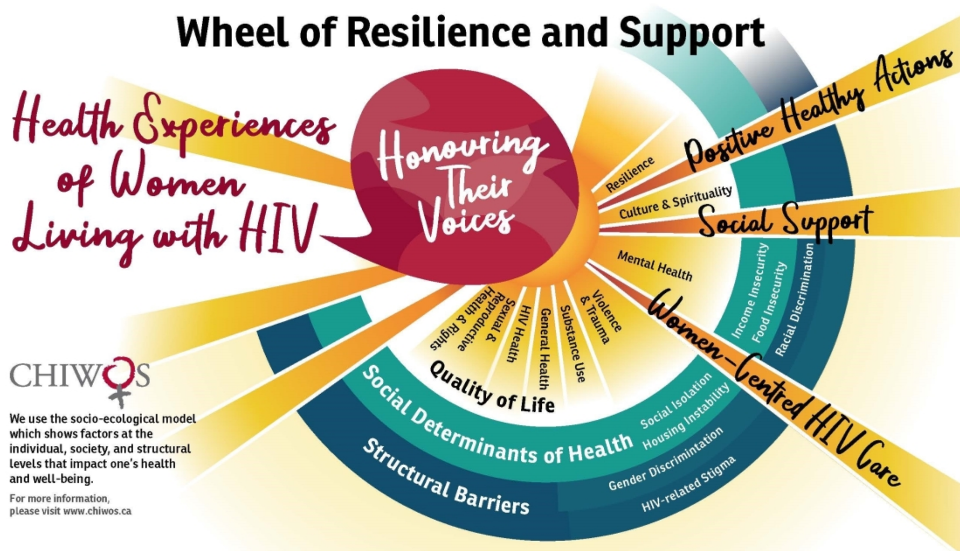

Figure 3: CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

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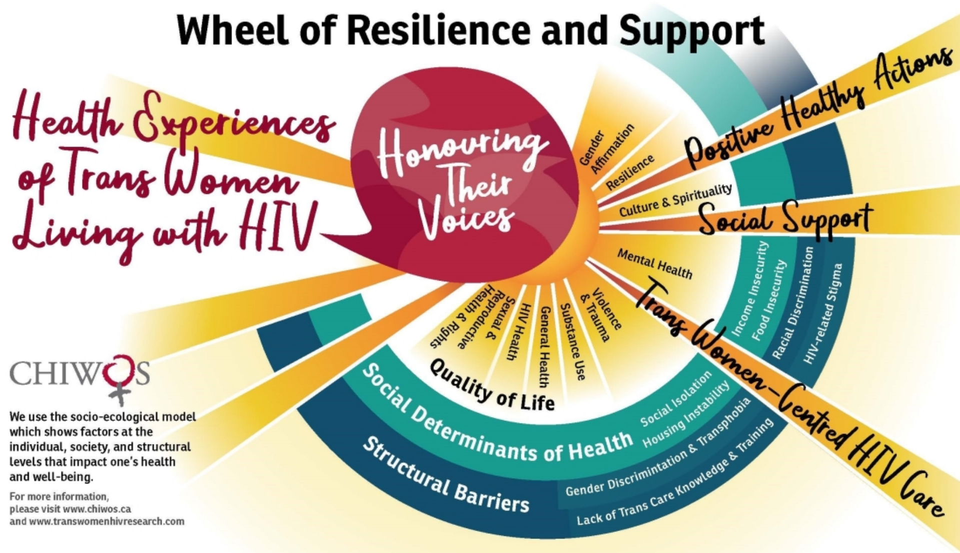

Figure 4: CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

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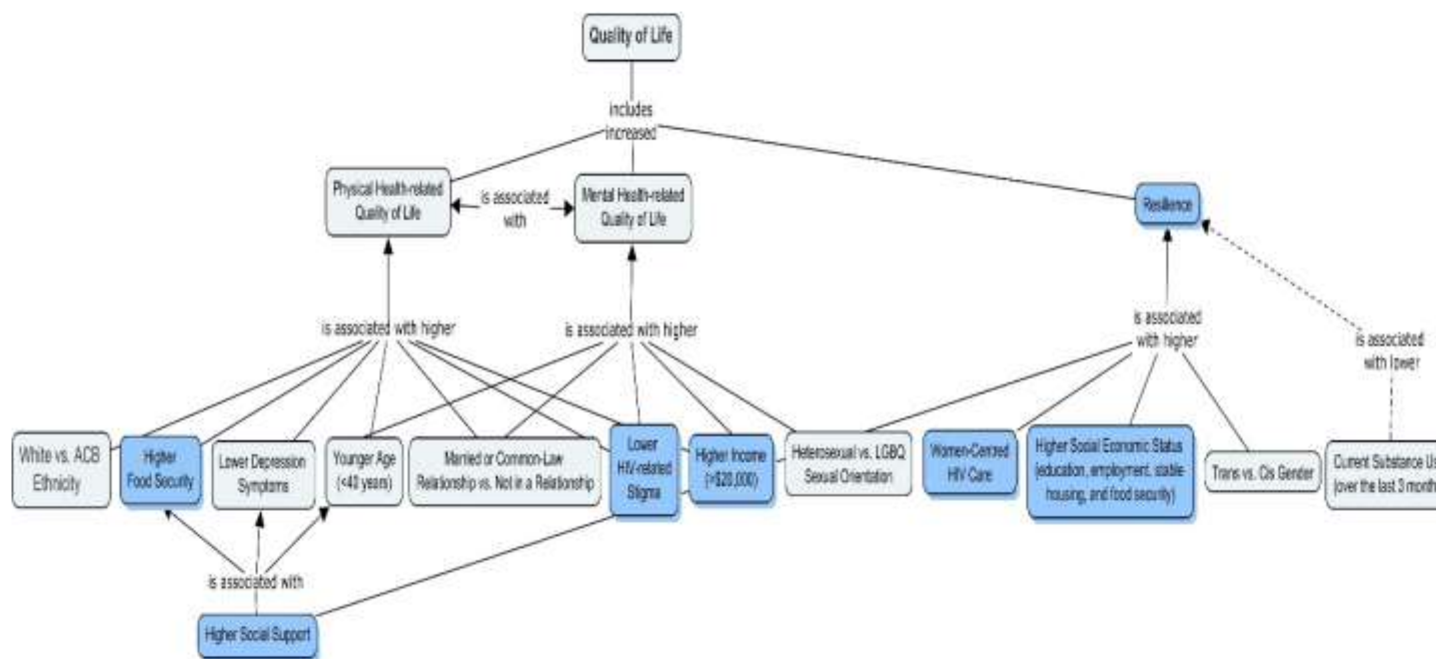
Supplementary Figure 1: Quality of Life Concept Map



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Our definition of Quality of Life (QOL) extends beyond one's physical and mental health status. It is expanded to also include QOL's relationship with resilience and overall wellbeing. QOL was measured using the SF-12 scale.

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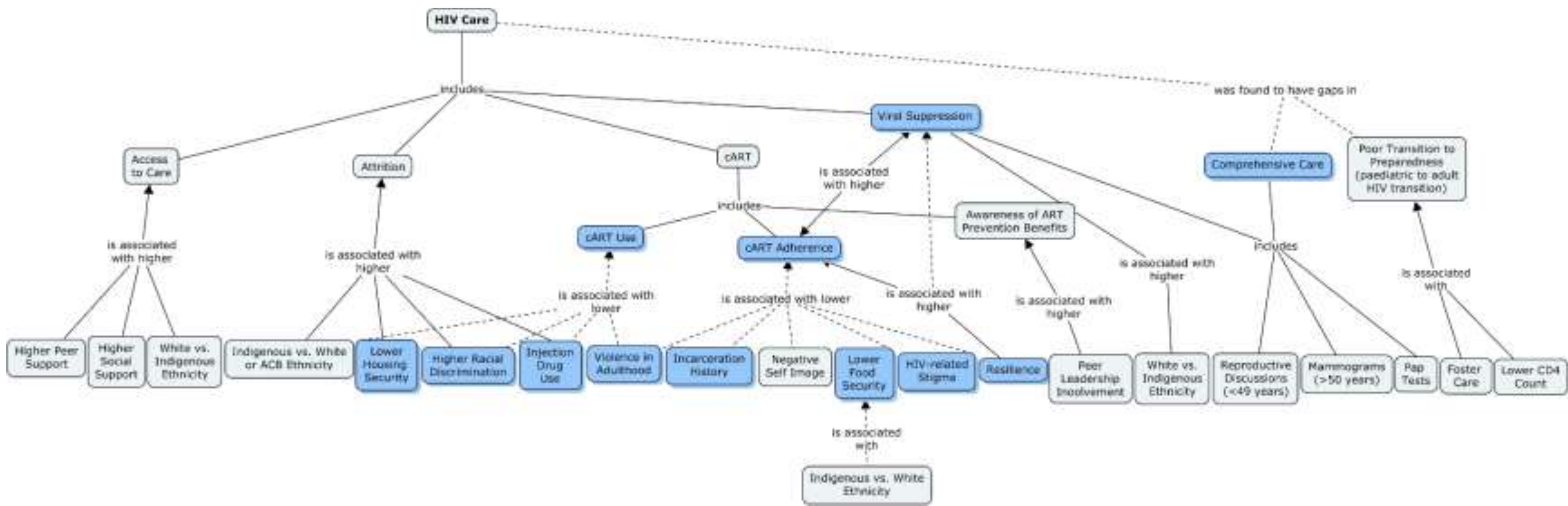
Supplementary Figure 2: HIV Care Concept Map



Attrition refers to reduction in the % at each stage of the HIV care cascade. These stages are: 1) access to care, 2) cART use, 3) cART adherence, and 4) viral suppression.

Comprehensive care is defined by four indicators: Pap test, viral load suppression, reproductive discussions, and mammograms.

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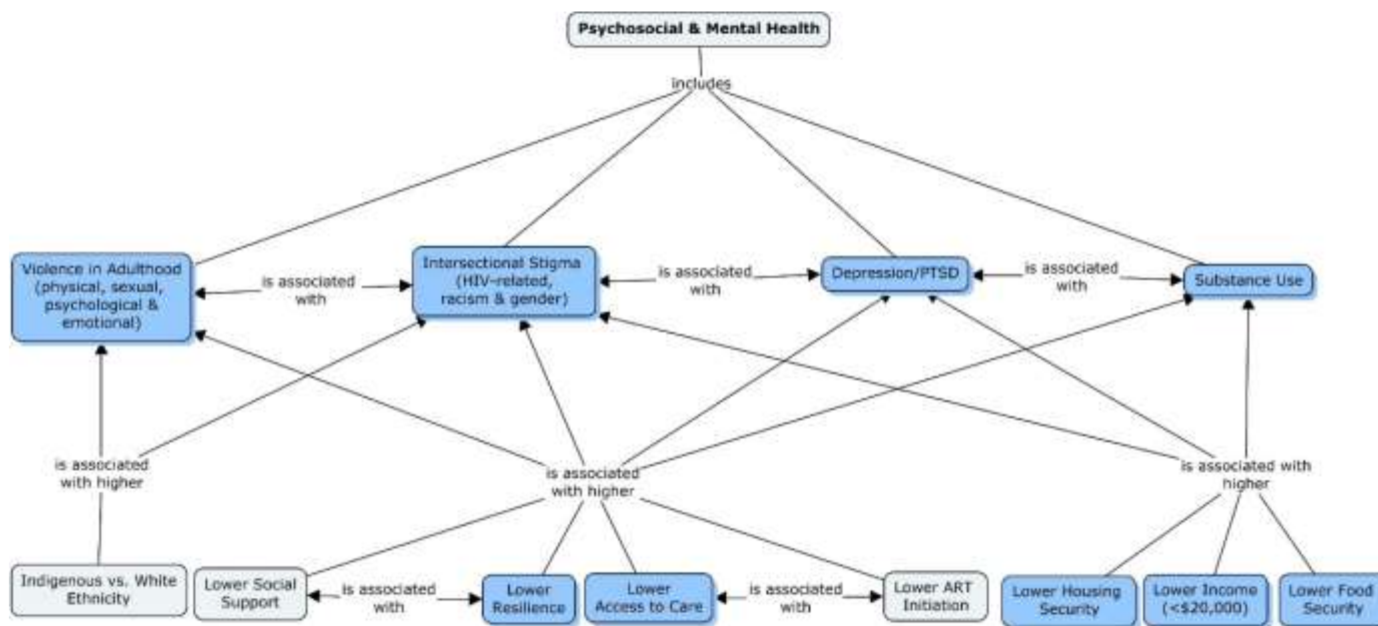
Supplementary Figure 3: Psychosocial and Mental Health Concept Map



Intersectional stigma, violence, depression/PTSD, and substance use are associated with each other. Also, access to care was measured using the Barriers to Access to Care 12-item scale.

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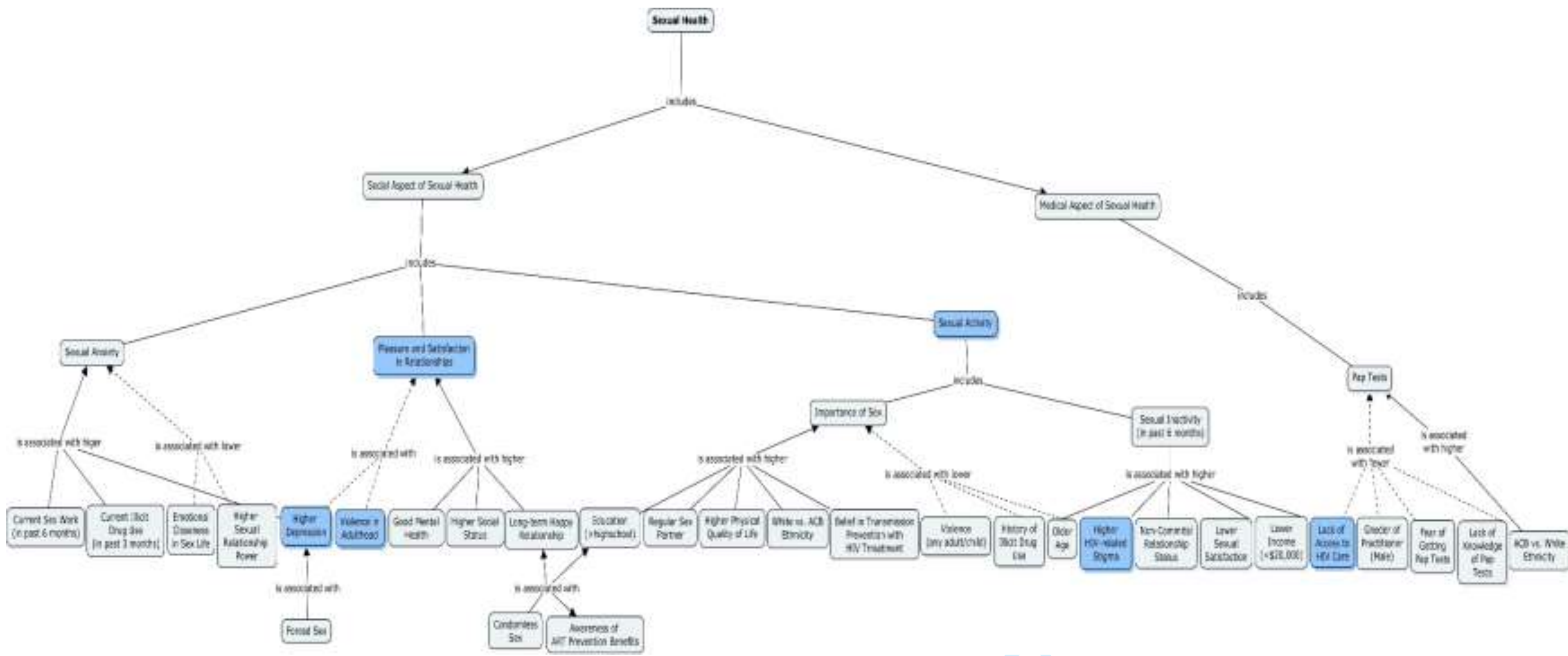
Supplementary Figure 4: Sexual Health Concept Map



There are various medical aspects of sexual health, including the experiences and management of sexually transmitted infections; however, CHIWOS has not yet analyzed data on them.

Sexual activity was defined as consensual sex (oral or penetrative) in the past six months based on the questionnaire used; but it is understood to represent much more including sexual desire, sexual needs, sexual being, and more.

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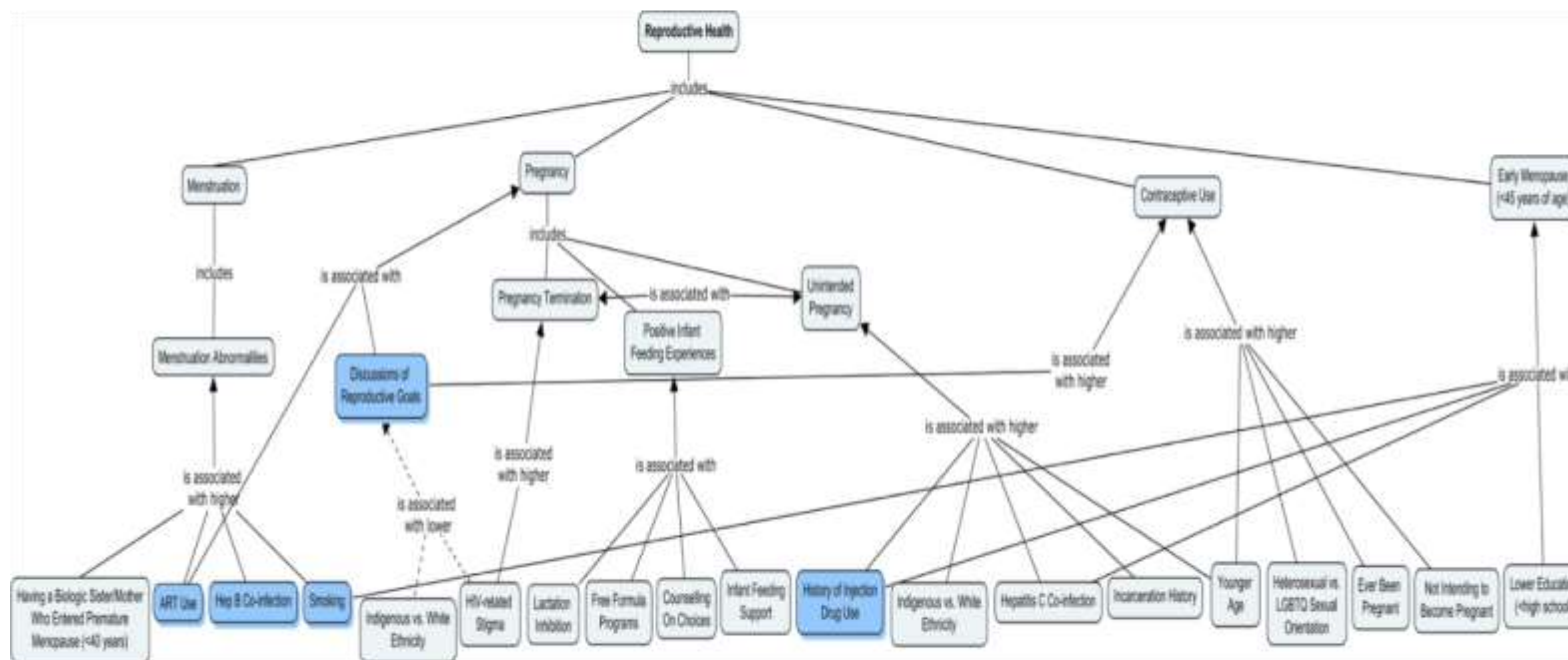
Supplementary Figure 5: Reproductive Health Concept Map



CHIWOS findings showed a narrow range of contraceptive methods used.

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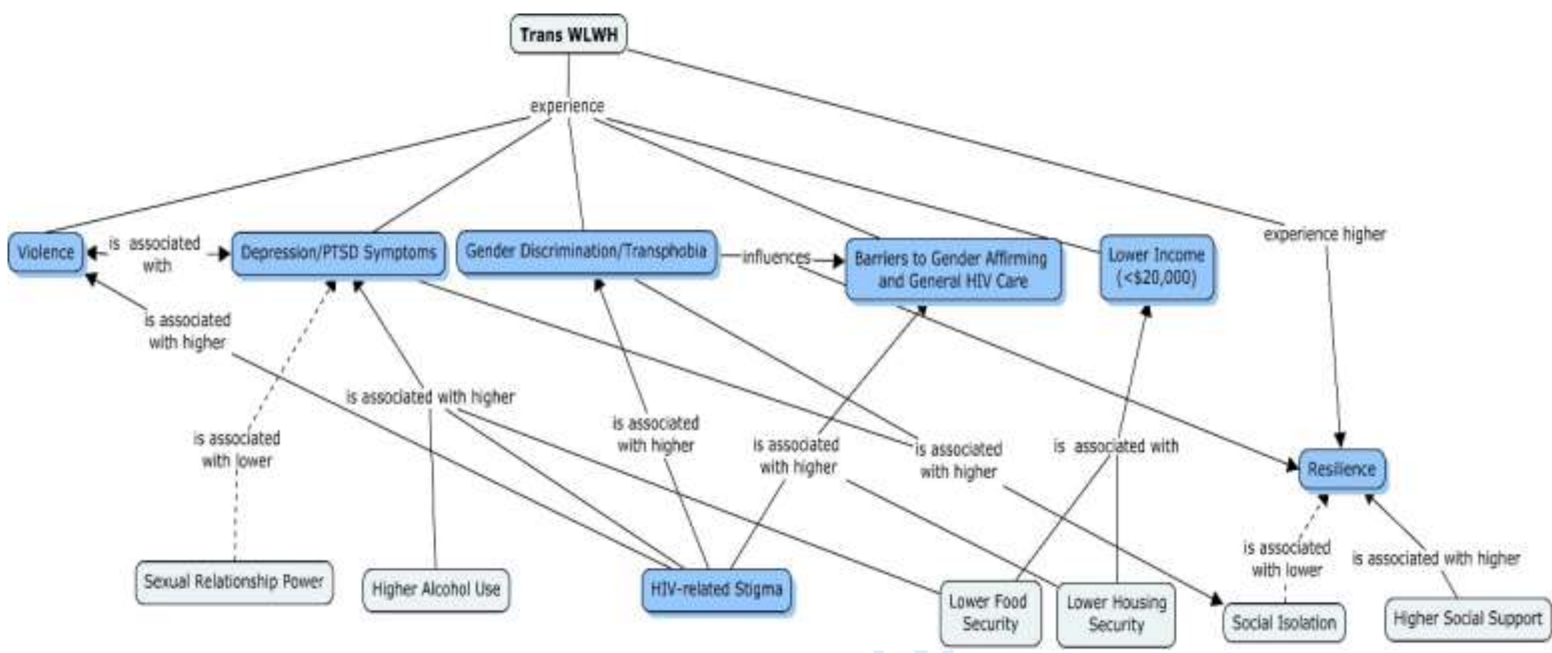
Supplementary Figure 6: Trans WLWHIV Concept Map



Social isolation is the absence of social and economic supports (i.e., lower income, housing, and food services) which are barriers to ongoing engagement in HIV care. These variables are in comparison to cis-gender women.