



Presented by



Webinar co-organized
by CATIE and the
Sharing Together For
Life (STFL) study group

September 14 in French
September 15 in English
2015

With the participation of

**Ginette Tremblay and
Dada Bakombo**

Co-Founders and
Ambassadors of STFL



Program funded by the Canadian Institutes of Health Research



Our presenters



Ginette Tremblay



Ginette Tremblay has dedicated her life to helping people. During her 25-year nursing career, she completed a bachelor's degree in education, a bachelor's degree in psychosocial intervention models at Concordia University and rational emotive therapy studies.

Her work with the HIV/AIDS community started in 1992 when she began to facilitate grief support groups at the Pierre-Ainault centre in Montreal and became a volunteer support worker at the Centre for AIDS Services of Montreal--Women (CASM).

Ginette soon became a volunteer at AIDS Community Care Montreal (ACCM), where she facilitated support groups and later became a Case Manager. During this period, she moved to the Outaouais region for a year and a half to work at the Bureau régional d'Action Sida (BRAS) as a support coordinator.

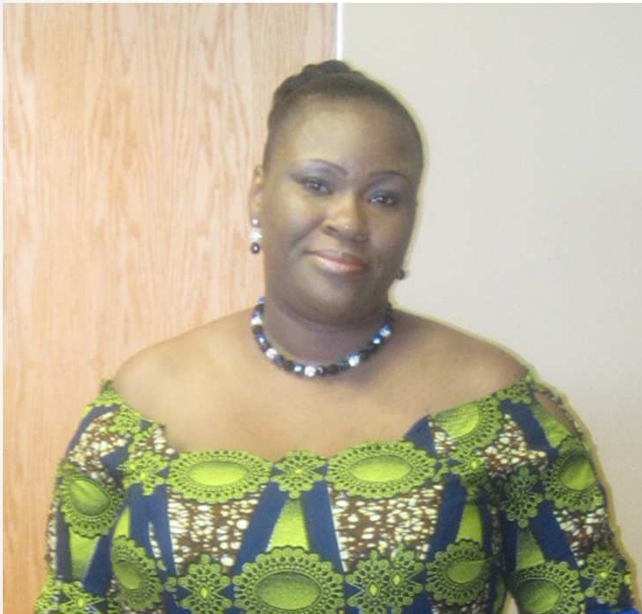
Ginette has worked with the HIV/AIDS community for 20 years and was honoured for her contributions by the Farha Foundation in 2010.



Our Presenters

Dada Bakombo

Wife and mother, Dada Bakombo is a UQAM graduate in educational interventions in family and community settings. She is also working towards her degree in psychosocial interventions. After joining GAP-VIES in 2005, she worked as a facilitator in living environments, a coordinator for the African component of “*Pour une réponse interreligieuse au VIH/SIDA*” (an inter-religious response to HIV/AIDS program) and a care and volunteer action coordinator.



She has served as a coordinator for the Sharing Together For Life program and has worked as a research assistant on many research projects, including the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS), the study on the impact of food safety on the health of people living with HIV/AIDS, the study on the emotional and sexual health of women living with HIV (“*Plurielles*”), and the second generation monitoring study of Anglophone African and Caribbean communities in Montreal. She continues to work with people living with HIV, providing them with the support they need in an atmosphere of respect and professionalism.



Our presenters



Joanne Otis

Joanne Otis is a professor in the sexology department of UQAM. Her research work involves analyzing psychosocial and cultural factors related to sexual health, as well as the development, cultural validation, implementation, and evaluation of applied programs. She works with various populations: teens in schools, street youth, men who have sexual relations with other men, and people living with HIV. She is known for conducting participatory research projects in partnership with local HIV/AIDS groups located in Quebec, in Canada and abroad.

Our Presenters



Lyne Massie

Lyne Massie holds a Bachelor's degree and a Master's degree in sexology from UQAM. She has worked with local HIV/AIDS advocacy groups and currently works as a research coordinator in UQAM's sexology department. She has coordinated various research projects and has evaluated two programs to improve the quality of life of women living with HIV in Quebec and Mali: "Sharing Together For Life" and "*Plurielles*."

Presentation of Partners



Centre de santé et de services sociaux
Jeanne-Mance



UQÀM



Centre universitaire de santé McGill



Université de Montréal

Presentation Structure



Program Presentation

- ✓ History
- ✓ Description and implementation
- ✓ Objectives
- ✓ Principles
- ✓ Structure and procedure

Program Implementation

- ✓ Barriers, facilitators
- ✓ Tips and advice

Program Impacts



Program Presentation

The Story of STFL (1/3)



Qualitative Participatory Study 2002-2004

- CHU Sainte Justine Mother and Child University Hospital Center, Gap-Vies, C.R.I.S.S., COCQ-sida and UQAM research team
- 42 WLHIV took part in the study
- Description of life experiences since starting antiretroviral (ARV) drugs from a social, familial, personal and medical perspective.

Situational Analysis 2005

- Consultation with key informants/discussion groups conducted with WLHIV
- Evaluation of available programs and services
- Creation of conditions favourable for the development of a program
- Selection of the issue of disclosure as a priority because it diminishes the amount of control which WLHIV feel they have in all aspects of their lives

Pilot Project/Validation 2006-2007

- Birth of a partnership-based dynamic
- Active collaboration and participation between the research team and key informants through various working committees (steering, technical and monitoring)
- 4 implementation settings in Montreal: CASM, CRISS, GAP-VIES and UQAM
- Participation of 38 women in the workshops
- Formative evaluation

The Story of STFL (2/3)



Provincial Training 2008

- October 23-24, 2008
- 26 participants (facilitators/WLHIV)
- 17 institutions/community organizations represented

Implementation and Evaluation of the Program in Quebec 2009-2010

- 85 women took part in the workshops
- 15 community organizations
- Various Quebec regions: Greater Montreal, Centre du Québec, Laurentians, Outaouais, Estrie, Mauricie and Quebec City
- Evaluation of the implementation, impacts and appropriation process by WLHIV and facilitators

Community Forum 2010

- November 20, 2010
- Facilitators / WLHIV
- 80-90 participants from across Quebec
- Facilitators and WLHIV rallied around a common project
- Sharing of knowledge and experiences

The Story of STFL (3/3)



Cultural Adaptation of the Program in Mali 2010-2011

- Cultural adaptation conducted in collaboration with Coalition Plus (France) and ARCAD-SIDA (Mali)
- The intervention (10 workshops) was implemented twice at 6 sites in Bamako (Mali)
- Evaluation of short-term effects (N=96 WLHIV)
- Plans to offer the program again
- The program will be called **Gundo So**

“Sharing Together For Life” Portal 2011-2013

- Reflections/Exchanges
- “Leaving footprints”
- Sharing knowledge and experiences
- Professional practical tools (guides, collective work by WLHIV, STFL portal: www.pouvoirpartager.uqam.ca)

Collaboration with CATIE 2014-2015

- English translation of the Facilitator’s Guide
- Dissemination of the Facilitator’s Guide through CATIE website and Ordering Centre
- Webinar on the Facilitator’s Guide
- STFL case study <http://www.catie.ca/en/pc/program/sharing-together-life>

Program Description



- ✓ “Sharing Together For Life” (STFL) is an empowerment program created **WITH, BY** and **FOR** women living with HIV (WLHIV).

- ✓ It addresses the following themes:
 - The HIV adaptation process;
 - Situations where the issue of disclosing one’s HIV status may come up;
 - Potential challenges surrounding the disclosure of one’s HIV status; and
 - Potential strategies related to the issue of disclosing or not disclosing one’s HIV status

- ✓ STFL is seeking to fill a void given that there are so few programs and services for WLHIV that deal with the issue of disclosure.

Program Implementation Approaches



- ✓ In the form of discussion groups (4 to 8 women):
 - This program can be offered as 9 weekly meetings:
 - during the day, or
 - in the evening (standard approach),
 - On weekends, as part of a closed or open retreat (intensive approach)
- ✓ In the form of individual meetings (1x or 2x/week)
- ✓ An intensive weekend retreat and individual meetings offers the best approach in contexts where it's difficult to have the women meet several times or if the organization doesn't reach many women.



Program Objectives (General and Specific)

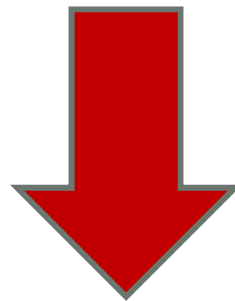
- ✓ The program gives WLHIV the tools they need to deal with the daily challenges they face surrounding the disclosure or non-disclosure of their HIV-positive status.
- ✓ The aim of this program **IS NOT TO PROMOTE** disclosure of HIV status, but **RATHER** to allow women to **SHARE** the experiences they have had when faced with the decision to disclose or not disclosure their status.
- ✓ **Specific objectives:**
 - Make a proactive and thoughtful decision about whether or not to disclose their HIV status in various contexts
 - Plan strategies allowing them to move forward with the decision to disclose or not disclose their HIV status
 - Better manage difficult situations or negative experiences in the context of a planned disclosure or unwanted disclosure



Approach Proposed to Participants

The program allows the women to:

- ✓ See where they are when it comes to disclosing or not disclosing their HIV-positive status to the people in their lives.
- ✓ Gain a better understanding of the challenges surrounding the issue of disclosure and non-disclosure.
- ✓ Better deal with the burden of their secret
- ✓ Make a non-coerced and informed decision based on the specific context
- ✓ Move forward with their decision after developing an action plan and creating disclosure/non-disclosure management strategies



So women can gain more
control over their lives

Guiding Principles of the Program (1/3)



- ✓ Every woman can **FIND HER OWN SOLUTIONS**.
- ✓ Disclosure is a recurring issue in the life of every woman living with HIV.
- ✓ Every woman living with HIV goes through her own journey.
- ✓ The program neither promotes disclosure nor non-disclosure of HIV status.
- ✓ By sharing their experiences and journey, women gain insights and support.
- ✓ No one is forced to share and those who do are always treated with respect.



Guiding Principles of the Program(2/3)

✓ **Attitudes between facilitators and participants**

- Respectful and non-judgmental
- Attentive and empathetic
- Formal commitment to maintaining confidentiality
- Supportive

✓ **Expected roles of facilitators**

- Guide, coach and facilitate
- Not direct the women
- Not give their personal opinions
- Not impose their personal values
- Inform the participants of their rights and obligations in regards to disclosure of their HIV-positive status
- Be qualified to facilitate a focus and support group

Guiding Principles of the Program(3/3)



✓ Expected roles of participants

- Own their emotions and speak in the first person (“I”)
- Explore the pros and cons of disclosure in each situation
- Share their strategies with the other participants
- Support the other participants
- Validate the other participants’ strengths

Summary Table of Program Meetings



1-WELCOME	Outlining expectations and commitment of the program
2-PORTRAITS OF WOMEN	Setting the tone
3-LEARNING TO LIVE WITH HIV	Learning about the HIV adaptation process
4-LIFE SITUATIONS	Exploring of the various situations surrounding the issue of disclosing or not disclosing one's HIV-positive status
5-CONTROLLING MY OWN DESTINY	Making the decision to disclose and planning strategies for disclosure
6-SHARING TO BETTER SUPPORT EACH OTHER	Making the decision to keep the secret and planning strategies
7-SECRETS TO KEEPING YOUR SECRET	Making the decision to keep the secret and planning strategies
8-ONE, TWO, THREE, HUSH!	Making the decision to keep the secret and planning strategies
9-MESSAGES FROM WOMEN	Assessing skills learned and developing solidarity

Meeting Procedure

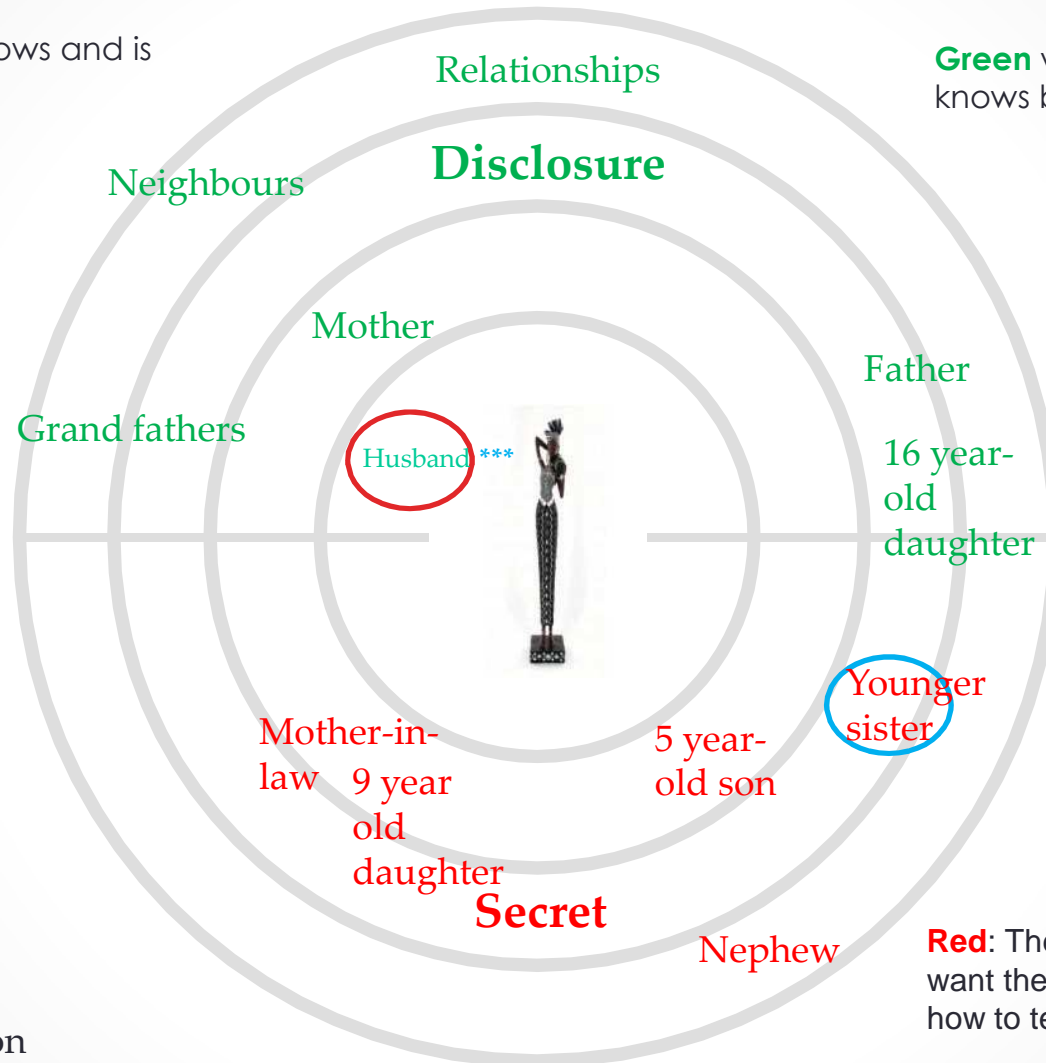
- ✓ **Each meeting is structured in the same way.**
- ✓ **Duration: 3 hours**
 - Welcome – review of the previous meeting.
 - Presentation of the theme and objective of the meeting.
 - Sharing personal experiences and feelings about the theme of the meeting.
 - 1st interactive activity
 - Break
 - 2nd interactive activity
 - Group discussion
 - Meeting debrief

Example 1: "The People in my Orbit"



Green : The person knows and is handling it well.

Green with **red** circle: The person knows but is not handling it well.



Red: The person doesn't know and I want them to know but I don't know how to tell them or can't.

Red with **Blue** circle: The person doesn't know and I want to keep it that way.

* Low moral obligation

** Medium moral obligation

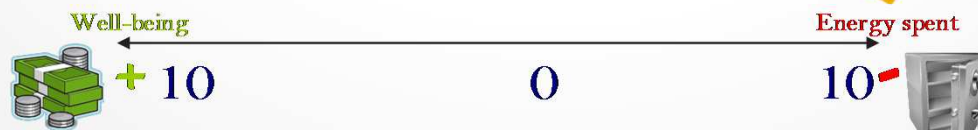
*** High moral obligation



Example 2: My Savings Account



Context: Not telling my kids		
Pros	Deposit	
Protecting them from being stigmatized	10	10
Not making them sad	10	10
	Total Pros	20
Cons	Withdrawals	
Lying about my situation	6	6
Having to hide my medication	8	8
	Total Cons	14
Grand Total		
Total Pros – Total Cons		6



H8



Required Materials

H7

- ✓ Logbook for each participant
- ✓ Art supplies for each participant (colour crayons – wood/wax/felt-scissors, glue, varied colour boxes, varied stickers, magazines, etc.)
- ✓ Positive Women: Exposing Injustice documentary and accompanying guide
- ✓ TV and DVD player
- ✓ Blackboard or flip-chart – chalk or crayons.
- ✓ Ink pens.
- ✓ Monopoly-type money (\$1, \$2, \$5, \$10, \$20 bills).
- ✓ Opaque box or closed container containing feathers.
- ✓ Large cardboard or large piece of fabric (to create a mural)
- ✓ Private room
- ✓ Refreshments and snacks (or meal).
- ✓ Music player

Total approximate cost: \$500 (including meals and materials):

Slide 23

- H7** I assume this is the one used in English based on the facilitator guide
Helene, 31/07/2015
- H8** I assume this is correct based on the English guide
Helene, 31/07/2015

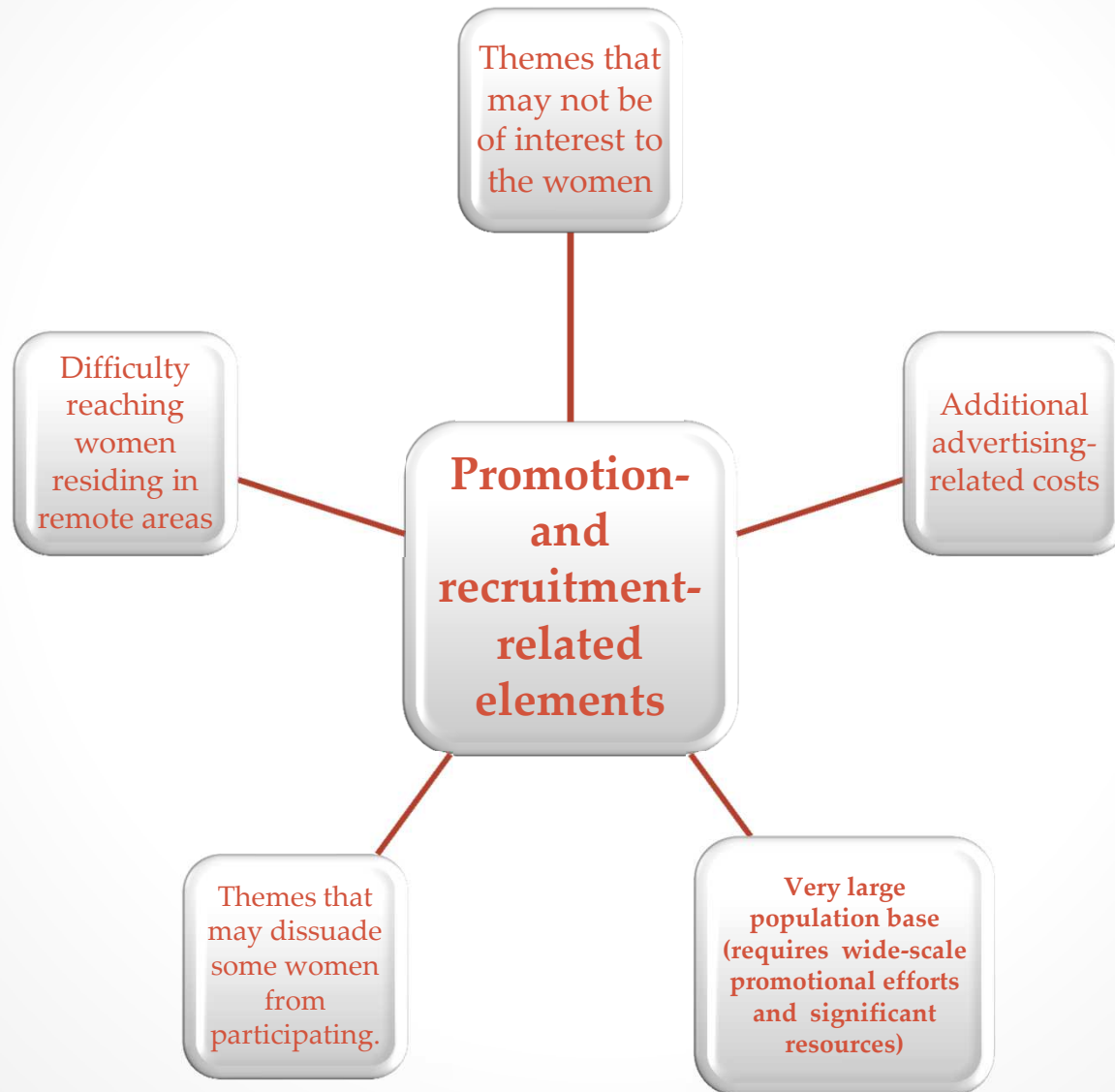


Program Implementation

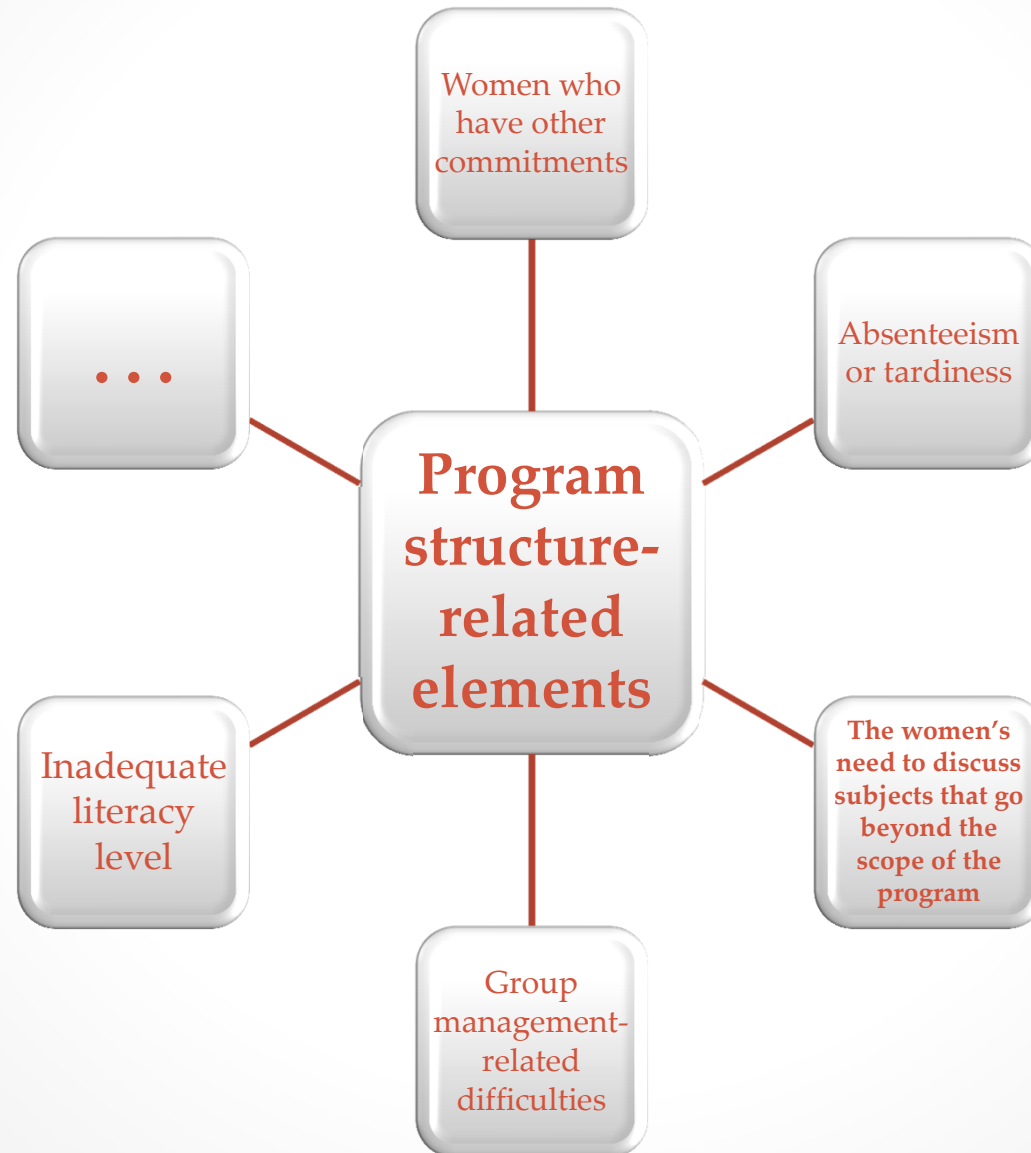
Implementation Barriers (1/3)



Implementation Barriers(2/3)



Implementation Barriers(3/3)



Implementation and Facilitation Tips and Advice (1/3)

- ✓ Before the start of the program
 - Promotion
 - Recruitment strategies
 - Group composition and characteristics
 - Program implementation approaches
 - Documentation
 - Arrangements and incentives
 - Preparation of facilitators and support

Implementation and Facilitation Tips and Advice(2/3)

- ✓ During the program
 - Support of facilitators
 - Support of participants

Implementation and Facilitation Tips and Advice(3/3)

- ✓ During each meeting
 - Program facilitation

- ✓ After each meeting
 - Thank the participants
 - Complete the logbook
 - Offer moral support to participants

- ✓ Sustainability factors
 - Active participation of the WLHIV

Adaptation

- ✓ Can STFL be offered to other groups, such as men, mixed groups, men who have sexual relations with other men, transgender people?

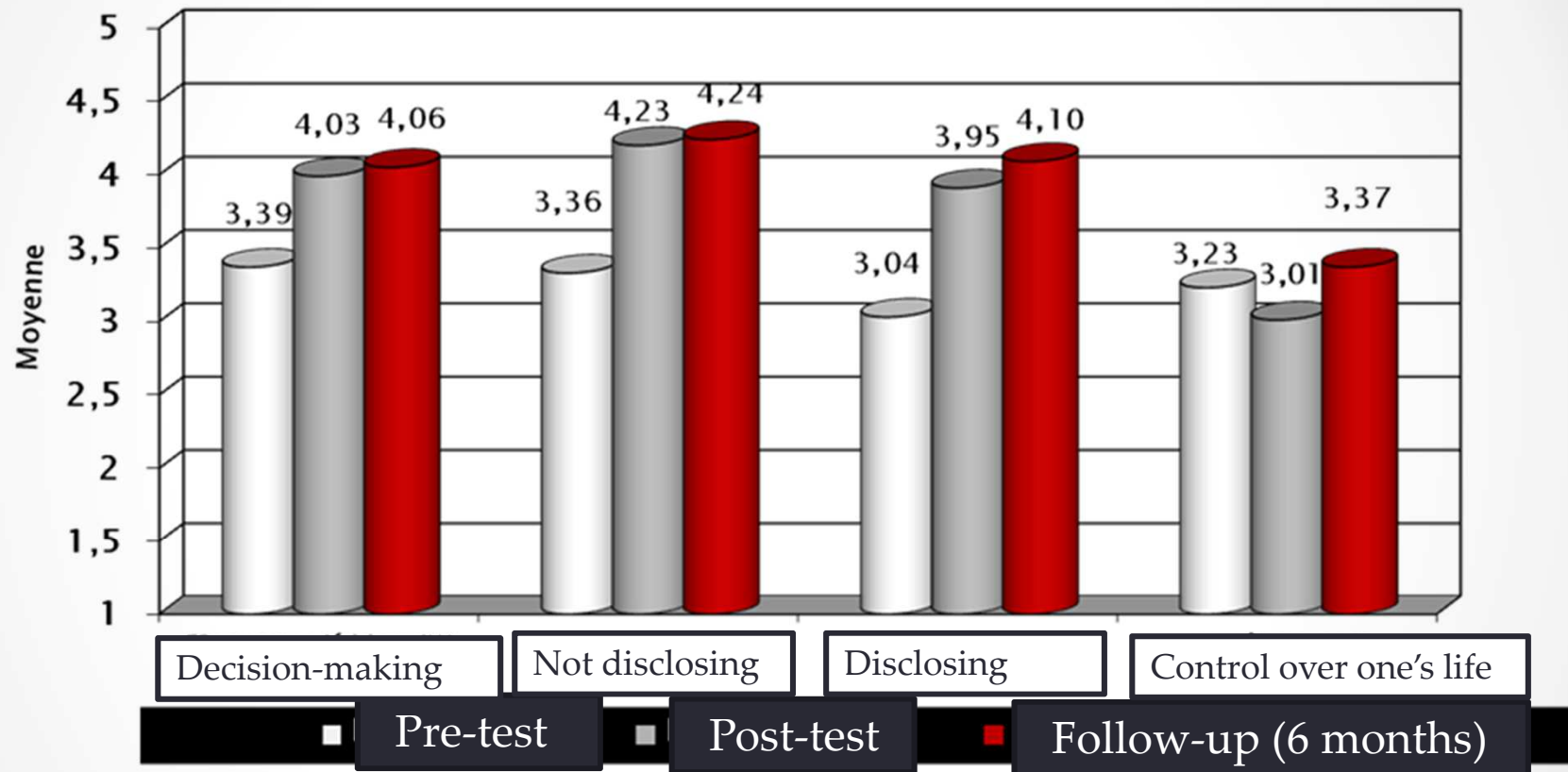
It can by:

- **Adopting a multicultural approach in our practices**
- **Adapting the tools (activity sheets) to the target clientele**



Program Impacts

Program Evaluation Results (1/2)



On a scale from 1 (very low) to 5 (very high), *** $p \leq 0.001$

PE = Personal Effectiveness *** $p \leq 0.001$

Program Evaluation Results(2/2)

Factors related to mid-term impacts

- ✓ While the mid-term program impacts **do not seem to vary** by implementation setting, age, country of origin, mother tongue, marital status, income, being treated or not treated for HIV, or the percentage of people who disclosed their HIV status...
- ✓ ...it seems that the program impacts are greater among:
 - **Mothers;**
 - Women with a higher education; and
 - Women living with HIV **for a shorter period of time.**

Participant Testimonials

“Sharing Together For Life allowed me to develop tools and to meet and share with other women who are dealing with the same issues.” (Charlotte, from Quebec, 30-39 age group)

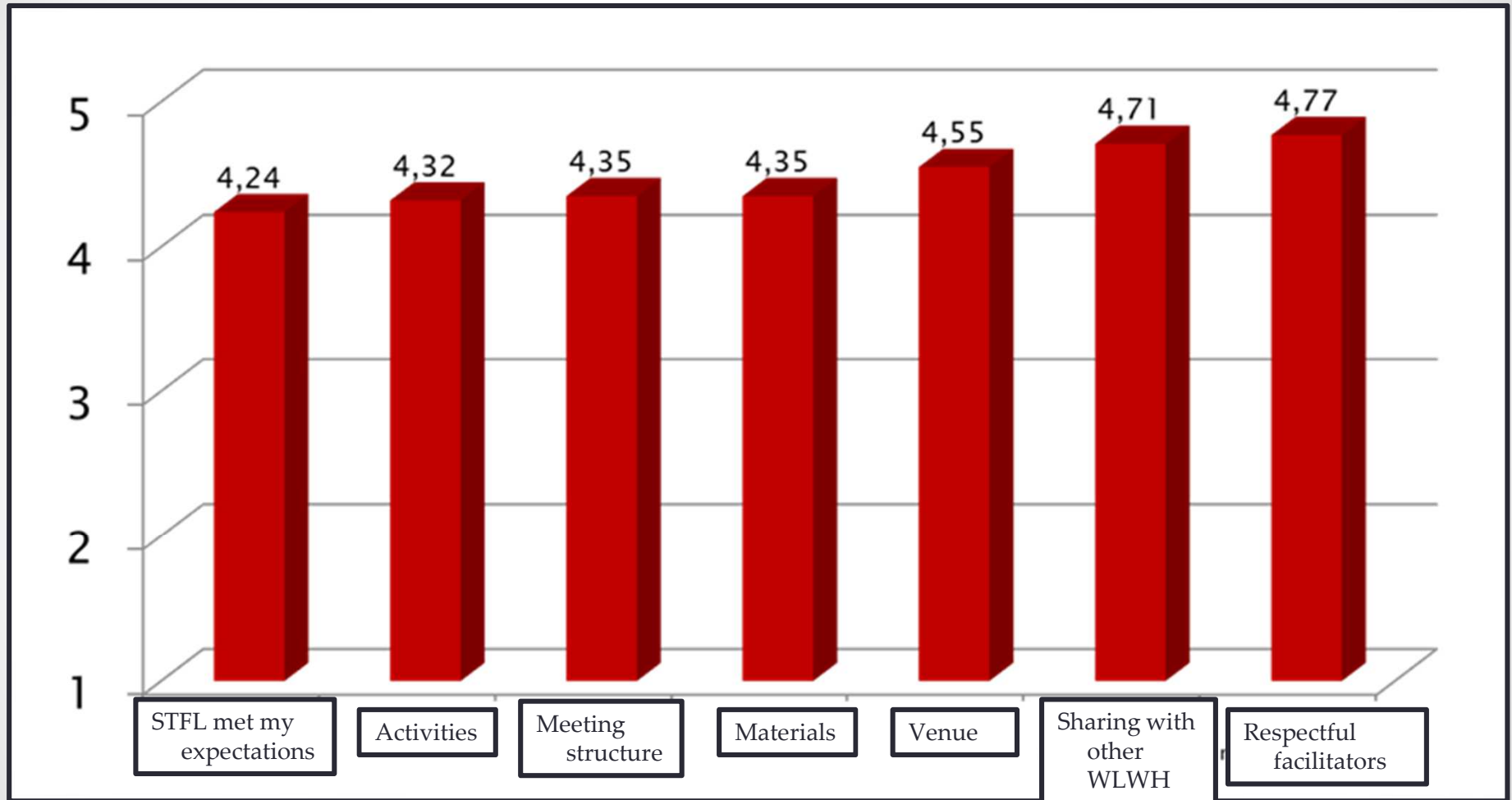
“It gave me courage and self-esteem. I know who, where and when to tell or not tell. It also encouraged me to continue my involvement with HIV support groups and organizations....” (Simone, originally from Congo, 40-49 age group)

“I used to think I should tell everyone about my status but the meetings allowed me to see who I really needed to tell and how to go about it.” (Marie, originally from Burundi, 20-29 age group)

“I don’t rush into telling now. I take my time. I think about it more and ask myself if it’s really necessary for this person to know my status and, more importantly, I now realize that not disclosing it doesn’t make me a liar.” (Dominique, from Quebec, 40-49 age group)

“When I decide to tell someone now, I’m prepared and less anxious to get it over with. It doesn’t matter if things don’t go exactly as planned because now I feel in control.” (Sophie, originally from Asia, 40-49 age group)

Satisfaction Level of Program Participants



On a scale of 1 (not at all satisfied) to 5 (totally satisfied)

Where to obtain the Facilitator's Guide



Canada's source for
HIV and hepatitis C
information

La source canadienne
de renseignements sur
le VIH et l'hépatite C

www.catie.ca/sharingtogether



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