Developing a women-centred HIV care (WCHC) model: using the findings from the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS)

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Presented at the 8th International Workshop on HIV & Women
Boston, MA, USA– March 2-3, 2018
Acknowledgments

We would like to acknowledge that we gather on the traditional territory of Massachusetts Nation, Nipmuc Nation, Wampanoag Tribe of Gay Head, and Mashpee Wampanoag.
Conflicts of Interest Disclosure

- In the past 2 years, I have received funds from Gilead Sciences, Merck Canada Inc. and Viiv Healthcare for research, travel & presentations.

- There are no relationships to disclose related to this work.
Background

- **Women with HIV experience vast social inequities and poorer health outcomes than men with HIV**
  - Social inequities: power imbalances, intersecting oppressions, issues related to social determinants of health\(^1\)
  - Poorer health outcomes: linkage to care, ART use, viral suppression, depression, isolation, anxiety,\(^2,3\) & high rates of violence and trauma\(^4\)

- **Women with HIV have unique social and health concerns requiring complex care**
  - Medical care: HIV, comorbidities, aging issues
  - Women’s health care: sexual and reproductive needs
  - Social needs: housing, food security, sense of belonging

“My female patients’ care is complex and they need their women’s health, psychosocial needs and HIV care addressed. How do I do that? What is the best way to do that?”
Launched the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS) in 2011

- Applies Community-based research (CBR) practice - *by, with & for* women living with HIV … hired & trained as research assistants, etc.

- **Guiding Frameworks:** Critical Feminism, Anti-Oppression, Social Justice, GIPA, MIWA, Social Determinants of Health

**AIM:** to develop an all-encompassing “Women-centered HIV Care” (WCHC) model to address the unique health & social needs of women living with HIV

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Methods

- We applied Change Management Theory to develop our WCHC model
  - A theory introduced by Lewin in the 1940s\(^5\)

- We used the NHS North West Leadership Academy adapted version with 10 practical steps:
  - 1) initial problem identification -> 2) ground work and communication -> 3) data obtainment -> 4) problem diagnosis -> 5) action planning -> 6) implementation -> 7) follow up and stabilisation -> 8) assessment of consequences -> 9) ongoing monitoring and 10) learning from the process.
  - For the purpose of developing our model of care, we used the first five steps.


\(^7\)http://www.nwacademy.nhs.uk/sites/default/files/86_1722011_lewin_s_change_management_model.pdf
Methods – Change Management Theory

1. Defined the problem – by women with HIV in Canada & Globally

2. Conducted a Literature Review

3. Conducted 11 focus groups with 77 women with HIV

4. Analysed quantitative baseline survey data from of 1422 CHIWOS participants

5. Held Stakeholder Meetings & incorporated their feedback

DEVELOPED THE MODEL
Results

Literature Review
Definition of WCHC: “Care that supports women living with HIV to achieve the best health and wellbeing as defined by them. This type of care recognizes, respects, and addresses women’s unique health and social concerns, and recognizes that they are connected. Because this care is driven by women’s diverse experiences, it is flexible and takes their different needs into consideration”.1,2

Focus Groups
- Addresses HIV and women’s health care priorities, and protects against HIV-related stigma
- Recognizes and responds to structural barriers that limit women’s access to care, such as violence, poverty, motherhood, HIV-related stigma, and challenges to safe disclosure
- Fosters peer support and peer leadership in its design and delivery to honor the diversity of women’s experiences, overcome women’s isolation, and prioritize women’s ownership over the decisions that affect their lives.

2Carter et al. (2013). Women-specific HIV/AIDS services: identifying and defining the components of holistic service delivery for women living with HIV/AIDS. JIAS.
# CHIWOS Survey Results: Demographics

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Total (n=1422)</th>
<th>British Columbia (n=356)</th>
<th>Ontario (n=713)</th>
<th>Quebec (n=353)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Median Age (IQR)</strong></td>
<td>43 (36-51)</td>
<td>44 (37-51)</td>
<td>41 (34-49)</td>
<td>46 (38-53)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Gender identity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.804</td>
</tr>
<tr>
<td>Cis woman</td>
<td>1359 (96%)</td>
<td>342 (96%)</td>
<td>679 (95%)</td>
<td>338 (96%)</td>
<td></td>
</tr>
<tr>
<td>Trans woman/other Gender identity</td>
<td>63 (4%)</td>
<td>14 (4%)</td>
<td>34 (5%)</td>
<td>15 (4%)</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Indigenous (First N, Métis, Inuit)</td>
<td>318 (22%)</td>
<td>161 (45%)</td>
<td>149 (21%)</td>
<td>8 (2%)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>585 (41%)</td>
<td>139 (39%)</td>
<td>280 (39%)</td>
<td>165 (47%)</td>
<td></td>
</tr>
<tr>
<td>African/Caribbean/Black</td>
<td>418 (30%)</td>
<td>28 (8%)</td>
<td>227 (32%)</td>
<td>163 (46%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Other ethnicity</td>
<td>103 (7%)</td>
<td>28 (8%)</td>
<td>57 (8%)</td>
<td>17 (5%)</td>
<td></td>
</tr>
</tbody>
</table>
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<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education (≥ High school)</strong></td>
<td>1191 (84%)</td>
<td>260 (73%)</td>
<td>629 (88%)</td>
<td>302 (86%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$20 000 CAD/year</td>
<td>904 (65%)</td>
<td>259 (73%)</td>
<td>425 (60%)</td>
<td>220 (62%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>$20 000 - $40 000/year</td>
<td>284 (21%)</td>
<td>53 (15%)</td>
<td>155 (22%)</td>
<td>76 (22%)</td>
<td></td>
</tr>
<tr>
<td>≥ $40 000</td>
<td>194 (14%)</td>
<td>33 (10%)</td>
<td>108 (15%)</td>
<td>53 (15%)</td>
<td></td>
</tr>
<tr>
<td>Food insecurity (% food insecure) (n=1418)</td>
<td>510 (36%)</td>
<td>135 (38%)</td>
<td>232 (33%)</td>
<td>143 (41%)</td>
<td>0.027</td>
</tr>
<tr>
<td>Housing (% unstable housing)</td>
<td>152 (11%)</td>
<td>59 (17%)</td>
<td>84 (12%)</td>
<td>9 (3%)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Prevalence of experiences of adulthood violence among women with HIV in Canada (n=1312)

<table>
<thead>
<tr>
<th>Experienced violence in adulthood (&gt;16 years old)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any type of violence*</td>
<td>1054 (80%)</td>
</tr>
<tr>
<td>Physical violence</td>
<td>817 (74%)</td>
</tr>
<tr>
<td>Sexual violence</td>
<td>579 (44%)</td>
</tr>
<tr>
<td>Verbal violence</td>
<td>973 (74%)</td>
</tr>
<tr>
<td>Control</td>
<td>608 (46%)</td>
</tr>
</tbody>
</table>

*Associated with province, ethnicity, income, substance use, PTSD & clinical outcomes

Depressive Symptoms among women in CHIWOS

- Used CES-D 10
  - Score range: 0-30
  - Higher scores = higher depressive symptoms
  - Cronbach-α = 0.88

- CES-D score of ≥10 indicates presence of depressive symptoms
  - Mean score = 10.03 (SD=7.56)

N=1370

n=666 (48.6%) with depressive symptoms
n=704 (51.4%) without depressive symptoms

Logie et al.; Under preparation
Pap Testing among women in CHIWOS

Guideline recommendation:

➢ Annual Pap Testing for women after HIV diagnosis in Canada

Pap testing in sample (n=1190):

➢ 2/3 adhere to guidelines
➢ 1/3 non-adherence to guidelines
  • 17.7% had a Pap test between 1 and 3 years ago
  • 4.8% had a Pap test between 3 and 5 years ago
  • 4.6% had a Pap test 5+ years ago
  • 4.3% never had a Pap test

Percentage of women who received an annual Pap Test, by province (%)

De Pokomandy et al.; Submitted
Cascade of HIV Care among women in CHIWOS

96% retained in care & 88% initiated on cART

Kerkerian et al.; Submitted
Conclusions of CHIWOS analyses

- The experience of violence is central
- **HIV Care** is relatively good
- Poorer **women’s health care**
- Poor **mental health** and potentially care

- Put together with **Focus Group results**
  - Address **structural barriers**
  - Incorporate **Peer support**

... We developed **OUR MODEL**
Results – The House

Across the Life course of women covering age-related issues
Results – The House

Across the Life course of women covering age-related issues

Peer Support
Leadership
Capacity Building

Competent HIV Care
Competent Women’s Health Care
Competent Mental Health Care

Person-Centered Care w/ Attention to Social Determinants of Health & Family

Trauma- and Violence-Aware Care
Other consideration

Who is Providing Care?

Isn’t this a Primary Care Model?

**Physician that is Primary HIV Care Provider**
(n=1313)

- Family Physician
- Immunology
- Unknown/Other Specialty
- Infectious Diseases
- Microbiology

**Distribution of Care Provision Types**
(n=1422)

- No Family Physician or Specialist
- Family Physician Only
- Specialist Only
- Family Physician and Specialist

CHIWOS
**WCHC Model with Multiple Modes of Delivery**

**Mode 1** – Primary care, nurse, NP delivery … **IDEAL MODE**

**Mode 2** – Shared care b/w Primary care & Inf. Dis. specialist

**Mode 3** – Infectious Disease Specialist Delivery **SPECIALIST LEARNS ALL ASPECTS**
FLEXIBILITY IS KEY

Selection of Mode of Care

We want the WCHC model to be flexible and applicable to all possible settings:

- Where women live
- What services are available

RURAL: one nurse, one NP, one doctor assistant

URBAN: all services in one setting, primary care delivery

IN BETWEEN: multi-organization service
Next Steps

- Our next step is to develop a user-friendly toolkit and checklists to allow organizations to implement WCHC for improving the care and outcomes of women with HIV.

* Funded by a CIHR Foundation Grant this year
# Working with the WHO to submit a grant to launch in 1 country per 6 WHO regions
Acknowledgments

Thank-you to all our community and clinical partners!

**B.C.**: Oak Tree Clinic at BC Women’s Hospital, AIDS Vancouver Island, BC Centre for Excellence in HIV/AIDS, Cool Aid Community Health Centre, Downtown Community Health Clinic, Keys Housing and Health Solutions (Positive Haven), Living Positive Resource Centre, Positive Living Fraser Valley, Positive Women's Network (closed), Positive Living North, and Vancouver Island Persons with AIDS Society.

**ON**: 2-Spirited People of the 1st Nations; 519 Community Centre; ACCKWA; Africans in Partnership Against AIDS (APAA); AIDS Committee of Durham Region; AIDS Committee of Guelph and Wellington County; AIDS Committee of Simcoe County; AIDS Network Hamilton; Alliance for South Asian AIDS Prevention; Black Coalition for AIDS Prevention; Bruce House; Casey House; Centre Francophone; Elevate NOW; Fife House; Hemophilia Ontario; HIV/AIDS Regional Services (HARS); Maggie’s: Toronto Sex Worker’s Action Project; Peel HIV Network; Positive Living Niagara; Positive Pregnancy Program: P3; Prisoners with AIDS Support Action Network; Réseau Access Network; Toronto PWA Foundation; Women’s Health in Women’s Hands; Children’s Hospital of Eastern Ontario; Kingston Hotel Dieu Hospital; Health Sciences North, Sudbury Regional Hospital, HAVEN Program; Lakeridge Health; Maple Leaf Medical Clinic; McMaster Family Practice; Ottawa General Hospital; Riverside Family Health Team; SIS Clinic, Hamilton Health Sciences; St. Joseph’s Healthcare London; St. Michael’s Hospital; Sunnybrook Health Sciences Centre; Toronto East General Hospital; Toronto General Hospital; William Osler Health System; Windsor Regional Hospital, HIV Care Program.

**QC**: ACCM; L’ARCHE de l’Estrie; ASTT(e)Q; BLITS; BRAS-Outaouais; CACTUS; CASM; Centre des R.O.S.E.E.S; Centre Sida Amitié; Corporation Félix Hubert d’Hérelle; COCQ-SIDA; GAP-VIES; M.A.I.N.S-Bas St-Laurent; Maison Plein Coeur; Maison Dominic; Maison du Parc; Maison Re-Né; MIELS-Québec; Le MIENS Chicoutimi; Portail VIH/sida du Québec; Sidaction Mauricie; Sida-Vie Laval; Stella, l’amie de Maimie; UHRESS-Notre-Dame du CHUM.
We honour and remember the 55 CHIWOS participants from across Canada who have passed away and are no longer with us but will always remain in our hearts.

In memory of Marisol Desbiens
CHIWOS PRA and valued colleague

Feb 23, 2018