SHARING
TOGETHER
FOR LIFE

Facilitator’s Guide

A PLACE OF SHARING AND REFLECTION BETWEEN WOMEN LIVING WITH HIV ON THE ISSUE OF DISCLOSURE AND NON-DISCLOSURE

FACILITATOR'S **GUIDE**

SHARING TOGETHER FOR LIFE

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Facilitator’s Guide

Sharing Together for Life

To tell each other and to confide in all
safety and security, without fear of being judged,
discriminated against or stigmatized.

This guide, originally developed by the Canada Research Chair in Health Education, at Université du Québec à Montréal (UQAM) and published in 2013, was adapted and translated into English from the original French version in partnership with CATIE in 2015.

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Production of the English version of the guide funded in part by the ViiV Healthcare Positive Action Canada HIV/AIDS Innovation Program, 2013.

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2015 edition published by
The Canada Research Chair in Health Education
Université du Québec à Montréal
P.O. Box 8888, station Centre-Ville
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CANADA

CHAIRE de recherche du Canada
en éducation à la santé
UQÀM

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To quote this document
Massie, L., Otis, J., Côté, F., Côté, J.K., Fernet, M., Mensah, M.N. & Lévy, J.J., cofounders and ambassadors of Sharing Together for Life (2015). Sharing Together for Life Facilitator's Guide: A place of sharing and reflection between women living with HIV on the issue of disclosure and non-disclosure (English edition). Montreal: Canada Research Chair on Health Education, Université du Québec à Montréal.

ISBN 978-2-9813738-5-4 (English edition)
(Édition originale : 978-2-9813738-2-3, Chaire de recherche du Canada en éducation à la santé, Montréal)
Legal Deposit -Library and Archives Quebec, 2015
Legal Deposit -Library and Archives Canada, 2015
CATIE Ordering Centre No: ATI-26516
(aussi disponible en français, ATI-26515)

Printed with assistance from CATIE, 2015

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Acknowledgments

The Canada Research Chair in Health Education would like to thank the members of the Canadian Institutes of Health Research (CIHR) who made possible the original version of this guide.

We would like to thank all of the people who represent HIV/AIDS community groups in Quebec along with the staff of the Hôpital Sainte-Justine, the Centre de Santé et de Services Sociaux Jeanne-Mance and the Coalition des organismes communautaires québécois de lutte contre le SIDA (COCQ-SIDA), who were important partners on this journey. They are the co-founders of this training and facilitation guide.

We would also like to thank the women who helped evaluate the program from 2006 to 2008 and who took part in its assessment in Quebec between 2008 and 2011. They are the ambassadors of Sharing Together for Life.

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TRAINING AND IMPLEMENTATION **GUIDE**

Learning to live with HIV and the issue of disclosure in the daily lives of HIV-positive women

QUALITY OF LIFE

Since the introduction of antiretroviral therapies in the mid-1990s, a limited number of studies have been conducted on the quality of life of women living with HIV (WLHIV) (1,2). WLHIV appear to have a much lower quality of life and generally receive less social support than HIV-negative women (3, 4). WLHIV also enjoy a lower quality of life than HIV-positive gay men (7, 8, 9).

THE PROCESS OF ADAPTING TO LIFE WITH HIV

Living with HIV often triggers emotional responses similar to those experienced by people who have lost a loved one (the stages of denial, anger, sadness, pleading, fear, anxiety and eventually acceptance). Following the initial shock of the diagnosis, WLHIV experience these emotions differently and at different times in their lives (12). Given the chronic nature of the disease, some authors (12, 14) have suggested that acceptance is not the end of the process of adapting to life with HIV; rather, it is the starting point from which individuals learn to live with HIV and make the necessary lifestyle changes to live positively with HIV. Acceptance is therefore a necessary step if one is to learn to cope with HIV on a daily basis (i.e., learn to live with it) (15, 16). At the **denial** stage, individuals can question the truthfulness of the diagnosis, reject it and be unwilling to discuss their health condition. They may also neglect or reject the treatment. **Anger** often hides a deep sorrow and generally occurs when someone realizes that denial is no longer useful. Anger can be expressed through irritability and outbursts against others, against oneself or against life in general. **Pleading** is a step during which someone tries to reach a compromise with people or with concepts such as time, life, destiny or a superior power that will allow them to go back in time. **Anger** and **anxiety** occur when individuals understand the reality of their situation and realize the impact of HIV in the different spheres of their life. At this stage, people can go through a temporary depression and seek help to lessen the impacts of the disease on their daily life. They will see a glimmer of hope and start to make room for new projects. **Acceptance** is a turning point in an individual's life and relates to their values, relationships and lifestyle (10, 11, 13, 17). Finally, to **integrate** HIV into the different areas of their life, individuals need to reorganize their life to enjoy well-being and balance. This adaptation process is not set in stone and the steps do not occur in a linear fashion. Depending on the situation, people can go through these steps several times since they are never final. The HIV adaptation process is complex and the emotions associated with the different stages vary in duration and intensity (15).

Studies suggest that when women are diagnosed with HIV, their quality of life is primarily affected in the areas of mental health, physical, sexual and social functions (18, 19, 20, 21, 22, 23, 2). The various dimensions of quality of life are greatly affected by the stress associated with disclosing one's HIV positive status to one's circle (24, 25). Although disclosure has been associated with improved mental health and greater social support in some studies (26, 27, 28, 29), it appears more often to be an issue that individuals need to revisit and that requires reflection and vigilance on a daily basis, in all aspects of their life (30, 31, 32, 33). These results are consistent with those of qualitative research involving more than 40 WLHIV in Montreal, conducted between 2002 and 2004 (33).

DISCLOSURE: TO WHOM AND HOW MUCH?

WLHIV generally engage in four types of disclosure. The first one, **secret disclosure**, involves disclosure to a very small number of people who will keep the information strictly confidential. Often, the confidant is someone's partner or mother. With this type of disclosure, the WLHIV limits her social life to avoid disclosure and she may feel alone and isolated (32, 34). The second type, **selective disclosure**, is what almost half of women choose to do (34). Women assess each situation before disclosing their status. They open up to people with whom they have meaningful relationships, who can keep their secret or who can help them with regard to their health. Some external factors can facilitate selective disclosure, such as transmission risk to a partner through sexual contact. The third type, **full disclosure**, is done by very few women—only 13 percent in the study conducted by Sowell and al. (34). They choose to do so for social, political or educational reasons (35). The fourth type is **unwanted disclosure**. Although this type of disclosure is poorly documented, studies show that it happens and that it is most often family members and health professionals who breach confidentiality. Sharing Together for Life deals with all types of disclosure.

THE SIGNIFICANT BURDEN OF DECIDING WHETHER OR NOT TO DISCLOSE

A few studies involving WLHIV deal with the weight of the decision-making process and of the consequences of disclosure (23, 30, 36, 37, 40). Individuals may decide to disclose their status for personal reasons or because they need to express their feelings about the disease. For some women, disclosure brings the satisfaction of being honest. For others, it paves the way for them to receive tangible emotional support to manage the disease as well as practical help in areas such as transportation or child custody. WLHIV may choose to disclose their status for altruistic reasons, either to prevent people close to them from being placed at risk or to educate others to prevent infection. Women may also disclose their status to gauge the reaction of other people, to develop supportive and close emotional relationships or because they have things in common with the person to whom they are disclosing. When people react positively to the disclosure, the woman who made the disclosure may experience comfort and hope, she may want to become better informed about HIV, she may be encouraged to seek help, she may feel supported in disclosing her status to others, and the soundness of the relationship may be confirmed (29, 33, 41).

There are also a variety of reasons why women may choose not to disclose their status. WLHIV may feel guilt, shame or disgrace because of their infection. In some communities, disclosure carries greater risk because rumors could ruin someone's reputation. Some WLHIV are so afraid of being rejected or misunderstood that they do not disclose their status and forgo the emotional and financial support they could possibly get from their family and their community. Others fear conflict with their partner, which could involve insults and even violence. Some women may also want to keep their secret in the interest of others. For instance, mothers and other women may want to protect their family circle from the social stigma attached to HIV and also from the worry they could experience about their health. The quality of a woman's personal relationships can also affect her decision: she may choose not to disclose her status to people with whom she has a superficial relationship, especially some sexual partners. When women do not disclose their status to these people or choose to wait to do so, it is because they fear negative consequences (30, 33, 34, 36, 37, 38, 39, 40, 42, 43), including being sued.[1]

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[1] Since October 2012, Canadian laws on non-disclosure of HIV-positive status have evolved. The Supreme Court of Canada has ruled that a person is obligated to disclose his/her HIV-positive status before any sexual activity that could lead to transmission, even if the risk is low (67).

IMPACT OF DISCLOSURE

Disclosing one's HIV-positive status can lead to many consequences and reactions. WLHIV commonly experience a variety of negative reactions after disclosing their status, such as disbelief, denial, avoidance, rejection, surprise, shock, pain, anger, blame, worry, fear of contamination, embarrassment, pity, doubts as to the relationship and refusal to talk about HIV (29, 32, 33, 41).

However, disclosure does not necessarily lead to negative consequences. According to some studies, while the vast majority of respondents expect negative reactions from their confidant, these expectations are not always well-founded (44, 45). Sandelowski et al. (32) listed more than 90 studies; 24% of them presented the comments of women who experienced positive consequences after disclosing, including favourable reactions.

While there are benefits to disclosing one's HIV-positive status (support, understanding, closeness, relief, awareness, etc.), a number of considerable risks remain for WLHIV. These risks can affect women's physical security and their psychological well-being (32, 46, 47). Under these circumstances, keeping one's status a secret makes sense. Sharing Together for Life helps women become aware of these issues, to figure out if they want to keep their secret or disclose their status after analyzing their circumstances (e.g., disclosing to their child, to a new partner, etc.) and to come up with real solutions to help them live with their decision.

The Story of Sharing Together for Life

Thanks to major therapeutic breakthroughs since 1996, people living with HIV can make plans and aspire to a better quality of life. However, interventions to improve the quality of life of people living with HIV, especially women, remain extremely rare in Quebec.

THE BIRTH OF THE PROJECT

In 2002-2004, a qualitative participatory study was conducted among WLHIV in the Montreal area to better understand their needs and to explore their life experiences since the introduction of antiretroviral therapy (ART). Forty-two women of Caucasian, Haitian and African descent aged 25 to 51 took part in the study. They shared the impact of ART on their social, family, home and personal lives as well as their relationships (33). Results from the study showed that the quality of life of these women is impacted by their lack of control over day-to-day aspects of their lives, in particular because of the heavy burden of disclosing their HIV-positive status. The way in which individuals approach the issue of disclosing or keeping a secret varies for different types of relationships, be it with a sexual partner, a spouse, children, family, friends, colleagues, health professionals or others. Although it is in the background, it is omnipresent and must be revisited.

THE PILOT PROJECT

In light of the knowledge acquired through the stories of these 42 women and considering that there were few existing initiatives that met their needs, a pilot project was undertaken in 2006-2007. Its purpose was to develop, implement and validate intervention mapping[2] for these women, to give them greater control over the decision to disclose their status or to keep it a secret, in the different spheres of their life. This pilot project, called Sharing Together for Life, was designed and implemented in collaboration with stakeholders from community, social and health organizations and with the participation of 38 WLHIV in the Montreal area.

The results obtained through the validation of the program confirm its relevance and usefulness and demonstrate that the program improves the ability of women to disclose their HIV-positive status (or to keep it a secret) in a well thought-out and proactive manner (48).

PROGRAM EVALUATION AND IMPLEMENTATION IN QUEBEC

In 2008-2011, the program was improved and implemented throughout Quebec so that a greater number of women could benefit from it. At the outset of this process, a committee of WLHIV who had taken part in the pilot project designed training sessions to teach individuals how to use the facilitator’s guide for the program. This training was offered and assessed during “Outillons-Nous” educational sessions provided by the Coalition des organismes communautaires québécois de lutte contre le VIH (COCQ-SIDA) to 26 stakeholders from several regions in Quebec (49). In 2009-2010, the revised program was offered by 13 stakeholders and seven volunteers (WLHIV) who had received the training. The impact of the program was assessed through the active and ongoing involvement of 15 agencies in Quebec as well as 85 women. The results of this assessment confirm those obtained during the pilot phase and demonstrate that not only does the program have significant short-term impacts for the Quebec participants but that these effects last over time (six months after the intervention) (50, 51, 52). The program seems to empower participants with regard to the issue of disclosure, giving them a feeling of greater personal efficacy in managing the secret or disclosing it and giving them a greater sense of control over their lives. The assessment also provides lessons learned about the implementation of such an intervention in rural areas or in other sociocultural settings and about factors that promote a sense of

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[2] Targeted intervention is an approach that allows the integration of theories, empirical data from the literature and information collected in the field from the target population during the development of an educational health program (59, 60, 61).

ownership over such an intervention for WLHIV and for the organizations that support them (53, 54, 55, 56). Finally, in the spring of 2011, the creation of six shared appreciation groups (SAG)[3] allowed WLHIV and stakeholders to talk with the research team about aspects of the facilitator's guide they felt needed to be improved or revised. The knowledge obtained through these processes was used to produce the current version of the facilitator's guide for Sharing Together for Life.

CULTURAL ADAPTATION OF THE PROGRAM FOR IMPLEMENTATION IN MALI (AFRICA)

Since the Sharing Together for Life program seems to be highly adaptable to various contexts, it quickly generated interest from Central American and African organizations. In Mali, the community association ARCAD SIDA, which works to prevent HIV infection, empowers people living with HIV/AIDS and advocates on their behalf, showed an interest in Sharing Together for Life. Although the social and cultural context is different, the issue of disclosure greatly impacts day-to-day life in Mali, as it does for WLHIV in Quebec. Keeping a secret is often a short-term solution and disclosing to one's spouse is often complicated for many Malian women (which is also the case in Quebec), especially in the context of polygamy. Given these circumstances, the ARCAD-SIDA team wanted to help women acquire practical tools to make educated decisions and to implement action plans to live with their decision. Thanks to the support of the Canadian Institutes for Health Research and the Fondation de France, the team in Mali and the Canada Research Chair in Health Education at UQAM (in partnership with Coalition Plus, of which COCQ-SIDA is a member) reviewed the program in detail and adapted it to the reality of the women who use their services (57). In total, 96 women took part in the adapted workshops. Following their participation in the program, they said they felt that the burden associated with the secret surrounding their HIV-positive status had been lessened. In addition, they received moral support from other WLHIV and gained a greater sense of control over their lives (70). Therefore, Sharing Together for Life shows promise with regard to being adaptable for implementation in other sociocultural contexts.

In the current social and legal context, helping WLHIV better manage the issues that surround disclosure has never been more relevant. This facilitator's guide has been produced so that a greater number of WLHIV can share their knowledge and reflect together on their reality and, more specifically, on the difficult issue of disclosing their HIV-positive status.

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[3] The concept of the shared appreciation group (SAG) was developed by COCQ-SIDA to consolidate community interventions and their foundation, that is, the awareness of a common goal and the participation of all members, in particular in the assessment of the intervention (COCQ-SIDA, 2005, p. 57). During the assessment stage of Sharing Together for Life, SAGs were used to document the ownership path of facilitators and WLHIV.

Development stages of the program

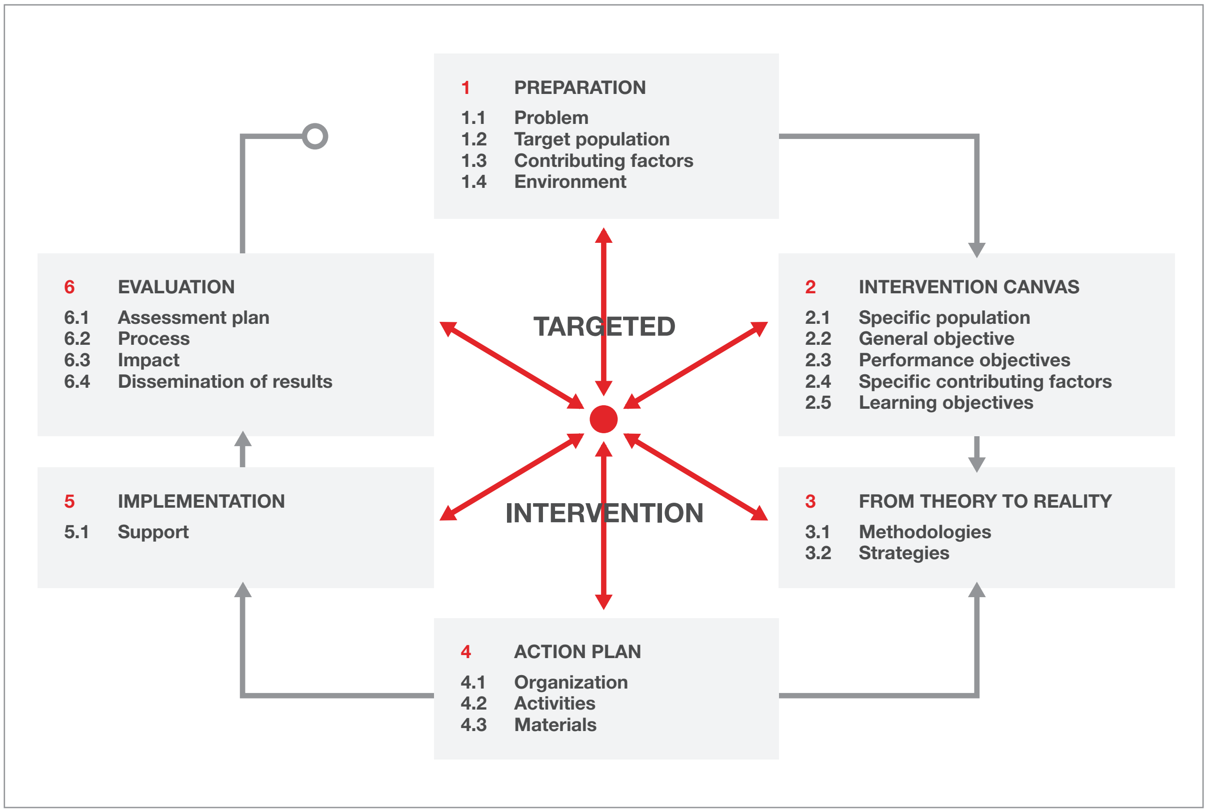
TARGETED MEASURES (INTERVENTION MAPPING)

Sharing Together for Life was created using a targeted approach (intervention mapping) (58, 59). This planning framework has been used in the creation of several health education programs (60, 61, 62, 63, 64). However, targeted interventions for WLHIV have not yet been reported in the literature in this field.

Targeted intervention occurs through an iterative process that creates and follows six steps (61, 65) (see Figure 1).

Three processes underpin each of these steps: 1) review of documentation and application of theories, 2) inclusion of empirical data and 3) consideration of qualitative and quantitative data obtained by interacting with program participants. Community participation is inherent to this approach. The sections below detail the actions taken for each of these steps and describe how WLHIV and stakeholders took part in each of them.

FIGURE 1 Targeted intervention process modelling



Source: Godin, G. (2005). La prévention du VIH, des ITS et de l'hépatite C: outil de travail pour développer vos projets. Groupe de recherche sur les comportements en matière de santé. ISBN 2-923002-01-6. Available online: http://www.godin.fsi.ulaval.ca/Fichiers/Rapp/ITS%20final.pdf

STEPS OF THE TARGETED INTERVENTION

Step 1 took place between 2004 and 2005. This step, which focuses on preparation, involved an analysis of the results from research among 42 WLHIV (33), consultations with key informants, a summary of available programs and services (66) as well as the creation of three working committees to shape the project: 1) the monitoring committee, which was made up of researchers (supervision and scientific guidance role); 2) the pilot committee, which consisted of the executive directors of the participating organizations (strategic role, ensuring the feasibility of the project); and 3) the technical committee, which consisted of WLHIV and stakeholders (operational role).

The pilot project, which was conducted in 2006-2007, allowed us to complete steps 2 to 4. In **Step 2**, the development of the intervention canvas, we established objectives and structured them to better define the intervention matrix that guided the program development (the original matrix is available from the program's authors). It reports on the objectives established by the technical committee for the targeted intervention.

The behavioural objective of the program is to help women acquire and consolidate the skills they need to disclose (or not to disclose) their HIV-positive status in a well thought out and proactive manner. To achieve this objective, participants develop skills to: 1) recognize that it is possible to live positively with HIV, 2) recognize the contexts in which the issue of disclosure or keeping one's status a secret occurs, 3) assess the potential challenges related to disclosure or keeping one's status a secret in different contexts and 4) plan strategies related to disclosure or keeping one's status a secret (performance objectives). Next, learning or change objectives help describe what participants must learn in terms of knowledge, attitudes and more specific skills to meet each of the performance objectives that lead to the achievement of the behavioural goal.

Step 3 is the selection of theories on intervention methods and practical strategies, which was conducted by the research team (the monitoring committee). The theoretical methods that were selected take into consideration the learning objectives identified in the intervention matrix. Members of the technical committee creatively suggested practical strategies related to these methods, given their knowledge of the realities faced by WLHIV. Readers interested in accessing all of the theoretic methods that support the selected practical strategies are invited to contact the authors.

Step 4 is the action plan. The objectives, methods and strategies developed in the earlier steps led to educational activities. It was at this point in the process that the participation of WLHIV on the technical committee was most fruitful, as the theoretical methods and strategies were translated into an action plan and organized program. The educational activities that emerged from this process are described in the facilitator's guide.

Steps 5 (implementation) **and 6** (evaluation) were completed first by adopting, implementing and validating the program on a small scale and then by conducting a summary assessment of the validated program. This summary assessment, which took place between 2008 and 2012, led to the program being offered to 85 WLHIV in Quebec, thanks to the participation of 15 community organizations. In these two steps stakeholders and WLHIV trained the facilitators, the program was implemented in several regions in Quebec, WLHIV and stakeholders shared their life experiences (in a province-wide community forum), and sharing and knowledge transfer activities were planned and completed. The sharing activities were part of the last evaluation phase of Sharing Together for Life and included the improvement of the facilitator's guide; the creation of a collective work with, by and for WLHIV; the creation of a Sharing Together for Life portal on the issue of disclosure for WLHIV; and the organization of a community activity during which final assessment results were discussed and professional practice tools were developed, introduced and distributed to WLHIV and stakeholders of the project.

Description of Sharing Together for Life

The Sharing Together for Life program aims to meet a need, given the scarcity of programs for WLHIV that deal with the issue of disclosure.

Using the principle of empowerment[4], the program helps women to share what they experience when the question of disclosure arises, to carefully consider and proactively choose to disclose or not to disclose their status depending on the situation, and to equip themselves with the tools needed to assert themselves in making these choices.

DESCRIPTION OF PROGRAM OBJECTIVES AND MEETINGS

The program consists of nine weekly meetings, lasting on average 3 hours each. The summary table on page 18 presents an overview of the program. The first meeting (Welcome) provides women with more information about the program (goals, themes of meetings, duration, type of activities) and enables them to think about their expectations of the program and to discuss their level of engagement. The second meeting (Portraits of women) is a social event, an opportunity for women to share personal stories. Participants get to know the group's participation rules and the importance of their role within the group. The third meeting (Learning to live with HIV) deals with the adaptation processes related to HIV. This meeting allows women to take stock when it comes to accepting their status and to realize that it is possible to live positively with HIV. At the fourth meeting (Life situations) women also identify everyday situations in which the issue of disclosing or keeping a secret is brought up. Subsequently, they evaluate potential issues surrounding disclosure in a given situation (Meeting 5: Controlling my own destiny), plan strategies they deem appropriate and achievable (Meeting 6: Sharing to better support each other), then use their knowledge in a second situation where they would be confronted with dealing with the issue of keeping a secret (Meeting 7: Secrets to keeping your secret and Meeting 8: One, two, three, HUSH!). In the final meeting (Meeting 9: Participants' messages) the program comes full circle through the creation of a collective mural. It also enables participants to describe how they feel after these meetings and how together they can help other WLHIV.

PROGRAM STRUCTURE

Each meeting is structured the same way. As an introduction, each participant is asked to recall the previous meeting and to talk about how it impacted their daily life. Each participant is also invited to share their experiences and feelings about issues and possible strategies to deal with disclosing or keeping a secret. Next, two experiential activities (interactive games, thinking exercises with drawings and objects, impact techniques using movement, expression, objects or images) help participants to express an opinion on their real-life experiences. There is often a break between these activities. Meetings end with a group discussion that allows each participant to take stock of their own situation. Finally, some time is spent evaluating the meeting. During this period, participants are invited to express how they feel after the meeting and to share what they liked most and least along with their favourite moment of the meeting. It is important to note that over the course of the program, participants create a journal as they engage in each activity.

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[4] This concept is based on the general notion that people and communities have a right to take part in decisions that affect them and that they already have the skills required to participate in decision-making or that they are able to develop them (69).

Summary table of program meetings

It is recommended that nine group meetings be held. The program is designed for the meetings to be held in the sequence listed in the table below.

STAGE	MEETING	GOALS	ACTIVITIES
		AT THE END OF THE MEETING, THE PARTICIPANT WILL BE ABLE:	THE GOALS WILL BE MET WITH THE FOLLOWING ACTIVITIES:
Outlining expectations and commitment to the program	**1 “Welcome”**	To recognize, express and assess their expectations for the program	“My first page” “Continuum”
		To show their commitment to the program	“To what extent…?”
Setting the tone	**2. “Portraits of women”**	To abide by the group’s participation rules and to recognize the importance of actively engaging in the program	“Presentation and explanation of participation rules”
		To understand that each member of the group depends on the others	“Interdependence”
		To take stock of their personal situation with respect to disclosure before beginning the program	*Positive Women: Exposing Injustice*
Learning about the HIV adaptation process	**3. “Learning to live with HIV”**	To talk about their view of HIV	“How I see HIV”
		To know the different steps of the HIV adaptation process	“My life journey with HIV”
		To think about accepting their HIV-positive status	“My life journey with HIV”
		To take stock of their progress since their HIV-positive diagnosis	“My life journey with HIV”

STAGE	MEETING	GOALS	ACTIVITIES
		AT THE END OF THE MEETING, THE PARTICIPANT WILL BE ABLE:	THE GOALS WILL BE MET WITH THE FOLLOWING ACTIVITIES:
Exploring the various situations surrounding the issue of disclosing or keeping a secret	**4. “Life situations”**	To recognize the multiple situations surrounding the issue of disclosure.	“In what situations”
		To recognize situations where there is a legal obligation to disclose and those where it may be best to disclose for medical reasons	“Should I tell or not tell?”
		To decide to whom to disclose or from whom to keep a secret	“The people in my orbit”
		To decide in which situations they feel a moral obligation to disclose	“Tell me about your world”
Making the decision to disclose and planning strategies for disclosure	**5. “Controlling my own destiny”**	To identify the pros and cons of disclosure	“Pros and cons”
		To choose one context in which they wish to disclose	“The pros and cons scale”
		To identify the pros and cons of disclosing in the chosen context and to assess their importance	“The pros and cons scale”
		To discuss their interpretations of disclosure	“My winning hand: brainstorm”
		To think about positive and negative factors associated with disclosure	“My winning hand: positive and negative factors of disclosure” “My winning hand: card game”
		To assess the decision to disclose in the chosen context (to go ahead or change their mind)	“My conclusions”

STAGE	MEETING	OBJECTIVE	ACTIVITIES
		AT THE END OF THE MEETING, THE PARTICIPANT WILL BE ABLE:	THE GOALS WILL BE MET WITH THE FOLLOWING ACTIVITIES:
Making the decision to disclose and planning strategies for disclosure	**6. “Sharing to better support each other”**	To know the different types of disclosure	“Sharing knowledge and experiences: disclosure types”
		To share a positive disclosure experience and a difficult one	“Sharing knowledge and experiences: sharing”
		To identify strategies to: 1. Prepare for disclosure (before) 2. Disclose (how to) 3. Prepare for others’ reactions (after)	“Sharing knowledge and experiences: disclosure strategies”
		To develop a practical action plan based on the context (anticipated disclosure)	“My strategic plan”
		To validate the personal strategies put in place in the past to disclose in a specific context (experienced disclosure)	“My strategic plan”
		To think about their vision of disclosure and figure out if they are ready to disclose	“My strategic plan: My strategies card”
		To support other participants in their disclosure process	“Encouragement card”
Making the decision to keep a secret and planning strategies	**7. “Secrets to keeping your secret”**	To identify the pros and cons of keeping a secret	“Pros and cons”
		To focus on one context where keeping a secret is an issue	“My savings account”
		To identify the pros and cons of keeping a secret in the specific context and assess their importance	“My savings account”
		To discuss how the secret is perceived	“My box of secrets”
		To become aware that it may be difficult to control the secret of their HIV-positive status	“My box of secrets”

STAGE	MEETING	OBJECTIVE	ACTIVITIES
		AT THE END OF THE MEETING, THE PARTICIPANT WILL BE ABLE:	THE GOALS WILL BE MET WITH THE FOLLOWING ACTIVITIES:
Making the decision to keep a secret and planning strategies	**8. “One, two, three, HUSH!”**	To share one positive experience of keeping a secret and one difficult one	“Let’s share our secrets: sharing”
		To identify strategies for: 1. Maintaining the secret about their HIV-positive status 2. Maintaining the secret about their meds 3. Preparing for an unwanted disclosure	“Let’s share our secrets: managing your secret”
		To create a practical action plan to maintain their secret	“My secret recipe”
		To think about the impact of the secret in their daily life and to assess how they live with it.	“My secret recipe”
		To reassess the decision to disclose in the chosen context (to go ahead or change their mind)	“My secret recipe”
Assessing skills learned and developing solidarity (In exceptional circumstances this meeting could last more than 3 hours.)	**9 “Participants’ messages”**	To assess the skills learned that pertain to disclosure	“Feedback on My first page”
		To talk about what has been learned or to express solidarity with other participants	“Participants’ messages: collective mural and feedback”
		To share their experiences of the program with other participants	“Potluck”
		To feel solidarity with other participants	“Potluck”
		To develop relationships with other participants for the future	“Potluck”

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* The welcome meeting can be done as a group or with each participant individually.

** Please note that at the beginning of each meeting, participants are invited to reflect on the previous meeting and to discuss what they have learned.

*** Please note that at the end of each meeting, participants are invited to express their opinion of the program (what they loved the most, the least, their favourite thing and their suggestions to improve the meeting).

Foundational elements of the program

GUIDING PRINCIPLES OF THE PROGRAM

- **Everyone has the right to decide for themselves.**
  - ✓ In certain contexts, KEEPING one's secret is best.
  - ✓ In other contexts, REVEALING one's secret is best.

- **Everyone can find their own solutions**
  - ✓ Everyone can answer these questions: Who to tell or not tell? When? Where? Under what conditions? How?
  - ✓ Everyone can find solutions to deal with the negative or positive reactions of others.
  - ✓ Everyone can find solutions to deal with being "outed."

- **Disclosure is a recurring issue in the life of every person living with HIV.**
  - ✓ Over time, a person living HIV will have to keep evaluating disclosure-related issues, as situations may change.
  - ✓ The program provides the tools needed to evaluate these issues as contexts change or as new contexts emerge.

- **Every person living with HIV goes through their own journey.**
  - ✓ An individual may become overwhelmed or upset on their journey of adapting to life with HIV and may experience a wide range of emotions related to their condition.
  - ✓ Everyone deals with their HIV status at their own pace and in their own way.
  - ✓ The aim of the program is to help participants understand the stages involved in adapting to life with HIV and to find their bearings at each stage.

- **The program promotes neither disclosure nor non-disclosure of HIV status.**
  - ✓ The aim of the program is to allow participants to share their experiences surrounding the issue of disclosure and to help them become more thoughtful and proactive when it comes to deciding whether or not to reveal their status in various contexts.

- **By sharing their experiences and journey, participants gain insight and support.**

- **No one is forced to share their experiences. Those who do are always treated with respect.**

ATTITUDES OF FACILITATORS AND PARTICIPANTS TOWARD EACH OTHER

- ✓ Respectful and non-judgemental
- ✓ Attentive and empathetic
- ✓ Formally committed to maintaining confidentiality
- ✓ Supportive

ROLES OF FACILITATORS AND PARTICIPANTS

- **The facilitator's role is to:**
  - ✓ GUIDE, COACH, FACILITATE
  - ✓ NOT direct the participants
  - ✓ 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
- **The participants' role is to:**
  - ✓ Own their emotions, speaking in the first person ("I")
  - ✓ Explore the pros and cons of each situation
  - ✓ Share their strategies with the other participants
  - ✓ Support the other participants
  - ✓ Develop the other participants' strengths

APPROACH TO BE PROPOSED TO THE PARTICIPANTS

This program will adopt an approach that enables every participant to assess their own position on whether or not to disclose their HIV-positive status to the people around them; to gain a better understanding of the issues that may arise when choosing whether or not to disclose; to better deal with the burden of their secret; and ultimately to feel more in control of their life.

- **Making a non-coerced and informed decision based on the specific context**
  - ✓ Making a non-coerced, informed and thoughtful decision about whether or not to disclose requires conducting an in-depth analysis of the situation in a given context.
  - ✓ To this end, a number of activities and tools will be used to identify:
    - + CONTEXTS where it is not generally necessary for someone to reveal their HIV-positive status, where not telling may be best for their own well-being, and where they are legally required to tell (where disclosure pertains to sexual partners and obtaining insurance).

- + The PROS (advantages) of disclosing or not disclosing.
  - · “If I tell this person, these are the good things that could occur.”
  - · “If I don’t tell this person, these are the good things that could occur”.
- + The CONS (disadvantages) of disclosing or not disclosing.
  - · “If I tell this person, these are the bad things that could occur.”
  - · “If I don’t tell this person, these are the bad things that could occur.”
- + The OBSTACLES to overcome when choosing whether or not to disclose. An obstacle is something that, in the participant’s view, could keep them from doing what they want to do. It stands between the individual and their chosen course of action. Obstacles may be personal, international, social, cultural, economic, environmental or circumstantial in nature.
- + The WINNING CONDITIONS to overcome these obstacles and increase the odds of having a good experience when telling or not telling. A winning condition is an inner strength or resource that will help the participant overcome a given obstacle. Winning conditions may be personal, international, social, cultural, economic, environmental or circumstantial in nature.

✓ Once the participant identifies their pros, cons, obstacles and winning conditions, they can better evaluate the RELATIVE IMPORTANCE or weight of all these favourable and unfavourable elements, which will help them to make an informed decision.

MANAGING THE DECISION WITH STRATEGIES AND A CONCRETE ACTION PLAN

✓ Once the participant’s decision is made, they have the tools they need to decide on strategies to use to reveal their status or keep it secret.

✓ For these strategies to be effective, the participant must create a concrete action plan. Who will they tell/ not tell? When? Under what conditions? With the help of which person or resource?

✓ It is essential to this process that the participants share their own positive or negative experiences.

✓ The participants must also create a Plan B within this action plan so they can be prepared to:

- + deal with unexpected negative reactions of the person they tell, if they choose to disclose
- + deal with being “outed” if they have chosen not to tell

Tips to implement and facilitate the program

—

Here are a few strategies to optimize the planning and execution of the program:

Before the program starts…

▸ Program promotion

- ✓ When they are introducing the program to participants, facilitators should not focus on the term “disclosure” because it will then be difficult to mobilize participants. Instead, they should explain that the program is a discussion and reflection group for people living with HIV and that the experiences and insights shared by the participants will help them better deal with the daily issues and challenges they face.

- ✓ **The program promotes neither disclosure nor non-disclosure of HIV-positive status but rather educates people living with HIV so they can make thoughtful and informed decisions and take control of their lives.**

RECRUITMENT STRATEGIES

- ✓ Facilitators should promote the program as much as possible so they can recruit as many participants as possible. The people for whom the program is intended should have access to information about the program (e.g., you could make announcements in your organization’s newsletter, distribute flyers and post signs in your area.)

- ✓ Facilitators can also call people who use their organization’s resources.

- ✓ It may be helpful to team up with hospitals offering specialized services to people living with HIV (an immunodeficiency clinic) to promote the program, so do not hesitate to meet with them and to get them involved in promoting your services.

FORMING GROUPS

- ✓ It is preferable to have four to eight participants per group because including more people could make it more difficult to schedule meetings and would give each participant less time to share.

- ✓ Forming homogenous or heterogeneous groups (according to the participants’ profile) is at the facilitators’ discretion. In forming groups, facilitators should consider the participants’ socio-demographic characteristics (age, sexual orientation, socio-economic status, ethnicity, number of years since diagnosis, etc.).

- ✓ Including participants with different views on the issue of disclosure can be beneficial as others’ opinions and experiences may open the participants up to new ways of thinking about and dealing with their situation.

- ✓ Some participants may be illiterate or have a different first language. It is important to consider this when facilitating program activities (e.g., the facilitator could read the exercise instructions and a co-facilitator could translate into the person’s first language, if possible).

✓ The program is for participants who meet the following eligibility criteria:

  + A desire to share: The participant must be willing to talk about the issue of disclosure/non-disclosure and to share their experiences with other people living with HIV.
  + Availability and commitment: The participant must be able to attend nine meetings and must be willing to take part in group discussions.
  + Concerns: The participant must have some concerns surrounding the issue of disclosure/non-disclosure.
  + Emotional stability: The participant must be past the shock of their diagnosis* and must be emotionally stable**.

* For some people, this stage is brief; for others, it is longer. Most women move beyond shock within 6 months of their diagnosis, on average.

** It is advisable to hold one-on-one sessions before the program starts with participants in crisis who want to join the program

STRATEGIES TO REACH WOMEN DURING THE PROJECT

✓ After recruiting a participant who meets the eligibility criteria and wishes to participate, you must have a strategy for reaching them afterwards that is appropriate for their situation. Be sure to keep their contact information in a secure location to ensure that it remains confidential.

✓ It may be necessary to call the participants every week to remind them of meetings.

✓ If necessary, you can help the participants to come up with reasons to explain to their loved ones where they are going every week (e.g., I'm attending a discussion meeting at the women's centre; I'm in a book club; I'm taking a writing class, etc.). However, be sure to tell the participants they cannot use you as an alibi. In addition, tell them that if you have to call them and someone else answers the phone, you will only use your first name.

PLANNING MEETINGS

✓ The program should ideally be offered at times that are convenient for the participants.

✓ Shorter meetings can be held weekly or an intensive workshop can be held over a weekend, during a stay at a cottage or retreat centre or other location.

✓ Partnering with other organizations can make it easier to launch the program (more material, financial and human resources).

✓ The program can be offered to groups, to individuals (one facilitator and one participant) or to dyads (two participants and one facilitator).

PREPARATION OF FACILITATORS AND SUPPORT

- ✓ Facilitators who moderate meetings must understand the reality of people living with HIV and be familiar with current legislation regarding disclosure of HIV-positive status.

- ✓ Facilitators must have taken a workshop on group facilitation or possess the skills required to facilitate discussion and support groups. If this is not the case, one of the co-facilitators should be a professional from the organization offering the program or have group facilitation experience.

- ✓ Finally, the facilitators must be able to get help and support from their colleagues and from officials of the hosting organization (before, during and after the meetings).

Before each meeting…

REFRESHMENTS AND SNACKS

If the meetings are held in the afternoon, the facilitators should provide refreshments or snacks to hold the participants and the facilitators until dinnertime.

VENUE

- ✓ The meeting place should be chosen carefully. The room must be available from week to week and the facilitators must be able to access it at least 30 minutes beforehand to prepare it. It should also be in a location that appeals to most of the participants (discreet location, little traffic, etc.).

- ✓ The meetings may have to be held at a set location outside the hosting organization’s offices if, for instance, the hosting organization lacks a suitable room or if the participants do not want to be seen at the organization’s offices because this would reveal their HIV-positive status. If the program is being offered to a single participant, the meetings could take place at the participant’s home.

- ✓ Meetings can take place outside the hosting organization’s office hours. Some participants may feel more comfortable attending the group meetings at a time when no one else is in the office.

- ✓ The facilitators should arrange the chairs so as to promote group interactions (in the shape of a circle or “U”).

- ✓ The facilitators should set up the audiovisual equipment and ensure that everyone can see what is being presented.

MATERIALS

✓ The facilitators must obtain the materials required for each of the nine meetings:

  + Logbook
  + Adult-sized scissors (the largest size)
  + Good-quality glue sticks
  + Good-quality coloured pencils, wax crayons or felt markers
  + Cardboard of various colours
  + Magazines (e.g., Chatelaine)
  + Pens
  + Paint and paintbrushes
  + A large cardboard mural (paper or fabric)
  + A device to play a DVD and music (participants will be invited to bring in music CDs)

LOGBOOK

✓ The facilitators can determine what form the logbook will take (scrapbooking album, folder, binder, etc.) on their own or with the participants.

✓ The facilitators must ensure that the support and activity sheets will fit into the participants' logbooks.

DOCUMENTATION

✓ The facilitators can give the participants various documents, brochures and flyers over the course of the meetings. A list of relevant documents is included in Appendix 1. The facilitators are encouraged to update this list.

✓ The facilitators can also provide phone numbers where the participants can obtain more information (HIV and sexual health hotlines, support and referral organizations).

✓ The facilitators can post articles or posters on HIV to create an atmosphere that is conducive to learning.

ARRANGEMENTS AND INCENTIVES

✓ To encourage and facilitate the participants' attendance, the hosting organization can offer to provide day-care for those with kids, supply public transportation tickets to cover travel expenses, serve snacks at the break, or offer any other incentive that is likely to appeal to the participants.

Here are a few strategies to optimize the success of the program:

During each meeting…

PROGRAM FACILITATION

- ✓ Given the serious nature of the topic and to ensure that program meetings run smoothly, joint program delivery (i.e., delivered by two facilitators) is strongly suggested. The co-facilitators must ensure that they are always available to participants by arriving before each meeting and staying until the last person has left.

- ✓ Since the program promotes neither disclosure nor non-disclosure of HIV-positive status, it is essential that facilitators respect the decision-making process of each participant. Facilitators are resource people whose role is to provide the participants with support and guidance.

- ✓ The facilitators are responsible for carrying out program activities, answering participants' questions and providing them with information relevant to their situation, while organizing the discussions and synthesizing the material raised at the meetings so the participants can draw their own conclusions. If the facilitators are unable to answer participants' questions, they should direct them to appropriate resources or bring answers to the next meeting.

- ✓ It is important for facilitators to give the participants time to speak. Facilitators should scan the room and look at everyone during group discussions, not just some people. This way, they will be able to see the raised hands of all participants who wish to speak.

- ✓ It can be helpful for facilitators to display the participants' work (on flip charts) in the room so they can see what they have accomplished during the session.

- ✓ Before each meeting, facilitators are encouraged to identify the specific tasks each will perform to clearly establish who will do what and to ensure an equitable division of labour.

A FEW POSSIBLE SCENARIOS:

- ✓ Each of the co-facilitators can identify the activities they would like to moderate during a meeting.

- ✓ One facilitator can moderate the whole meeting and the other facilitator can prepare the room and materials, help the participants during activities, etc. The roles can be reversed at the next meeting.

- ✓ Many other scenarios are also possible. What is important is that the co-facilitators clearly identify and split up their tasks ahead of time.

After each meeting…

- ✓ After each meeting, the co-facilitators must set aside up to 30 minutes to put the materials away and review the meeting. They can also both take notes to be kept in the facilitator's logbook (e.g., what went well, what didn't go as well, points to follow up on at the next meeting, etc.).

During the program…

- ✓ The co-facilitators will need personal, professional and organizational support. Their professional team can be a major resource for them. The co-facilitators must receive the support of their coordinator and colleagues.
- ✓ During the program, it may be helpful for the co-facilitators to share the experiences, difficulties and successes they are having, initially with each other, but also with their coordinator or colleagues.
- ✓ The facilitators should identify a colleague or someone in the field with whom they can talk, if necessary. If they can't talk to someone in the field, they should talk to someone they know, taking care to preserve the participants' anonymity.
- ✓ The facilitators will occasionally have to offer post-meeting support to participants who have been particularly affected by certain activities.

The future of the program…

- ✓ Ultimately, the program would benefit from having former participants become facilitators, providing they have taken facilitation workshops and have the skills to coach people dealing with the issue of disclosure. This would be a wonderful opportunity for people living with HIV to get involved with the organization to support their peers. It would allow them to take control of their health and well-being and to help others do the same, to improve the quality of their own lives and that of others, and to ensure the future of the program.

Good luck with the program!

Key themes of the program

Program facilitators must be familiar with and understand the reality of people living with HIV. The following questions and answers will allow you to better understand what people living with HIV experience or to rethink your views. More importantly they will help you to assess your knowledge and identify themes you wish to learn more about before you start facilitating meetings.

THEME 1 | LEGAL RIGHTS AND OBLIGATIONS IN REGARDS TO DISCLOSURE OF HIV-POSITIVE STATUS

1. Are people living with HIV legally required to disclose their status to their sexual partner(s) in Canada?

Answer: YES

According to the Supreme Court of Canada, people living with HIV are legally required to disclose their status before having sex that involves a realistic possibility of HIV transmission, even if that risk is low. Those who do not disclose their status may be found guilty of aggravated sexual assault by the courts even if the sexual partner did not contract HIV (source: Canadian HIV/AIDS Legal Network, 2012).

Answer: NO

However, people living with HIV are not legally required to disclose their status before having vaginal sex if (1) their viral load is low or undetectable and (2) they use a condom. For further information, consult the Canadian HIV/AIDS Legal Network at http://aidslaw.ca or the COCQ-SIDA HIV/AIDS legal hotline (1-866-535-0481, ext. 34, http://www.cocqsida.com/ressources/vih-info-droits.html).

2. Are people living with HIV legally required to disclose their status to people in their lives and to alternative medicine practitioners (massage therapists, acupuncturists, chiropractors, osteopaths, etc.)?

Answer: NO

Generally (with the exception of insurance and situations involving the realistic possibility of HIV transmission through vaginal or anal sex with anything higher than a “low” viral load), no one can force people living with HIV to disclose their HIV-positive status, as this information is confidential. People living with HIV do not have to disclose their HIV-positive status to friends, to family members, to their employers, to co-workers or to alternative medicine practitioners if that is their decision. It is up to them to decide whom they wish to tell or not tell and under what circumstances.

3. Are people living with HIV legally required to disclose their status to traditional health care professionals such as family physicians?

Answer: NO

Since health care professionals are required to take universal precautions (such as wearing gloves and sterilizing instruments and materials), people living with HIV are not required to disclose their HIV-positive status or other health problems to health care professionals. However, to receive care that is appropriate for your current health status, it is best to inform the health care professionals you consult.

4. **Are people living with HIV legally required to disclose their status to insurance companies, for example, when obtaining personal life insurance or disability insurance?**

Answer: YES

In the case of personal life insurance and disability insurance, the company has the right to ask about HIV status. If the person fails to disclose it, not only can the company refuse to pay out eligible benefits but the person would be found guilty of fraud and their policy could be cancelled. There would also be a mention of the fraud in the person's federal insurance file, which would prevent them from obtaining insurance afterwards.

THEME 2 | POSSIBLE REACTIONS TO LEARNING YOU HAVE A CHRONIC DISEASE

1. **Do people living with HIV go through emotions and reactions that can be likened to mourning?**

Answer: YES

People who are told they have the HIV virus can experience many emotions, such as shock, denial, anger, sadness or even depression, resignation, acceptance, adaptation and integration. Most of these emotions, which usually occur after the loss of a loved one, can also occur when someone learns they have a chronic disease like HIV. These reactions are part of a necessary process that people must go through to learn to live with their chronic disease. Some people may go through certain stages more than once, while others may go through the stages in a different order or at a different pace.

THEME 3 | HIV: MODES OF TRANSMISSION AND HIGH-RISK BEHAVIOURS

1. **Are there more women with the HIV virus than men?**

Answer: NO

Worldwide, there are almost as many women living with HIV as men (World Health Organization, 2013). However, the disease is experienced differently by men and women. In Canada, a growing proportion of reported HIV cases have been in women since 1985 (Public Health Agency of Canada, 2010), while in Quebec, it is men who are the most affected (Institut national de la santé publique du Québec, 2012). If you would like to obtain information on the epidemiology of HIV in your province or country, feel free to contact the available resources.

2. **Are women at greater risk of contracting HIV than men?**

Answer: NO

When having protected sex, women have the same risk of contracting HIV as men. What puts a person at greater risk of contracting HIV is engaging in high-risk behaviours (e.g., having condomless sex, sharing IV drug injection supplies).

Answer: YES

Women who have unprotected sex are more vulnerable to contracting HIV for biological, cultural and socio-economic reasons. From a biological perspective, a woman's vaginal mucosa is more exposed than the head of a man's penis during sex. Men also transmit more sexual fluids than women during sex and there is a greater amount of the virus in sperm than in a woman's vaginal secretions. Finally, vaginal and anal tissues are more sensitive to the micro-tearing that can occur during vaginal or anal penetration. Worldwide, girls have less access to education than boys and thus have less knowledge about sexuality, HIV and ways of protecting themselves. From a socio-economic perspective, more women live below the poverty line than men. Women are also more financially dependent on men to meet their needs and those of their children and are thus less likely to demand that a condom be used if their partner refuses to wear one (World Health Organization, 2013)

THEME 4 | CHALLENGES SURROUNDING DISCLOSURE OF HIV-POSITIVE STATUS

1. Is there more than one type of disclosure?

Answer: YES

There are four types of disclosure: need-to-know disclosure (very few people know, often only the treating physician and the partner), selective disclosure (certain people are told after the individual has assessed the situation), full disclosure (many people are told; the individual is not selective about whom they tell) and undesired disclosure or “being outed” (confidentiality has been breached by someone who was told in confidence).

2. Are there advantages to revealing one’s status?

Answer: YES

Telling can have positive effects in many areas of a person’s life. In terms of their professional life, the individual may be eligible for benefits available to people with a disability, such as student bursaries. In terms of their relationships with family and friends, the individual might receive support from loved ones and make new friends. In terms of their love life, telling could solidify and deepen the bond between the person and their partner. There can also be personal benefits, in that the person may feel relieved that they no longer have to lie.

3. Are there disadvantages to revealing one’s status?

Answer: YES

Overall, people have fairly good experiences when they tell, or at least the negative consequences associated with telling are not that severe. However, telling can lead to negative consequences in various areas of the person’s life, for their career, their personal relationships and their socio-economic prospects: for example, telling could result in the person losing their job, to rejection or manipulation by friends, it could prevent the person from becoming a Canadian citizen, and it could shock or sadden family members who are told.

THEME 5 | CHALLENGES SURROUNDING NOT DISCLOSING ONE’S HIV-POSITIVE STATUS

1. Are there advantages to not revealing one’s status?

Answer: YES

Some of these advantages may include protecting one’s kids from being stigmatized and socially discriminated against, avoiding rejection, safeguarding the health of a loved one, keeping one’s job, avoiding being personally stigmatized and discriminated against, etc.

2. **Are there disadvantages to not revealing one's status?**

Answer: YES

Some of these disadvantages may include feeling isolated, being "outed," having to live with the burden of the secret, always having to hide, having to lie about one's health, leading a double life, etc.

3. **Can people living with HIV file a complaint if they believe their right to keep their HIV status confidential has been violated?**

Answer: YES

In the case of unlawful interference with a person's Charter rights or freedoms, the person has the right to demand the cessation of such interference and to obtain compensation for the moral or material prejudice resulting from this interference. In the case of unlawful and intentional interference, the court may assign punitive damages to the individual responsible for the interference.

For information about HIV and the law in Canada:
Canadian HIV/AIDS Legal Network
www.aidslaw.ca
416-595-1666

For information and advice about HIV and the law in Quebec:
Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-Sida):
www.cocqsida.com (in French only)
514-844-2477 ext. 34 or 1-866-535-0481 ext. 34

To contact federal (Canadian government) agencies responsible for protecting human rights or privacy:
Canadian Human Rights Commission
www.chrc-ccdp.ca
1-888-214-1090 • TTY 1-888-643-3304

Office of the Privacy Commissioner of Canada
www.priv.gc.ca
613-947-1698 or 1-800-282-1376 • TTY 613-992-9190

THEME 6 | THE PROCESS INVOLVED IN MAKING DISCLOSURE-RELATED DECISIONS

1. **Do you think disclosure-related decisions should only be made after careful consideration?**

Answer: YES

The disclosure of one's HIV-positive status is an ongoing process, not a one-time event. Telling may affect not only the person living with HIV who is making the disclosure but also the person who is told and their family and friends. Being prepared for making the disclosure increases the odds that things will go well and helps the person better anticipate, reduce or manage possible consequences of telling. Given the complex issues surrounding HIV status disclosure (the challenges and consequences of telling), people should be able to decide for themselves if they wish to tell or not tell. People who work with people living with HIV should respect the wishes of individuals who want to keep their status a secret, offer support to those who have concerns about disclosing their status and coach those who wish to reveal it.

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Quick references for the facilitator’s guide

The following icons flag different elements of the facilitator’s guide and are included to make it easier to navigate through the guide.

OBJECTIVE OF THE MEETING

DURATION

DURATION OF ACTIVITY

REQUIRED MATERIALS

MEETING PLAN

BREAK

END OF THE MEETING

VARIATION
This box indicates another way of doing the activity.

TIP
This box suggests ideas to simplify the activity or explain its purpose.

CONTENT DETAILS
This box provides information that explains or complements the content of the activity.

IMPORTANT NOTE
This box includes notes to the facilitator on important messages to convey to participants.

EXERCISE
This box explains how activities are to be done and how participants are to be guided.

NOTE TO FACILITATOR
This box provides suggestions that facilitators can use to make the meetings run more smoothly and to encourage the participants’ involvement.

WEEKLY REFLECTION
This box indicates the homework that the participants must complete for the following week.

Testimonials from women who took part in the Sharing Together for Life program

Here is what a few women had to say after participating in the program :

"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 and so on." (Simone, originally from Congo, 40-49 age group)

"This program helped me a lot and made me want to keep on living. Now I feel like a woman and hold my head up high, without shame or fear, because I know that I have the right to enjoy life like everyone else." (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)

"I received the moral support I needed. I met other women in the same situation and now I know when, where and how to disclose my status or keep it to myself." (Clotilde, originally from Rwanda, 40-49 age group)

"I can honestly say that these workshops made a big difference in my life. Now, I'm much more comfortable when I tell people my status." (Jasmine, originally from Burundi, 30-39 age group)

"It made me think about how to reveal my status to friends and the people in my life. The facilitators we worked with were very nice and the atmosphere was great." (Debbie, originally from Burundi, age 50))

"I realized that not telling people my status works for me overall." (Lucie, originally from Asia, 40-49 age group)

"It 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)

"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)

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MEETING 1

WELCOME

Overview

Meeting 1 | Welcome

OBJECTIVE OF THE MEETING

For the facilitator
To establish contact with each of the participants.

For participants
To establish contact with the group and decide whether or not to take part in the program.

DURATION

- 3 hours

REQUIRED MATERIALS

- A logbook for each participant
- Art supplies for each participant (scissors, glue, pencil crayons, various stickers, various magazines, etc.)
- Moral commitment and confidentiality agreement” form (two copies per participant)
- A pen for each participant
- Appointment cards (memory aid)

MEETING PLAN

1. Welcome ▸ 15 minutes
2. Presentation of program components ▸ 10 minutes
3. Presentation of the logbook ▸ 10 minutes
4. Activity: “My first page” ▸ 50 minutes

   Break ▸ 15 minutes

5. Commitment and expectations of participants (“Continuum” and “To what extent...?” exercises) ▸ 1 hour
6. Sign the “moral commitment and confidentiality agreement” form ▸ 5 minutes
7. Participants’ preference(s) (appointment card) ▸ 5 minutes
8. Question period ▸ 10 minutes

   End of the meeting

Meeting 1 | Welcome

OBJECTIVE OF THE MEETING

For the facilitator
To establish contact with each of the participants.

For participants
To establish contact with the group and decide whether or not to take part in the program.

DURATION

- 3 hours

REQUIRED MATERIALS

- A logbook for each participant
- Art supplies for each participant (scissors, glue, pencil crayons, various stickers, various magazines, etc.)
- “Moral commitment and confidentiality agreement” form (two copies per participant)
- A pen for each participant
- Appointment cards (reminder)

VARIATION

While it is recommended that all participants attend this first meeting as a group, alternatively the facilitator can conduct individual meetings with each participant.

Advantages of individual meetings:

- Learn the specific needs of each participant.
- Have a discussion with each participant to find out if the workshop objectives and the intervention approach (group reflection) meet the participant’s needs. If the workshops are not appropriate, direct the participant to specific resources or offer them individual support sessions that can use materials adapted from the program workshops.

Advantages of a group meeting:

- Saves time.
- Establishes contact with the other participants.
- Takes place in an environment where many participants can be engaged.

MEETING PLAN

15

1. WELCOME

1.1 INTRODUCTION OF THE FACILITATOR ▸ 5 minutes

- The facilitator welcomes the participants and introduces herself or himself: first name, professional background, interest in the program.

1.2 INTEREST AND EXPERIENCE OF THE PARTICIPANTS ▸ 10 minutes

- The facilitator asks the participants how they heard about the program and what they hope to get out of it.
- The facilitator can also ask if they have ever participated in the program and, if so, what they got out of the experience.

10

2. PRESENTATION OF PROGRAM COMPONENTS

- The facilitator explains the purpose and objectives of the program and presents:
  - the proposed number of meetings
  - the length of each meeting
  - individual themes that will be discussed
  - educational activities that will be carried out

See next page for content details.

CONTENT DETAILS: PRESENTATION OF PROGRAM COMPONENTS

Objectives of the program

The program is designed to help participants become more proactive and thoughtful when it comes to the issue of whether or not to disclose their HIV-positive status and to help them...

- realize it is possible to lead a full life with HIV
- recognize situations where the issue of disclosing their HIV status may come up
- evaluate potential issues surrounding the disclosure of their HIV status in various situations
- plan strategies related to the disclosure of their HIV status
- put to use their acquired knowledge in other situations where the issue of disclosing their HIV status may come up

Meeting themes

The program includes nine meetings (of around 3 hours each) on the following themes:

1. **Welcome**: establishing contact with the facilitator and the other participants in the group.
2. **Portraits of women:** recognizing the importance of taking part in the program and creating cohesiveness among the participants
3. **Learning to live with HIV:** the process of adapting to life with HIV
4. **Life situations:** scenarios where the issue of disclosure or the secret may come up
5. **Controlling my own destiny**: possible consequences of disclosing one's HIV status in various situations
6. **Sharing to better support each other:** disclosure strategies in various situations
7. **Secrets to keeping your secret:** possible consequences of revealing one's secret in different situations
8. **One, two, three, HUSH!:** strategies to keep one's secret in different situations
9. **Participants' messages:** group mural and wrap-up of the program.

Types of educational activities used in the program

- group discussions
- interactive games
- drawing-based reflection exercises
- impact techniques using movement, expression, objects or images
- documentary, video

IMPORTANT NOTES

+ The facilitator should explain to the participants that this isn't group therapy but rather a discussion group that promotes learning, reflection and group discussions. It is a structured program, with predetermined objectives through which participants can pursue their own path.
+ The facilitator should remind the participants that **the program does not advocate disclosing their HIV status or keeping it secret**. It does not, in any way, advocate that they should or should not disclose their HIV status to those around them. The purpose of the program is to allow them to share the experiences they have had when the issue of disclosing their HIV status has come up, to be more thoughtful and proactive when the issue of disclosing their HIV status arises in various situations, and to learn tools they can use to either disclose their HIV status or keep it secret, if that is their decision.
+ Finally, the facilitator should explain to the participants that **whatever they wish to share is up to them** and that they can count on the group to be supportive and respectful.

10

3. PRESENTATION OF THE LOGBOOK

- The facilitator presents several types of blank logbooks to the participants and asks them each to choose one.
- The facilitator explains that the logbook will serve as a reflection, tracking and learning tool during the meetings and that they can use it to do specific activities at home if they wish, providing they bring their logbook back to each meeting. The logbook can also be kept by the facilitator in a secure location.

NOTE TO FACILITATOR

+ The following exercises can either be done as a group or individually, depending on the circumstances.

50

4. ACTIVITY: “MY FIRST PAGE”

- The facilitator gives each of the participants a logbook and a sheet of white or coloured cardboard.
- To complete their “first page,” the participants are asked to spontaneously answer this question: What would you like to get out of the workshops?

TIPS

- Encourage the participants to use their creativity and imagination. They can use drawings, scrapbooking, music lyrics, or even words or images cut out from a magazine to do the exercise.
- Encourage the participants to collect images, bits of writing or wrapping paper, phrases from magazines, ribbons and other materials at home, which they could use to create the pages of their logbook. The idea is to collect things they like and that reflect their feelings.

- As a follow-up to this exercise, the facilitator asks those who wish to share with the group what their first page represents.
  Make sure that all participants have the opportunity to express themselves.

VARIATIONS

- The facilitator can suggest to the group that they put their first page on a table so everyone can see what the others have done, but without making them feel like they have to officially present their first page.
- This activity can be finished at home for those who wish to do so.
- If time permits, this activity can also be continued at the next meeting.

BREAK ▸ 15 minutes

5. COMMITMENT AND EXPECTATIONS OF PARTICIPANTS

- To find out what the participants expect from the program and their anticipated level of commitment, the facilitator can suggest doing the “Continuum” and “To what extent...?” exercises.
- The group can do one of the exercises or both, if time permits.

“CONTINUUM” EXERCISE

Impact technique using movement

Instructions

+ The participants are asked to stand in the middle of the room and form a circle, facing away from each other.
+ The facilitator then asks them to think about their objectives for the program.
+ To illustrate to what extent having these expectations (objectives) met is important to them, the facilitator asks each participant to walk towards the wall (the wall facing them). The wall represents having all of their expectations (objectives) of the program met.

Implementation

“Where you are right now (the middle of the room) represents the starting point of our meetings or the support you are seeking here. The wall in front of you represents having all your expectations of the program met. Now, please show me how important this is to you by moving towards the wall.”

Objectives

The point of this exercise is to have the participants share the reasons that led them to take part in the program and to be realistic about what they can expect to get out of it. The facilitator can ask the participants to clarify their expectations to validate them or to let them know what they can and cannot expect to get out of the workshops.

Source *:* Beaulieu, D. (2006). *Techniques d’impact en psychothérapie, relation d’aide et santé mentale.* Québec, Québec. Impacts! Éditions, 310 pages, © 1997

“TO WHAT EXTENT…?” EXERCISE

▸ Impact technique using expression

Instructions

+ Going around the table, ask the following two questions:

  1. *To what extent are you prepared to share your feelings and experiences with the group?*

  2. *To what extent are you prepared to support others’ feelings and experiences?*

+ Ask the participants to answer these two questions using a scale from 0 to 10 (where 0 means “not at all” and 10 means “fully”).

Source : Beaulieu, D. (2006). *Techniques d’impact en psychothérapie, relation d’aide et santé mentale.* Québec, Québec. Impacts ! Éditions, 310 pages, © 1997

5

6. SIGNING OF THE “MORAL COMMITMENT AND CONFIDENTIALITY AGREEMENT”

- The facilitator reads the “moral commitment and confidentiality agreement” form aloud and asks the participants if they have any questions.

  The facilitator then asks the participants to sign two copies of the form. Only first names or pseudonyms should be used. This symbolic gesture conveys the message that each person in the group vows to keep confidential everything their fellow participants have shared during the meetings.

- The facilitator keeps a copy of the form and gives the other copy to the participants to put it in their logbooks.

5

7. PARTICIPANTS’ PREFERENCE(S)

- If it is an individual meeting, the facilitator asks the participant to indicate their availability and meeting time preferences. This way, the facilitator can create one or more groups based on each participant’s availability and preferences or choose meeting times that work best for most of the participants.

NOTE TO FACILITATOR

+ If the meeting times have been predetermined, the facilitator can give each participant the **appointment card**. This card indicates the title, theme, location, time and date of each meeting.

  (This small card can be used as a reminder by the participants. It is discreet and can easily fit into a wallet.)

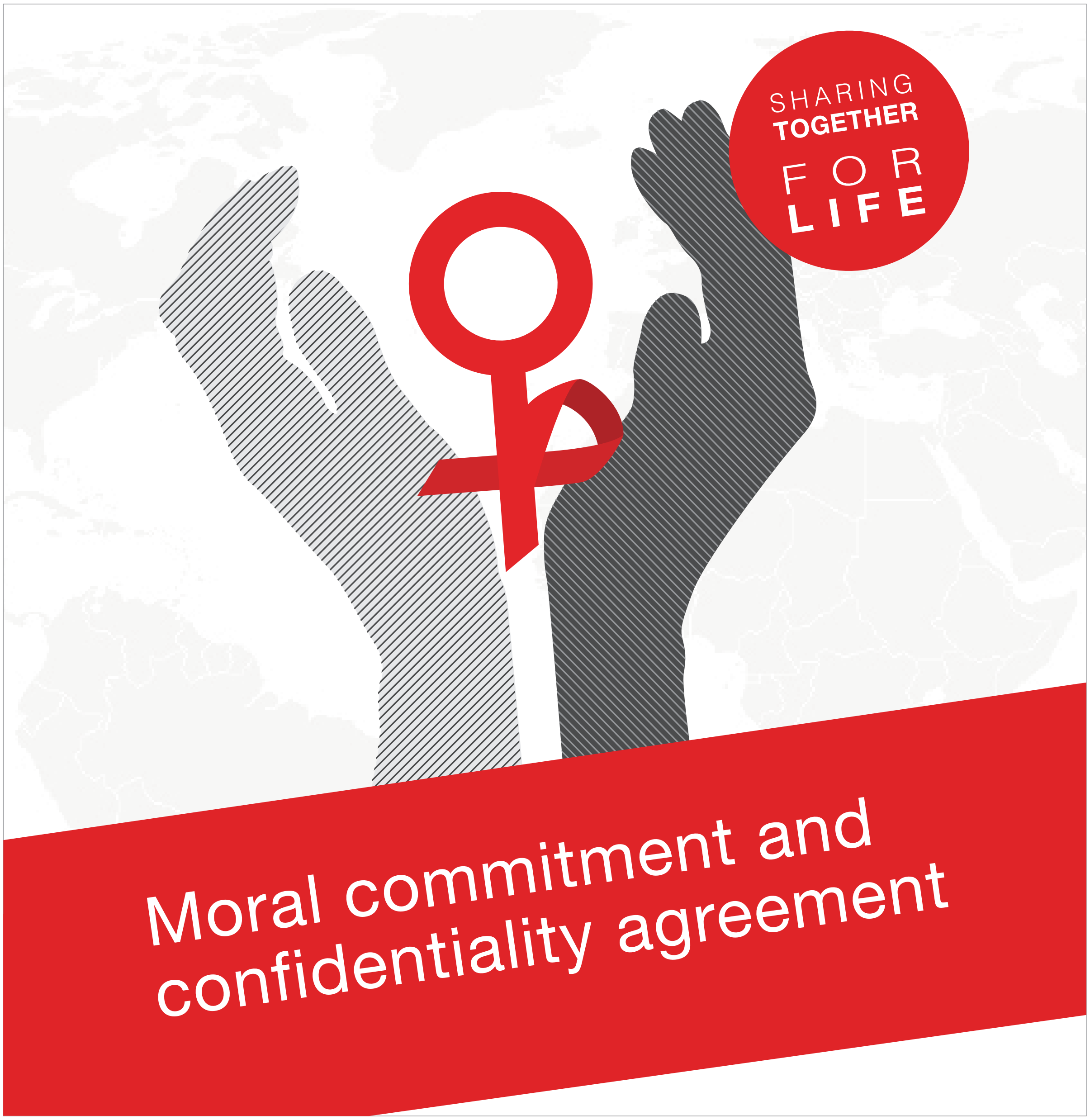
8. QUESTION PERIOD

- Before concluding the meeting, the facilitator asks the participants if they have any questions regarding their commitment to the program or the structure of the meetings and then answers them.
- The facilitator thanks the participants for their attendance and participation.

IMPORTANT NOTES

+ Give the participants a few minutes to talk if they feel uneasy. Appointments can be scheduled for later on if necessary.
+ If required, tell the participants about support contacts who would be happy to meet with them if they feel the need.
+ Inform the participants that the purpose of the next meeting will be to help the participants understand the importance of taking part in the program.

END OF THE MEETING



Moral commitment and confidentiality agreement

I, ____ (first name or pseudonym),

a participant in workshops on the issue of HIV status disclosure, undertake to maintain the confidentiality of all information shared by the other participants who attend these meetings, as well as all other personal information about the participants.

In witness whereof, I have signed ________________________________ (first name or pseudonym, if required)

On this date: ____________

MORAL COMMITMENT AND CONFIDENTIALITY AGREEMENT

Two copies of this form must be signed. The participant keeps one copy, and the other copy will be kept on file by the facilitator in a secure location

APPOINTMENT CARD

UQÀM
Université du Québec à Montréal

A place for sharing and reflection among women

(Year when the workshop is held) :
In partnership with
(Name and logo of the community organization) :

MEETING THEMES

1: “Welcome”
Date:

2: “Portraits of women”
Date:

3: “Learning to live with HIV”
Date:

4: “Life situations”
Date:

5: “Controlling my own destiny”
Date:

6: “Sharing to better support each other”
Date:

7: “Secrets to keeping your secret”
Date:

8: “One, two, three, HUSH!”
Date:

9: “Participants’ messages”
Date:

Indicate the time and place of the meetings

MEETING 2

Portraits of women

Overview

Meeting 2 | Portraits of women

OBJECTIVE OF THE MEETING

To help the participants understand the importance of taking part in the program and to create cohesiveness within the group.

DURATION

- 3 hours

REQUIRED MATERIALS

- Blackboard or flip chart and chalk or markers
- Positive Women: Exposing Injustice documentary and accompanying guide available online: http://www.positivewomenthemovie.org/video.html
- Computer and projector

MEETING PLAN

1. Welcome ▸ 40 minutes
2. Presentation of the theme and objectives of the meeting ▸ 5 minutes
3. Fostering an atmosphere of support and trust (group collaboration rules, “interdependence” exercise) ▸ 45 minutes

   Break ▸ 15 minutes
4. *Positive Women: Exposing Injustice* documentary and discussion ▸ 1 hour
5. Thoughts on the meeting ▸ 15 minutes

   End of the meeting

Meeting 2 | Portraits of women

OBJECTIVE OF THE MEETING

To help the participants understand the importance of taking part in the program and to create cohesiveness within the group

DURATION

- 3 hours

REQUIRED MATERIALS

- Blackboard or flip chart and chalk or markers
- *Positive Women: Exposing Injustice* documentary and accompanying guide
- Computer and projector

MEETING PLAN

40

1. WELCOME

1.1 INTRODUCTION OF THE FACILITATOR ▸ 5-10 minutes

- The facilitator welcomes the participants and introduces herself or himself. The facilitator also explains how they feel about facilitating the workshops and how the workshops will typically unfold.

1.2 INTRODUCTION OF THE PARTICIPANTS ▸ 20-30 minutes

May vary depending on the number of participants

- The facilitator goes around the table and asks the participants to state their name and how they feel about taking part in the workshops.

TIP

- This part of the meeting offers the participants a chance to express how they feel, which will give the facilitator a sense of their state of mind. Each participant should be allowed to speak for 2 minutes. It is recommended that the facilitator take part in this exercise as well.

VARIATIONS

Impact technique using expression

A word, feeling, colour or number

- In this exercise, participants are asked to answer the following question:
  "How do you feel about taking part in these workshops?" using a word, feeling, colour or number (e.g., on a scale of 0 to 10, where 10 means they are very happy to be taking part in the program)
- The facilitator can ask the participants to elaborate if they feel this is necessary and appropriate.

Source: Beaulieu, D. (2006). T*echniques d'impact en psychothérapie, relation d'aide et santé mentale.* Québec, Québec. Impacts! Éditions, 310 pages, © 1997

Other ice-breaker activities that can help the participants to get to know each other

True or false

- Going around the table, the facilitator asks the participants to tell two lies and one truth about themselves. The group must then guess which statement is true.

A quality corresponding to my first name

- Each participant states a quality that describes them, using the first letter or the first vowel of their first name.

My origins

- One by one, the participants tell the story or meaning behind their first or last name (as they wish).

An object that reflects me

- The facilitator puts various objects (a book, a key, a flower, a stuffed animal, an apple, a picture of a landscape, etc.) in the middle of the room. Each participant must then pick an object that represents them and explain the reason(s) to the group.
- The facilitator can also ask the participants to bring in their own object.

5

2. PRESENTATION OF THE THEME AND OBJECTIVES OF THE MEETING

- The facilitator tells the participants that the title of the meeting is Portraits of women**.**
- **Objectives:**
  - \+ to help the participants to understand the importance of taking part in the program
  - \+ to create cohesiveness within the group
  - \+ to create trust within the group

45

3. FOSTERING AN ATMOSPHERE OF SUPPORT AND TRUST

- It's important to foster an atmosphere that will allow the participants to feel safe when discussing their feelings and experiences related to their HIV status, especially in a group setting.

3.1 PRESENTATION AND EXPLANATION OF PARTICIPATION RULES ▸ 15 minutes

- To foster an atmosphere or trust and respect within the group, the facilitator goes through the "rules of group participation."
- The facilitator asks the participants to add rules to the list, if required. This list can then be posted in the room where the meetings will take place.

CONTENT DETAILS: RULES OF GROUP PARTICIPATION

- \+ Confidentiality should be respected (any personal information shared should remain between us).
- \+ Personal differences (age, sexual orientation, gender, ethnic background, religion, etc.) should be respected.
- \+ People should be allowed to speak freely; truly listening is important.
- \+ While no one is forced to share personal experiences, some level of commitment and participation is required from everyone during individual or group meetings.
- \+ Out of respect for the group, meetings will start at the scheduled time. Cell phones and other electronic devices should be turned off during meetings and people should wait for the break if they wish to go outside to smoke.
- \+ To promote participation and closeness, participants cannot miss more than two meetings; if they do, they will have to withdraw from the program, barring an unforeseen event. In such cases, missed meetings can be made up through individual meeting(s) with the facilitator.
- \+ Participants who expect to miss or be late for a meeting should notify the facilitator.

Source: Couture, M. (2004). *Les femmes et leur santé sexuelle : À votre santé…sexuelle ! Guide de l'animatrice.* Édition révisée. ÉMISS-ère, Longueuil, 58 pages.

TIP

Mobilization of the participants

It is essential that the facilitator set boundaries to ensure that the rules of group participation are followed (e.g., lateness will not be tolerated) and that they explain why it is important for participants to be on time (out of respect for the facilitators and the group, so the group is not kept waiting, etc.).

Tips

Should any of the participants arrive late for a meeting…

+ Discuss ways to keep this from happening again or to make up for lost time, such as shortening the break, extending the meeting, asking the participants to arrive a half hour earlier, calling participants the night before to remind them of the meeting, offering a snack before the meeting, etc.
+ During meetings, have the participants keep track of time to keep the meeting on course.
+ If the budget permits, hand out attendance slips to participants who came on time and took part in the meetings. This slip could entitle them to win an attendance prize, to be drawn at the end of meetings (e.g., gift card, jewelry, book, music, body lotion, etc.).
+ Consequences could be established for late participants (e.g., at the following meeting, the late participant might have to bring chocolate for the other participants, make coffee at the break, etc.). The consequences could be determined by the group members.

Telephone chain

+ To promote participation, the participants could decide that they will call each other before meetings.

3.2 INFORMING THE PARTICIPANTS ABOUT THE ROLE THEY WILL PLAY IN THE GROUP ▸ 15 minutes

- To explain how this discussion and reflection group works and the importance of participating at meetings, the facilitator then suggests doing the “Interdependence” exercise.

“INTERDEPENDENCE” EXERCISE

▸ Impact technique using movement

Instructions

- + The participants are asked to form a circle in the room. It is recommended that the facilitator join the circle as well.
- + The facilitator explains the exercise while doing it with the participants.

Objective

To recognize the participants’ value in the group and the important role they play during group meetings.

“We’re now going to do an exercise that will show you how important it is for you to come to group meetings and participate. This exercise will also show you how the meetings will evolve and make a difference in your lives. To start, if you look at yourself, you can see that you are isolated and occupy your own space within the circle (the facilitator makes the participants see that there is no contact between them). This represents the start of the meetings. The only thing you know about the other participants is that they are also living with HIV and that they have to deal with the issue of disclosing their HIV status or keeping it secret every day of their lives. So the first step to helping you see things a little more clearly, to ending your isolation, and to getting support or helping other women in the same situation is taking each other’s hands (the facilitator asks all the participants to take each other’s hands). This gesture symbolizes what you have done by joining this group. By coming here, you’ve agreed to recognize that you aren’t the only one who has concerns or who finds it difficult at times to disclose your HIV status. Now you can see that you are no longer alone. You are now part of a group. Each of you is an essential part of this circle. You are united (the facilitator helps them to realize that they are no longer alone because they have taken each other’s hands).

As these meetings progress, you will be asked to share your stories and experiences and to listen to those of others with empathy and respect. To illustrate the role you will play, I will ask you to take a few steps forward (the facilitator asks the participants to take two or three steps forward towards the middle of the room while holding hands). This sharing and listening will create a sense of solidarity and belonging (the facilitator helps the participants to see that they are now closer to each other than they were at the start of the exercise.)

Over the course of the meetings, you will also have the opportunity to support one another (the facilitator asks a participant to stand in the middle of the circle). To show that you support the person in the middle of the circle, I will ask you to make a gesture or say a few words (the facilitator gives them ideas and asks them to take turns: they can put their hands on the woman’s shoulder, take her hand, say they are there for her, tell her that she is no longer alone, etc.)

- ▸ Next, to illustrate the effects of some people not participating, the facilitator repeats the exercise by asking at least two people who are quite far from each other to not take any steps forward. This will create tension in the circle (the facilitator will then help the participants to see that the individuals’ lack of participation has a direct effect on the other members of the group).
- ▸ The facilitator ends this exercise with a group discussion: *“What did you think of this exercise?” “How did this exercise make you feel?” “What do you think leads some people to not contribute to the circle?”*.

Source : Beaulieu, D. (2006). *Techniques d’impact en psychothérapie, relation d’aide et santé mentale.* Québec, Québec. Impacts ! Éditions, 310 pages, © 1997

BREAK ▸ 15 minutes ◂

4. *POSITIVE WOMEN: EXPOSING INJUSTICE* DOCUMENTARY

1h

- The facilitator presents the *Positive Women: Exposing Injustice documentary.*
- Before screening the documentary, the facilitator describes the film.
- Without frightening the participants, the facilitator prepares them for what they are about to see by telling them that some of the scenes may bring back painful memories (see the discussion guide that accompanies the video for more information).

CONTENT DETAILS: *POSITIVE WOMEN: EXPOSING INJUSTICE*

Positive Women: Exposing Injustice
Available in English and French online: http://www.positivewomenthemovie.org/
Includes a discussion guide, which is only available in English.
This documentary takes the audience into the hearts and minds of four HIV-positive women who bravely speak out against the unjust criminalization of people who do not wish to disclose their HIV status.
It was produced by the Canadian HIV/AIDS Legal Network in 2012 and directed by Alison Duke (length: 45 minutes).

- *Positive Women: Exposing Injustice* is a documentary about women who learned they had HIV and how this diagnosis affected their health and their lives.
- Through images and words, it depicts women living with HIV and the issues they face surrounding the disclosure of their status.
- This documentary doesn't tell women with HIV how to treat others or themselves nor does it tell them what they should say about their HIV status, how they should say it or when should say it. The intent of *Positive Women: Exposing Injustice* is to start a conversation.
- The participants may see themselves in the stories told or have strong reactions, such as anger, sadness, joy, a sense of loss, regrets, guilt, etc., all of which are natural. Let them know there will be a discussion period after the documentary that will allow them to share their reactions with the others.

- After screening the documentary, the facilitator gathers the participants' comments, impressions and reactions. This group discussion will give those who wish to share an opportunity to talk about their own experiences with the other members of the group.

CONTENT DETAILS: DISCUSSION ON THE DOCUMENTARY

The facilitator asks the participants:

+ *How did you feel during the screening?*
+ *What images come to your mind after watching this documentary?*
+ *Could you relate to any these women's stories?*
+ *Which story affected you the most? In what way is your story different?*

The documentary may trigger emotional reactions for some participants. If this happens, it is important that the facilitator recognize this. The facilitator should be ready to welcome comments from participants and to allow them to share their personal stories, feelings or opinions about what was said in the film.

Source*:* Lapointe, J., and Voisard, P. (2000). *Histoires de dire. Québec.* Vidéo femmes, 14 pages.

VARIATIONS

Other films and documentaries could also be used during this meeting.

The following films and documentaries were selected because their content deals with issues surrounding disclosure of one's HIV-positive status. The facilitator is nonetheless advised to screen them ahead of time to determine if they are relevant for the group they are facilitating.

+ *Scenarios from Africa*
  (Available in eight languages, including French, English and Portuguese. www.globaldialogues.org. Also available on YouTube http://www.youtube.com/user/scenariosafrica)

  a) *Scenarios from the Sahel: Shared Hope*
  (Length: 5 minutes 53 seconds.). Directed by Cheick Oumar Sissoko (Mali). Based on an original idea by 21-year-old Andréa Ouédraogo, Burkina Faso.

  Annie feels hopeless when she confides her painful secret to her friend Myriame: she has just learned that she is HIV-positive. Myriame offers words of comfort and hope but Annie is still in shock and responds with violence. How can Myriame better understand what Annie is going through?

  b) *The Heart of the Matter*
  (Length: 8 minutes 41 seconds). Directed by Mahamat-Saleh Haroun. Based on an original idea by 20-year-old Sandra Nsambi Nzali, Republic of the Congo

  This is the story of young lovers. How can they, as individuals and as a couple, cope with the fact that one of them has HIV? What really matters in the end?

+ *The woman I have become*
  (Free. Also available in French, Somali and Swahili.)

  This documentary follows the lives of 8 African- and Caribbean-born women living with HIV in Toronto, Canada. It depicts the ups and downs of managing their disease and its effects on various aspects of their lives (family, health services, etc.).

  This educational tool was produced by Women's Health in Women's Hands (WHIWH) in collaboration with Black Coalition for AIDS Prevention, Voices of Positive Women, African Community Health Services, Africans in Partnership against AIDS, and the African & Caribbean Council on HIV in Ontario (2008). Directed by Alison Duke (length: 62 minutes).
  http://www.whiwh.com

VARIATIONS (continued)

+ ***Changing Voices: Stories of Living with HIV?***
(Free. English version available via the Victoria PLWHA website)

A series of 12 interviews with residents from Victoria, Australia, who are living with HIV. Through their stories, we learn about the impact of an HIV diagnosis, the challenges they have overcome and how they went on with their lives after their diagnosis. These stories defy stereotypes related to HIV and help break down the barriers of fear and ignorance that continue to surround HIV.

Educational tool produced by Joe Pearson (2010). Directed by Spencer Franks.
http://www.livingpositivevictoria.org.au

+ ***Strong Woman Song***
(Free. Also available in French. Includes a training and facilitation booklet.)

This educational DVD explores the impact of the disease on four HIV-positive women from different ethnic and socio-economic backgrounds (Aboriginal, Russian, Thai, African).

DVD produced by the Canadian Public Health Association and the Wabano Centre for Aboriginal Health in collaboration with Rooney Productions (2006). Directed by Robert Rooney (length: 15 minutes).

www.catie.ca/en/resources/strong-woman-song

5. THOUGHTS ON THE MEETING

- The facilitator goes around the table asking the participants what they got out of the meeting.
- The facilitator asks if anyone would like to share how they feel after the meeting. The participants answer using a word, a short phrase, a feeling, a colour or a number (for example, on a scale of 0 to 10, where 10 means the person feels very good).
- To wrap up, the facilitator thanks each of the participants.

IMPORTANT NOTES

+ Give the participants a few minutes to talk if they are not doing well. A subsequent meeting can be scheduled, if necessary.
+ If appropriate, tell the participants about support services they can access if needed.
+ Inform the participants that the theme of the next meeting will be **“learning to live with HIV”**.

WEEKLY REFLECTIONS

+ The participants are asked to think about what they learned during the meeting and to integrate this knowledge into their daily lives. The group will talk about how things went at the next meeting.
+ The participants are also asked to think about what HIV means for them and to bring in an image that illustrates this (an image from a book or magazine, a photo, an image taken from the Internet, etc.).

END OF THE MEETING

MEETING 3

Learning to live with HIV

Overview

Meeting 3 | Learning to live with HIV

—

OBJECTIVE OF THE MEETING

To help the participants realize that they can lead full lives with HIV

DURATION

▸ 3 hours

REQUIRED MATERIALS

+ A logbook for each participant
+ Art supplies for each participant (scissors, glue, pencil crayons, various stickers, various magazines, etc.)
+ A blackboard or flip chart; chalk or markers
+ A pen for each participant
+ “HIV in images” support sheet
+ “Annie’s story” support sheet
+ “The stages of adapting to life with HIV: emotional reactions after learning you have a chronic disease” support sheet

MEETING PLAN

1. Welcome ▸ 15 minutes
2. Presentation of the theme and objective of the meeting ▸ 5 minutes
3. Activity: “How I see HIV” ▸ 45 minutes

   Break ▸ 15 minutes
4. Activity: “My life journey with HIV” ▸ 1hour 25 minutes
5. Thoughts on the meeting ▸ 15 minutes

End of the meeting

Meeting 3 | Learning to live with HIV

OBJECTIVE OF THE MEETING

To help participants realize that they can lead full lives with HIV

DURATION

- 3 hours

REQUIRED MATERIALS

- A logbook for each participant
- Art supplies for each participant (scissors, glue, pencil crayons, various stickers, various magazines, etc.)
- A blackboard or flip chart; chalk or crayons
- A pen for each participant
- “HIV in images” support sheet
- “Annie’s story” support sheet
- “The stages of adapting to life with HIV: emotional reactions after learning you have a chronic disease” support sheet

MEETING PLAN

15

1. WELCOME

REVIEW OF THE PREVIOUS MEETING

- The facilitator asks the participants to reflect on the previous meeting and invites them to share their answers to the following questions:
  - *“How did the last meeting help you understand the importance of being part of this program?”*

5

2. PRESENTATION OF THE THEME AND OBJECTIVE OF THE MEETING

- The facilitator tells the participants that the title of the meeting is **Learning to live with HIV.**
- **Objective:**
  - to realize that it is possible to lead a full life with HIV.

NOTE TO FACILITATOR

Throughout the meeting, the facilitator should:

- support the participants on their journey to accepting their HIV-positive status and integrating it into their lives
- encourage the participants to support each other along their journey

Given the theme being explored, the facilitator should be aware that this workshop could run longer than expected. As such, they should plan a time before the end of the meeting to let the participants know this and determine how they wish to proceed (e.g., working through certain elements of the meeting more quickly, extending the length of the meeting or continuing certain activities during the next meeting).

45

3. ACTIVITY: "HOW I SEE HIV"

- The facilitator tells the participants that they will discuss how they see HIV. These views can be negative, positive or neutral. Many factors can influence how people see HIV: the number of years they have been living with the disease, their experience with the disease (few or no symptoms, the support and acceptance of those around them, experiences of rejection or discrimination, etc.), their attitudes towards the disease, etc.
- The facilitator reminds the participants that everyone has their own views of HIV; there are no right or wrong answers.
- The facilitator asks the participants not to comment on, criticize or judge others' views.
- The facilitator asks the participants who brought an image to describe it to the group and explain how it represents how they see HIV
- If there are participants who did not bring images, the facilitator can put some images on a table that represent various aspects of HIV ("HIV in images" support sheet). The facilitator then asks the participants to choose the image that best expresses what HIV means to them and, for those who wish to share, why it represents how they see HIV.

* **Make sure all participants are given the opportunity to express themselves.**

TIPS

+ The facilitator can choose images other than those suggested in this guide if they deem it necessary.
+ The facilitator can also ask the participants to do the exercise by drawing in their logbook or choosing an image from a magazine.

▸ If necessary, the facilitator can correct the participants' misconceptions about HIV or its treatments.

CONTENT DETAILS: MISCONCEPTIONS

HIV = death sentence

Antiretroviral therapy has significantly increased the life expectancy of people living with HIV, which now approaches that of uninfected individuals. HIV is now considered a chronic disease that infected people can learn to live with, so an HIV diagnosis is no longer considered a death sentence.

HIV treatments are complex and lead to many unpleasant or debilitating side effects

In recent years, significant advances have been made in reducing the side effects caused by HIV medications, and treatments are now much easier to follow (fewer pills to take). However, some people have more difficulty tolerating certain HIV medications. Although it isn't yet possible to completely eliminate the various side effects of HIV medications, there are several options for decreasing or getting rid of them. It is therefore important for patients to speak to their doctor about which HIV medications can offer them the best quality of life.

Being HIV-positive is incompatible with being pregnant

HIV-positive women can indeed become pregnant and give birth to a healthy child. A woman can become pregnant and not transmit the virus to her unborn child. To ensure she does not infect her partner, a woman can be artificially inseminated with her partner's sperm at home (by introducing the sperm into the woman's vagina using a dropper) or at a fertility clinic. Artificial insemination at a fertility clinic increases the odds of conceiving if the woman is having difficulty becoming pregnant.

In terms of the pregnancy itself, the odds of a woman transmitting the virus to her child are around 1% if she continues treatment during pregnancy and the treatment is administered to the newborn. Having a caesarean section and not breastfeeding also reduce the odds of transmitting the virus to the child.

CONTENT DETAILS: MISCONCEPTIONS (CONTINUED)

Women and HIV: stigma and discrimination

Some people believe that women who contract the HIV virus "asked for it." But being HIV-positive does not automatically mean that a woman is a prostitute, has unprotected sex with multiple partners or "shoots" drugs. On the contrary, HIV can affect married women, heterosexual women, mothers and religious women. Today, HIV affects as many women as men worldwide and sexual transmission of the disease among heterosexual partners is the most common mode of transmission.

People living with HIV can no longer enjoy sex

Some people living with HIV may see a decline in their sex drive after being diagnosed because of the shock of the diagnosis. Some may even choose to remain abstinent for a time, fearing they may transmit the virus, be rejected by others or be criminally prosecuted. Many people also believe that people living with HIV shouldn't have a sex life to make sure they don't infect others. However, safe sex is something that everyone should engage in whether they are HIV-positive or not. People living with HIV are entitled to have a healthy and fulfilling sex life. Most people living with HIV tell their sexual partners about their status and take precautions to protect them.

Sources

* Voices of Positive Women. (2009). *You can have a healthy pregnancy if you are HIV positive*. [brochure]. Toronto, CATIE. This brochure may be handed out to the participants during the meeting. Available in PDF at www.catie.ca

* Santé et services sociaux (2012). *Enceinte ou vous pensez le devenir.* [booklet]. s.l, Goverment of Québec.

CATIE – Canada's Source for HIV and Hepatitis Information. (2006). A practical guide to HIV drug side effects for people living with HIV. Toronto, CATIE, 46 pages.

Public Health Agency of Canada (PHAC). (2012). *PHAC population-specific HIV/AIDS status report: women.* Ottawa, PHAC, 177 pages.

VARIATIONS

+ If the activity was done in the participants' logbooks, the facilitator can suggest to the group that they put their work on a table so everyone can see what the others have done, but without making them feel like they have to officially present their work.
+ This activity can be finished at home for those who wish to do so. If time permits, it can also be continued at the next meeting.

BREAK ▸ 15 minutes ◂

85

4. ACTIVITY: “MY LIFE JOURNEY WITH HIV”

- The facilitator reads “Annie’s story” and asks the participants for their feedback (“Annie’s story” support sheet).
- The facilitator then writes the stages of adapting to life with HIV on the board, referring to the content details in the box below.

CONTENT DETAILS: THE STAGES OF ADAPTING TO LIFE WITH HIV

Emotional reactions after learning you have a chronic disease

(based on the Elisabeth Kübler-Ross model, 1970)

The stages are as follows:

+ **SHOCK**: “I’m in shock.” “This is a total shock to me.”

+ **DENIAL**: “It’s not true!” “No, not me!” “This can’t be happening!” “I’m dreaming, this is a nightmare!”

+ **ANGER (revolt)**: “Why me?”

+ **BARGAINING (negotiation)**: “Fine, I have no choice but to deal with it, but...” “OK, it’s happened to me, but...” “If I get better, I promise that...” “Give me another chance!”

+ **DEPRESSION (reflection)**: “I will never be the same.” “I’m all alone, no one cares, my life is over.”

+ **ACCEPTANCE (ownership)**: “I’ve accepted what has happened to me and I am moving forward.”

+ **INTEGRATION (transformation):** “I’m learning to live with HIV. I’m finding new purpose in my life.”

These stages are very common for people who are living with a chronic disease or dealing with grief, although not everyone goes through them in this order or at the same pace. For example, a person may experience shock after denial. And going through a stage once doesn’t mean an individual won’t go through it again. For example, a person may feel angry again after coming out of depression. These stages are part of an indispensable process that leads people to accept the disease and integrate it in their lives.

SOURCES :

Giraudet, J.-S. (2006). «*Annonce du diagnostic de maladie chronique à un patient*». Synoviale, no.151, 8-13.

Kolla, G.. (2006). *Accompagnateurs en traitements: Manuel de formation,* ACCM. Montréal, Québec, 124 pages.

Kübler-Ross, E. (1970). *On death and dying.* Macmillan, New York, 289 p.

Telford, K., Kralik, D. and Koch, T. (2006). “Acceptance and denial: implications for people adapting to chronic illness: literature review. *“Journal of Advanced Nursing,* 55 (4), 457-464.

- The facilitator asks the participants to answer the following question:
  - *“What does accepting your HIV-positive status mean to you?”*
- The facilitator then writes keywords relating to what the participants have said next to the stages of adapting to life with HIV, which were previously written on the board.
- After this activity, the facilitator reads the definitions of the words “Acceptance” and “Integration” (see content details in the box below) and draws connections, if any, with the participants’ statements that were written on the board.
- The facilitator then hands out a paper copy of the stages of grief after learning of a chronic disease (“The stages of adapting to life with HIV: emotional reactions after learning you have a chronic disease” support sheet).

CONTENT DETAILS: DEFINITIONS

Acceptance (ownership)

The person recognizes that they have contracted HIV. They recognize the fears associated with the disease and understand that it carries risks. They accept that the disease is part of their daily life; the disease is integrated (or “tolerated”). The person has redefined themselves as someone living with a chronic disease. They understand that they can no longer be the same person they were before and accept themselves as a person living with HIV but know that this not all they are. Moving beyond the initial shock allows them to see a future for themselves, even with the disease, and to want to keep on living.

“Acceptance of a chronic disease means that the patient ‘owns’ it. It’s an attitude that reflects a lucid acceptance of a reality or situation that they are choosing to deal with so they can move forward and learn to live with their chronic disease.” (Translation of Giraudet quote, 2006, pg. 9)

WHAT ACCEPTANCE IS NOT

The person makes the changes in their daily life that they need to make so they can lead a full life with HIV. At this stage, the person is striving to lead a balanced, healthy life with HIV and to find new meaning in their life.

Integration (transformation)

The person makes the changes in their daily life that they need to make so they can lead a full life with HIV. At this stage, the person is striving to lead a balanced, healthy life with HIV and to find new meaning in their life.

SOURCES :
Giraudet, J.-S. (2006). «*Annonce du diagnostic de maladie chronique à un patient*». *Synoviale*, no.151, 8-13.
Kolla, G.. (2006). *Accompagnateurs en traitements: Manuel de formation,* ACCM. Montréal, Québec, 124 pages.
Kübler-Ross, E. (1970). *On death and dying.* Macmillan, New York, 289 p.
Telford, K., Kralik, D. and Koch, T. (2006). «Acceptance and denial: implications for people adapting to chronic illness: literature review ». *Journal of Advanced Nursing,* 55 (4), 457-464.

- The facilitator then asks those who wish to share their experiences to do so one by one. The facilitator guides the exchange by asking the following questions:
  - *What did you feel when you learned that you had contracted HIV?*
  - *How did you process what you were being told?*

- *What part of having HIV makes you the saddest? The angriest?*
- *What part of having the disease concerns you the most?*
- *How do you cope with HIV? (How do you manage to live a good life with HIV? What are your secrets?)*
- *How do you envision the rest of your life?*

- The facilitator ends the exchange by thanking the participants for sharing. The facilitator reminds the participants that everyone comes to the point of accepting (or owning) their disease in their own way and at their own pace, that this can be difficult, and that there is help out there to support them along their journey.
- Finally, the facilitator suggests that they should feel free to seek professional help if ever they need help coping with the disease.

15

5. THOUGHTS ON THE MEETING

- After the meeting, the facilitator asks the participants "How are you feeling?" and gives each participant around 2 minutes to express their feelings.

VARIATION

- **Impact technique using expression**

A word, feeling, colour or number

- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., on a scale from 0 to 10, where 10 means they feel very good). The facilitator can then ask the participants to elaborate if she feels this is necessary and appropriate

Source: Beaulieu, D. (2006). *Techniques d'impact en psychothérapie, relation d'aide et santé mentale.* Québec, Québec. Impacts! Éditions, 310 pages, © 1997

NOTE TO FACILITATOR

- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting so they can offer them support, if necessary, or schedule an individual meeting to talk.

- The facilitator asks the participants what they liked about the meeting and what they didn't like as much. Where applicable, they can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.
- The facilitator tells the participants they can put their support sheets in their logbooks.

TIP

- The facilitator can write the participants' comments on a piece of paper or on the board. These comments can be used to help improve the content, form, or structure of the program

IMPORTANT NOTES

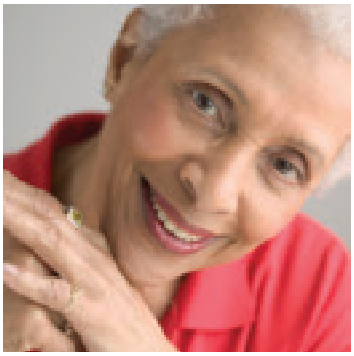
- Give the participants a few minutes to talk if they feel uneasy. A subsequent meeting can be scheduled, if necessary.
- If required, tell the participants about supportive contacts who would be happy to meet with them if they feel the need.
- Inform the participants that the theme of the next meeting will be **Life situations: contexts where the issue of disclosure and non-disclosure may come up.**
- Mention to the participants that the first meetings will be dedicated to the issue of disclosure and that the same number of meetings will then be dedicated to the issue of non-disclosure.

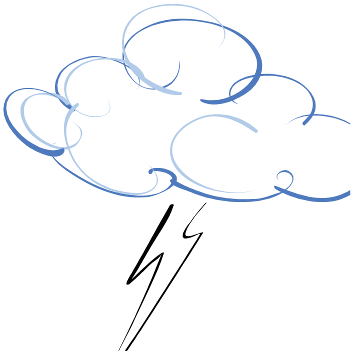
WEEKLY REFLECTION

- The participants are asked to think about what they learned during the meeting and to integrate this knowledge into their daily lives. The group will talk about how things went at the next meeting.

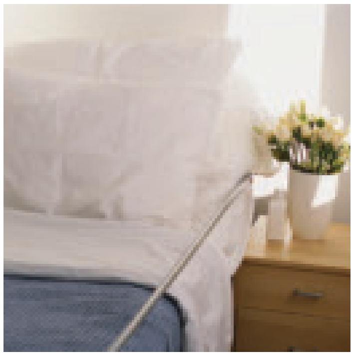
END OF THE MEETING

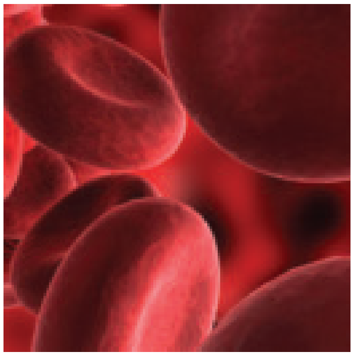
HIV IN IMAGES





HIV IN IMAGES





ANNIE'S STORY[5]

Annie, age 35, learns that she has a chronic disease: HIV. And no, there is no cure. Annie leaves the doctor's office, runs a few errands, goes home and calls her best friend to share the news with her. While preparing supper, she explains to her friend that she will have to adapt to her new reality. The next day, Annie goes to the offices of a non-profit organization that offers support services for women living with HIV and joins a support group whose first meeting will be held the following week. She calls her family to give them the news, prepares herself to tell her employer the following week and does some online research to learn more about the disease. Annie doesn't crumble. She faces the situation head on, without ever getting angry or crying.

The truth is, Annie DOESN'T EXIST!

*

NOTE TO FACILITATOR

+ The facilitator explains that when people learn they have contracted HIV, it is perfectly normal for them to be in shock and to feel like the rug has been pulled out from under them. They then go through other stages, in their own time, before coming to the point of acceptance (ownership). Few people react as Annie did and when they do, it's because they suspected they were HIV-positive or were prepared for the news. Overall, this would be the exception.

---

[5] Luong, J. (2008). "De l'annonce du diagnostic à l'acceptation: long fleuve tranquille ou chemin semé d'embûches? Accepter? Vivre mieux !" *Clair Magazine*, June-August, 10-11.

THE STAGES OF ADAPTING TO LIFE WITH HIV: EMOTIONAL REACTIONS AFTER LEARNING YOU HAVE A CHRONIC DISEASE

THESE STAGES ARE AS FOLLOWS:

SHOCK

"I'm in shock." "This is a total shock to me."

DENIAL

"It's not true!" "No, not me!" "This can't be happening." "I'm dreaming. This is a nightmare!"

ANGER

(Revolt): "Why me?"

BARGAINING

(Negotiation): "Fine, I have no choice but to deal with it, but..." "OK, it's happened to me, but..." "If I get better, I promise that..." "Give me another chance!"

DEPRESSION

(Reflection): "I will never be the same." "I'm all alone, no one cares, my life is over."

ACCEPTANCE

(Ownership): "I've accepted what has happened to me and I am moving forward."
"Acceptance of a chronic disease means that the patient 'owns' it. It's an attitude that reflects a lucid acceptance of a reality or situation that they are choosing to deal with so they can move forward and learn to live with their chronic disease." (Translation of Giraudet quote, 2006, pg. 9).

What acceptance is not: Acceptance does not mean being OK with having HIV or giving in to the disease.

INTEGRATION

(Transformation): "I'm learning to live with HIV. I'm finding new purpose in my life."

The person makes the changes in their daily life that they need to make so they can lead a full life with HIV. At this stage, the person is striving to lead a balanced, healthy life with HIV and to find new meaning in their life.

These stages are very common for people who are living with a chronic disease or dealing with grief, although not everyone goes through them in this order or at the same pace. For example, a person may experience shock after denial. Going through a stage once doesn't mean an individual won't go through it again. For example, a person may feel angry again after coming out of depression. These stages are part of an integral process that leads people to accept the disease and integrate it into their lives.

SOURCES :

Giraudet, J.-S. (2006). «*Annonce du diagnostic de maladie chronique à un patient*». Synoviale, no.151, 8-13.

Kolla, G. (2006). *Accompagnateurs en traitements: Manuel de formation.* ACCM, Montréal, Québec, 124 p.

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Telford, K., Kralik, D. and Koch, T. (2006). "Acceptance and denial: implications for people adapting to chronic illness: literature review ". *Journal of Advanced Nursing,* 55 (4), 457-464.

MEETING 4

Life situations

Overview

Meeting 4 | Life situations

OBJECTIVE OF THE MEETING

To give participants the skills they need to recognize situations where the issue of disclosing or not disclosing their HIV-positive status may come up

DURATION

- 3 hours

REQUIRED MATERIALS

+ A logbook for each participant
+ Red, green and blue pencils, crayons or markers for each participant
+ A blackboard or flip chart and chalk or markers
+ “The people in my orbit” activity sheet
+ “Should I tell or not tell?” game (“Very different obligations” activity sheet)
+ Contextual images (“Images of different contexts” activity sheet)

MEETING PLAN

1. Welcome ▸ 15 minutes
2. Presentation of the theme and objective of the meeting ▸ 5 minutes
3. Activity: “In what situations?” ▸ 15 minutes
4. Activity: “Should I tell or not tell?” ▸ 40 minutes

   Break ▸ 15 minutes
5. Activity: “The people in my orbit” ▸ 1 hour
6. Closing activity: “Tell me about your world” ▸ 15 minutes
7. Thoughts on the meeting ▸ 15 minutes

End of the meeting

Meeting 4 | Life situations

OBJECTIVE OF THE MEETING

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DURATION

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- “Should I tell or not tell?” game (“Very different obligations” activity sheet)
- Contextual images (“Images of different contexts” activity sheet)

MEETING PLAN

15

1. WELCOME

REVIEW OF THE PREVIOUS MEETING

- The facilitator asks the participants to reflect on the previous meeting. The following question is asked and the participants are invited to share their answers:
  - *“How did the last meeting help you to realize that people can lead full lives with HIV?”*

5 2. PRESENTATION OF THE THEME AND OBJECTIVE OF THE MEETING

- The facilitator tells the participants the title of the meeting: **Life situations**
- **Objective:**
  - to recognize situations where the issue of disclosure and non-disclosure may come up

NOTE TO FACILITATOR

Throughout the meeting, the facilitator should:

- support the participants along their journey to disclose or not disclose their HIV-positive status
- encourage the participants to support each other's journeys
- place no value judgements on participants' decisions, be it to disclose or not disclose their HIV-positive status

15 3. ACTIVITY: "IN WHAT SITUATIONS?"

- The facilitator asks the participants to think about different situations where the issue of disclosing or not disclosing their HIV-positive status may come up and to list them (e.g., in the workplace, among family members, in other relationships, with sexual partners, etc.).

- The facilitator writes the situations identified by the participants on the board.
  - Other situations can then be added by the participants and the facilitator.
  - Where applicable, the facilitator can list the participants' responses in categories.

VARIATION

- To facilitate this exercise, write different contexts on the board (e.g., family life, love life, work life, medical setting, social life, etc.) within which the participants can list the people associated with these contexts (e.g., partner, child, sister, mother, etc.).

CONTENT DETAILS: IN WHAT SITUATIONS?

The facilitator asks the participants about the people to whom they may or may not reveal their HIV-positive status: *"Whom have you told about your HIV-positive status? Whom have you not told? Have you felt or do you feel pressured to tell certain people?"*

Examples of people who might be told or not told about the participant's HIV-positive status

+ immediate family members, distant family members, child/children, partner/spouse, potential partners, co-workers, boss, dentist, nurse, doctor, esthetician

Examples of such people listed by context

Family life

- immediate family members
- distant family members
- child/children

Work life

- co-workers
- boss
- insurance company

Social life

- friends
- neighbours

Love life

- sexual partners
- partner, spouse
- potential partners

Medical/hospital setting

- dentist
- nurse
- doctor
- esthetician

4. ACTIVITY: “SHOULD I TELL OR NOT TELL?”

- The facilitator presents the “Should I tell or not tell?” activity, explaining the purpose of the game and how to play it.

ACTIVITY: “SHOULD I TELL OR NOT TELL?”

Purpose of the game

The purpose of the game is to get the participants to identify the type of obligation (i.e., legal, moral or medical) they may feel when it comes to disclosing their HIV-positive status in various situations.

Instructions

1. The facilitator separates the participants into three groups (two or three participants per group).

2. The facilitator then distributes the “Very different obligations” activity sheet and a dozen images from among all the suggested images (“Images of different contexts” activity sheet) to each group. Other images can also be suggested to the participants at the facilitator’s discretion.

3. For each image representing people, groups or institutions (e.g., dentist, doctor, family members, sexual partners, etc.), the groups must determine if it is medically, morally or legally important for them to disclose their HIV-positive status to these people. To this end, the participants are asked to put these people into one of three categories on the “Very different obligations” activity sheet. The participants should be allowed to use their own judgement during the exercise.

4. Once the exercise is over, each group is asked to present their work to the other participants.

5. As each group presents their work, the facilitator reproduces the participants’ responses on the game board (or blackboard/flip chart).

6. Finally, the facilitator asks the participants if the resulting board is closer to reality (the facts) or their own impressions.

Making a board game (optional)

To make a game board, divide a large piece of cardboard into the following three categories:

1. Medically important

2. Morally important

3. Legally important (“Very different obligations” activity sheet).

Laminate it.

Print and cut out images representing the various situations and laminate them (“Images of different contexts” activity sheet).

Affix pieces of Velcro on the back of each image and on the game board.

Alternative

The facilitator presents each image to the participants. As a group, the participants discuss which category the image should be added to (e.g., medically, morally or legally important). Once the group has come to a consensus, the facilitator puts the image on the game board (or writes what the image is on the blackboard or flip chart).

CONTENT DETAILS: “SHOULD I TELL OR NOT TELL?”

This activity allows the facilitator to inform the participants about their rights and responsibilities when it comes to disclosing their HIV-positive status and to answer any questions they may have. They should know that no person, group or institution can force people living with HIV to disclose their status. This information is strictly confidential. No person living with HIV is legally obligated to disclose their HIV-positive status to anyone if that is their decision, with a few exceptions (before having sex that poses a “realistic possibility of HIV transmission” and when obtaining insurance).

Sexual relationships

+ The image representing two people having sex should appear in the “legally important” column.
  - Under the law, a person living HIV has the legal duty to disclose their status:
    - “before having vaginal or anal sex without a condom (regardless of [their] viral load); and
    - “before having vaginal or anal sex with anything higher than a ‘low’ viral load (even if [they] use a condom).”

Source: Canadian HIV/AIDS Legal Network. (2012). *HIV non-disclosure and the criminal law: implications of recent Supreme Court decisions for people living with HIV*. Q&A. Available online: www.aidslaw.ca

Life insurance

+ The image representing the life insurance agent should appear in the “legally important” column. This would be true for any type of insurance
  - In terms of personal life insurance or disability insurance, the insurance company will ask you to disclose if you are HIV-positive. It is best to tell the truth or the company could refuse to pay out benefits in the event of death or disability.

Source: COCQ-SIDA. (2010). *Les mêmes droits que vous*.

Available online : http://www.cocqsida.com/mediatheque/publications/les-memes-droits-que-vous.html

CONTENT DETAILS: “SHOULD I TELL OR NOT TELL?” (CONTINUED)

Hospital setting

+ The images representing the doctor, nurse and dentist should appear in the “medically important” column.
  - To receive quality care that takes into account your state of health, it is best to disclose your HIV-positive status to the health professionals you consult.

Source: COCQ-SIDA. (2010). *Les mêmes droits que vous.* Available online: http://www.cocqsida.com/mediatheque/publications/les-memes-droits-que-vous.html

The facilitator is strongly advised to consult the Canadian HIV/AIDS Legal Network and COCQ-SIDA websites for the latest information on HIV disclosure and Canadian criminal laws.

VARIATIONS

+ The facilitator can give the participants relevant, up-to-date information on the law and their rights with respect to disclosing their HIV-positive status (see Appendix 1 for a list of publications).
+ A lawyer or specialist in this area could also be asked to speak to the participants to educate them and answer their questions. This activity could take place at a subsequent meeting or at a conference evening organized as part of the program.

BREAK ▸ 15 minutes ◂

60

5. ACTIVITY: “THE PEOPLE IN MY ORBIT”

- Using the concentric circles within the “The people in my orbit” activity sheet, the participants are asked to list the people in their orbit with whom the issue of disclosure may come up.
- Within the various concentric circles, the participants are asked to:

1. Indicate in green, in the upper semicircle, the person(s) (or their first names) who know about their HIV-positive status.
2. Indicate in red, in the lower semicircle, the person(s) (or their first names) who don’t know about their HIV-positive status or to whom they do not wish to disclose their status.

3. Circle in red, in the upper semicircle, the person(s) (or their first names) who are not handling the situation well.

4. Circle in blue, in the lower semicircle, the person(s) (or their first names) they would like to tell..

+ The facilitator asks the participants to put the people in their orbit in the various concentric circles, according to how important they are to them (the closer a person is to the centre, the more important that person is in their life).

5. Evaluate the extent of the moral obligation they feel to disclose their HIV-positive status to certain people, using blue asterisks.

CONTENT DETAIL: “MORAL OBLIGATION TO DISCLOSE”

+ For each of the people identified, the participants must determine to what extent they feel or have felt the moral obligation to disclose their HIV-positive status:

* **low** moral obligation

** **medium** moral obligation

*** **high** moral obligation

- To illustrate, the facilitator does the activity on the board using the sample version of the “The people in my orbit” activity sheet.
- The facilitator then encourages the participants to do the exercise themselves.
- To keep the activity simple, the participants need only list one or two people in each circle.
- Once everyone has completed the exercise, the facilitator leads a group discussion and asks the participants about the people in their orbit.
- Those who wish to share can then tell the rest of the group about the experiences they have had with the people in their orbit.

CONTENT DETAILS: “THE PEOPLE IN MY ORBIT”

Invite the participants to reflect on the “people in their orbit.”

- *Are you more “red” (secretive) or more “green” (open) when it comes to disclosing your status?*
- *How much has the issue of disclosure come up in your life?*
- *Are the people you have told the most important people in your life or people you really trust, or are they more people you aren’t that close to?*
- *When you have shared your status with people, did it generally go well?*
- *Are there people who are important to you that you haven’t told?*
- *Of those you haven’t told, whom would you like to tell?*
- *Of those you haven’t told, whom would you prefer never to tell?*
- *What do you think makes these two groups different?*

TIPS

- The concentric circle exercise is a great way for the participants to visualize all the people who are gravitating around them, as it provides a true picture of the configuration of their social network.
- This exercise also allows them to list the people with whom they have daily interactions. By putting an image of themselves inside this network, it becomes easier to see the extent to which disclosure is an issue within their network. It also allows them to see whether the people they have told are the people who are most important to them and with whom they have good relationships, or the opposite.

15

6. CLOSING ACTIVITY: “TELL ME ABOUT YOUR WORLD”

- **Group discussion:** The facilitator asks the participants what they got out of the activity on the people in their orbit and discusses with them the moral obligation they feel to disclose their HIV-positive status.

CONTENT DETAILS: “TELL ME ABOUT YOUR WORLD”

Closing activity

- Do you feel morally obligated to disclose your status to certain people (e.g., *“I feel like I should tell,” “I feel like I have to tell,” “I feel like it is my duty to tell”*)?

  Why do you feel this obligation?

  Why would it be/is it important for you to tell certain people?

  Why do you feel/did you feel that telling certain people was the right thing to do?

- Conversely, are there people whom you do not feel morally obligated to tell? Or people whom you feel morally obligated not to tell?
- What can you tell us about your relationship with these people?

7. THOUGHTS ON THE MEETING

- After the meeting, the facilitator asks the participants, “How do you feel?”
- The facilitator gives each participant around 2 minutes to express their feelings.

VARIATION

Impact technique using expression

A word, feeling, colour or number

- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., on a scale of 0 to 10, where 10 means they feel very good.) The facilitator can then ask the participants to elaborate if appropriate.

Source: Beaulieu, D. (2006). *Techniques d’impact en psychothérapie, relation d’aide et santé mentale.* Québec, Québec. Impacts! Éditions, 310 pages, © 1997

NOTE TO FACILITATOR

- This “How do you feel” exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, if necessary, or schedule an individual meeting to talk.

- The facilitator asks the participants what they liked about the meeting and what they didn't like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.
- The facilitator tells the participants they can keep their activity sheets in their logbooks.

TIP

+ The facilitator can write the participants' comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.

IMPORTANT NOTES

+ Give the participants a few minutes to talk if they feel uneasy. A subsequent meeting can be scheduled, if necessary.
+ If required, tell the participants about supportive contacts who would be happy to meet with them if they feel the need.
+ Inform the participants that the theme of the next meeting will be **Potential issues around the disclosure of their HIV status** in different situations.
+ The participants must think of a disclosure situation (either past or anticipated) that they wish to work on over the next two meetings. They should consider the people in their orbit when selecting their situation.
+ Mention to the participants that the first meetings will be dedicated to the issue of disclosure and that the same number of meetings will then be dedicated to the issue of non-disclosure.

WEEKLY REFLECTION

+ The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives. The group will talk about how things went at the next meeting.

END OF THE MEETING

VERY DIFFERENT OBLIGATIONS

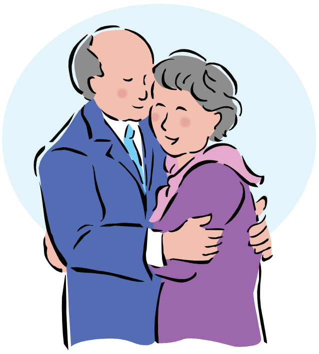
Arrange the following people, groups and institutions by type of moral obligation felt.

- Medically important

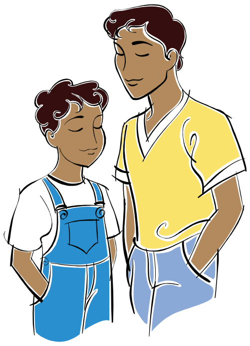
- Legally important

- Morally important

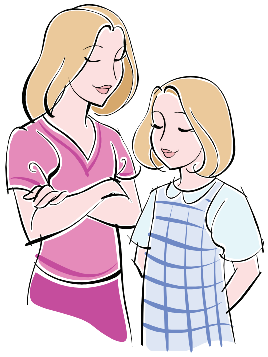
IMAGES OF DIFFERENT CONTEXTS



Parents



Brother(s)



Sister(s)

Extended family

Friends

Friends with young kids

Landlord

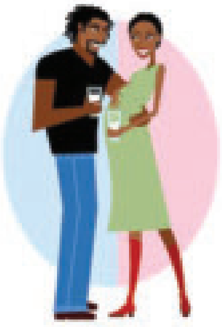
My kid(s)' school principal

Immigration officers

IMAGES OF DIFFERENT CONTEXTS

Romantic partners

Romantic partners



Romantic partners

Sexual partners

Sexual partners

School teacher

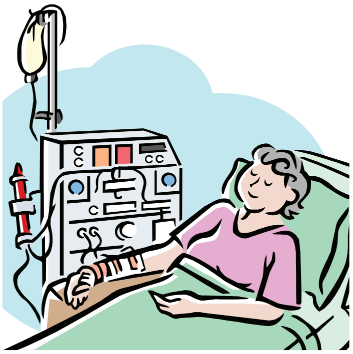
Dentist

Family doctor

Nurse

IMAGES OF DIFFERENT CONTEXTS


During a hospital stay


During a hospital stay


Body care or treatment professional | Massage therapist


Body care or treatment professional | Esthetician


Body care or treatment professional | Acupuncturist


Fitness centre


Life insurance agent


Travel

My kids

IMAGES OF DIFFERENT CONTEXTS

Co-workers

Employer/boss

“THE PEOPLE IN MY ORBIT” ACTIVITY SHEET

Green: The person knows and is dealing with it well.
Green with a red circle: The person knows but isn’t dealing with it well.

Red with a blue circle: The person doesn’t know and I want them to know, but I don’t know how to tell them or can’t.

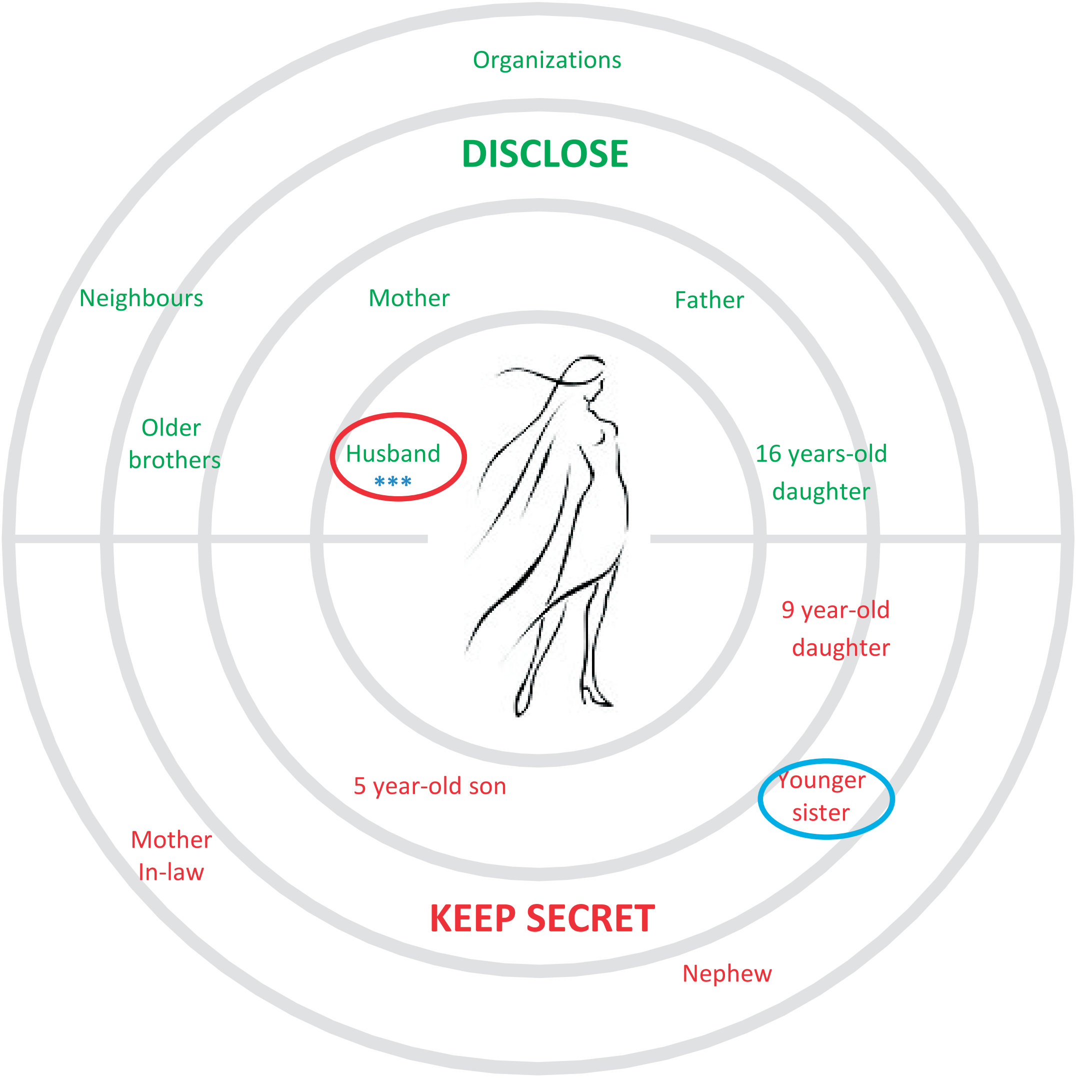
Red: The person doesn’t know and I don’t want to them to know.

*	Low moral obligation
**	Medium moral obligation
***	High moral obligaiton

“THE PEOPLE IN MY ORBIT” ACTIVITY SHEET – SAMPLE VERSION

Green: The person knows and is dealing with it well.

Green with a red circle: The person knows but isn’t dealing with it well.



+ Red with a blue circle: The person doesn’t know and I want them to know, but I don’t know how to tell them or can’t.

+ Red : The person doesn’t know and I don’t want to them to know.

* Low moral obligation
** Medium moral obligation
*** High moral obligation

MEETING 5

Controlling my own destiny

Overview

Meeting 5 | Controlling my own destiny

—

OBJECTIVE

To help the participants to assess potential disclosure issues

DURATION

▸ 3 hours

REQUIRED MATERIALS

+ Logbook for each participant
+ Blackboard or flip chart and chalk or pencils
+ Coloured pencils, crayons or markers
+ “Pros and cons scale” activity sheet
+ Four cards for each participant (“My winning hand”)
+ A pen for each participant

Optional:

+ Rosa and Prudence’s stories (“Rosa and Prudence, disclosure and its consequences” sheet)
+ “The allegory of the wise chameleon” sheet

MEETING PLAN

1. Welcome ▸ 15 minutes
2. Presentation of the theme and objective of the meeting ▸ 5 minutes
3. Activity: “Pros and cons” ▸ 15 minutes
4. Activity: “The pros and cons scale” ▸ 45 minutes

   Break ▸ 15 minutes
5. Activity: “My winning hand” ▸ 40 minutes
6. Closing activity: “My conclusions ▸ 30 minutes
7. Thoughts on the meeting ▸ 15 minutes

End of the meeting

Meeting 5: Controlling my own destiny

OBJECTIVE OF THE MEETING

To help participants to assess potential disclosure issues

DURATION

- 3 hours

REQUIRED MATERIALS

- Logbook for each participant
- Blackboard or flip chart and chalk or pencils
- Coloured pencils, crayons or markers
- “Pros and cons scale” activity sheet
- Four cards for each participant (“My winning hand”)
- A pen for each participant

Optional::

- Rosa and Prudence’s stories (“Rosa and Prudence, disclosure and its consequences”)
- “The allegory of the wise chameleon”

MEETING PLAN

15

1. WELCOME

REFLECTION ON THE PREVIOUS MEETING

- The facilitator asks the participants to think back to the previous meeting and invites them to answer, if they would like, the following question:
  - *How did the last meeting help you to identify when you would want to disclose your HIV status and when you might want to keep it private?*

5 2. PRESENTATION OF THE THEME AND OBJECTIVE OF THE MEETING

- The facilitator introduces the theme of the meeting (controlling my own destiny).
- **Objective:**

+ assessing potential disclosure issues

NOTE TO FACILITATOR

Throughout the meeting, the facilitator should:

+ support the participants through their process of deciding whether or not to disclose
+ ask the participants to support each other in this process
+ place equal value on both disclosing one's HIV-positive status and keeping it private

15 3. ACTIVITY: "PROS AND CONS"

- **Brainstorming:** The facilitator invites the participants to share personal experiences and identify the pros (positive consequences) and cons (negative consequences) of disclosure.

* **The pros and cons of keeping one's HIV status private will be discussed at future meetings.**

  + *What are the advantages of disclosure?*
  + *What are the disadvantages of disclosure?*

- The facilitator writes the participants' responses on the board or flip chart and then sorts their answers into different categories. The facilitator is encouraged to refer to the box below.

VARIATION

+ To facilitate discussion, the facilitator can write different categories on the board or flip chart (e.g. personal, relationship, family, professional/occupational, socio-economic). For each category, the participants identify the pros and cons of disclosure.

CONTENT DETAILS: “PROS AND CONS”

Brainstorming

The pros of disclosure (here is a possible list):

+ release, relief, loved ones will understand your situation better, getting support from loved ones, strengthening of friendship or romantic relationship, closeness/bonding, strategy to stop rumours about you, being able to share your experience (venting), creation of friendships, not having to lie or hide it anymore, receiving disability benefits such as scholarships, receiving support available to people living with HIV (such as food assistance), workplace accommodation

Example of sorting the pros into different categories:

Personal

- release/relief
- not having to lie or hide it anymore

Relationship

- getting support from loved ones
- stopping rumours
- creating friendships
- strengthening of friendships
- strategies for stopping rumours about yourself
- venting
- a way to discourage someone from being interested in you if you don’t want a relationship with them

Family

- strenghthening of romantic relationship
- closeness/bonding
- better understanding of your situation

Professional

- receiving disability benefits, such as scholarships
- receiving support available to people living with HIV, such as food assistance
- workplace accommodation

CONTENT DETAILS: “PROS AND CONS” (CONTINUED)

The cons of disclosure (here is a possible list):

+ trivialization, threats/violence, shame, being accused of infidelity, denial by loved ones, manipulation, rejection/separation, fear, shock, anger, burdening the person to whom you disclose, having to explain how you were infected, discrimination toward your children, cooling off of a friendship or romantic relationship, isolation, loss of employment, disclosure by others, being the victim of prejudice or discrimination, being refused tenancy, being refused Canadian citizenship, etc.

Example of sorting the cons into different categories:

Professional

- loss of employment
- victim of prejudice or discrimination
- fearful response from co-workers

Relationship

- victim of threats/violence/anger
- being accused of infidelity
- manipulation
- rejection/separation
- risk of others disclosing your status without your consent

Socio-economic

- being denied tenancy
- being denied Canadian citizenship

Family

- trivialization
- denial
- rejection
- shock/pain
- discrimination toward your children

VARIATION

+ The facilitator can introduce this exercise by reading “Rosa and Prudence, disclosure and its consequences.” Referring to the stories of Rosa and Prudence, participants then identify the pros and cons of disclosure.

45

4. ACTIVITY: “THE PROS AND CONS SCALE”

- While referring to their “The people in my orbit” activity sheet (from Meeting 4), each participant chooses a context in which the issue of disclosing their HIV-positive status has arisen or could arise.
- The participants write down the pros and cons of disclosure in this context on the “Pros and cons scale” activity sheet. It is suggested that participants include a maximum of three pros and three cons.
- The participants assess the importance of each pro and con, using a measuring stick to represent the weight of each pro and con in the chosen context.

CONTENT DETAILS: “THE PROS AND CONS SCALE”

Complete the “The pros and cons scale” activity sheet, referring to the example provided.

Instructions:

+ Participants choose a situation where they have disclosed or anticipate disclosing and write it at the top of the page.
+ Participants list a maximum of three pros and three cons for disclosure in that situation, under “Pros” and “Cons” at the bottom of the page.
+ Participants choose one colour for their pros and another for their cons (e.g., blue for pros and orange for cons).
+ Participants take a few moments to reflect on the importance of each pro and con.
+ After reflecting, each participant indicates the importance of each pro and con by marking each measuring stick at the appropriate height, filling in the stick with the colour they have chosen. The higher the colour on the stick, the more important the pro or con is to the participant (i.e., the more weight it has on their scale). The lower the colour is on the stick, the less important the pro or con is to the participant (i.e., the less weight it has on their scale). Each stick is marked from 1 to 10, with 1 being not very important and 10 being very important.
+ If the pros outweigh the cons, participants will conclude that there may be more benefits than drawbacks to disclosing in that context. However, if the cons outweight the pros, participants conclude that it might be better to not disclose, at least for now.

- Participants weigh the pros against the cons on the scale.
  - The facilitator asks the participants if the pros they identified are heavier on the scale than the cons or if the reverse is true.

TIPS

- Organizing one's thoughts about dislosure by theme and putting it on paper stimulates healthy reflection and often generates the energy needed to make a change, if applicable.
- The objective is to shed light on the positive and negative consequences of disclosure of participants' HIV status to generate helpful strategies. This process can provide space for reflection and inform participants on ways to change or strengthen their approach to the issue.

BREAK ▸ 15 minutes ◂

40

5. ACTIVITY: "MY WINNING HAND"

5.1 DISCLOSURE STATEMENTS ▸ 10 minutes

- Ask participants the following question and write their answers on the board or flip chart
- *When you think about the word "disclosure," what words come to mind?*

CONTENT DETAILS: DISCLOSURE STATEMENTS

People might associate the following words and phrases with disclosure:

- complicated, difficult
- prejudice
- fear of being rejected, stigmatized and discriminated against
- shame
- not knowing how to go about it
- lack of self-esteem and self-confidence
- relief, release
- acceptance
- openness, listening and support
- understanding
- confidentiality
- criminalization
- burden, etc.

▸ The picture of disclosure that emerges may be both positive and negative. Not everyone has the same disclosure experience. Furthermore, some participants may have never disclosed until now. Some are anticipating negative consequences, and others might be thinking there will be positive consequences. The idea is to point out to participants that not all words associated with disclosure are negative and that disclosure is not only a bad experience. Sometimes, it might not go as expected, and there may be a variety of obstacles hindering disclosure, but there are also ways to overcome those obstacles and minimize the negative consequences.

5.2 FACTORS FAVOURABLE AND UNFAVOURABLE TO DISCLOSURE ▸ 15 minutes

▸ The facilitator asks participants to reflect on factors that can make disclosure a positive experience and factors that can make it a negative experience. Participants can refer to their own lives (and to Rosa and Prudence's stories, if applicable).

- *What can help me to disclose (favourable conditions)?*
- *What can I do that would help me disclose (assets)?*
- *What or who could prevent me from disclosing (obstacles)?*
- *What can I do to overcome those obstacles (strengths)?*

- The facilitator divides the board or flip chart into four sections that correspond to the four questions above and writes the participants' answers in the appropriate sections. The facilitator completes the chart using the items in the box below.

CONTENT DETAILS: FAVOURABLE AND UNFAVOURABLE FACTORS

Factors favourable to disclosure (here is a possible list):

Things that could help me disclose my HIV status (**favourable conditions**):

+ learning to live well with HIV
+ having a good understanding of HIV
+ being comfortable educating and raising the awareness of people about HIV
+ surrounding myself with supportive people
+ feeling ready to disclose
+ trusting the person I am considering telling
+ believing that the person will be understanding and respect confidentiality, etc.

Things I can do that would help me to disclose (**assets**):

+ participating in support groups
+ observing whether people around me have prejudices, whether they understand HIV
+ reading up on the subject
+ giving myself some time
+ choosing carefully who I want to tell

Factors unfavourable to disclosure (here is a possible list):

What or who could prevent me from disclosing (**obstacles**):

+ fear of others' reactions
+ having young children
+ fear of stigma and discrimination
+ fear for my safety
+ family living far away
+ not knowing how to disclose
+ loved ones' ignorance of the illness, modes of transmission, symptoms, treatments, etc.

CONTENT DETAILS: FAVOURABLE AND UNFAVOURABLE FACTORS (CONTINUED)

Things I can do to overcome these obstacles (**strengths**):

+ prepare myself for all types of reactions
+ inform my children about HIV and equip them to cope with stigma
+ understand my rights, stand up for them and ensure that they are respected
+ wait to meet with family members in person
+ talk to healthcare professionals or other people who have already gone through a similar experience
+ arrange to be accompanied by healthcare professionals before or during disclosure
+ educate others and raise awareness about HIV (modes of transmission, symptoms, treatments, etc.)

5.3 CARDS ▸ 15 minutes

- The facilitator hands out the set of playing cards from the “My winning hand” activity sheet to each participant and ask them to spread out their cards. The facilitator then asks the participants to write an ideal condition for disclosure, an obstacle to disclosure, a factor that could encourage disclosure and one of their strengths that could help them to overcome an identified obstacle to disclosure on the corresponding cards, for the context they have chosen from their “The people in my orbit” activity sheet.

ACTIVITY: “MY WINNING HAND”

▸ Impact technique involving interaction with playing cards

Instructions:

+ After the group brainstorms, the facilitator distributes one card from each suit (hearts, clubs, spades and diamonds) and a pen to each participant (“My winning hand” activity sheet).

+ The facilitator asks the participants to identify, from the answers on the board or flip chart, the condition they believe is the most important for facilitating disclosure and to write it on the heart card (**their ideal condition**).

+ The facilitator asks the participants to identify the most significant obstacle to disclosure and to write it on the spade card (**obstacle**).

+ The facilitator asks the participants what they can do to reinforce the ideal condition (heart card) that facilitates disclosure and write it on the diamond card (**their asset**).

+ Lastly, the facilitator asks the participants what they can do to overcome the obstacle (spade card) and put that on their club card (**their greatest strength**).

The goal of this exercise is to make participants aware of the cards they hold in reality. The experience can make disclosure scenarios more tangible and allow them to realize that, although there are obstacles to disclosure, there are also conditions that could make disclosing easier. Participants might realize that there are things they can do to make disclosing a positive experience (e.g., preparing for others’ possible reactions). They might also realize that it is possible to face, overcome, avoid or eliminate some obstacles to disclosure. The goal is to help the participants recognize they possess assets and strengths that could help them overcome obstacles to disclosure. The hand of cards in the exercise is theirs, so they have the opportunity to construct a winning one before disclosure and, above all, they are masters at playing those winning cards (their assets and strengths) to give themselves the greatest chance of success in making sure their disclosure goes well, if that is what they decide to do.

Source: Beaulieu, D. (2006). *Techniques d’impact en psychothérapie, relation d’aide et santé mentale*. Québec, Québec. Impacts! Éditions, 310 pages, © 1997

30

6. CLOSING ACTIVITY: “MY CONCLUSIONS”

- **Group discussion**: The facilitator encourages the participants to decide if their hand of cards allows them to disclose their HIV status, if that is their decision. The facilitator questions the participants, and those who wish to participate in the discussion can do so:
  - + *Have you identified **ideal conditions** for disclosing your status? What would **reinforce** your ideal conditions? Are you facing **obstacles** to disclosure? Do you now foresee **obstacles** you had not considered before? Do you know of **ways to overcome** those disclosure obstacles?*

15

7. THOUGHTS ON THE MEETING

- The facilitator asks the participants how they feel following the meeting. Each participant should be given around 2 minutes to express their feelings.

VARIATION

Impact technique using expression

A word, an emotion, a colour or a number

- + The participants can be asked to answer the question by using one word, a short sentence, an emotion, a colour or a number (e.g., on a scale from 0 to 10, with 10 meaning they are doing very well).
- + The participants can then be invited to comment on their answers, if the facilitator feels this is necessary and appropriate.

Source: Beaulieu, D. (2006). *Techniques d’impact en psychothérapie, relation d’aide et santé mentale.* Québec, Québec. Impacts! Éditions, 310 pages, © 1997.

NOTE TO FACILITATOR

- + This exercise gives participants the opportunity to express how they are feeling. It also allows the facilitator to understand each participant’s state of mind following the meeting so that they can offer support if necessary or make appointments with individuals for further discussion.

- The facilitator asks the participants what they liked the most and what they did not like as much. The facilitator also asks them what the high point of the meeting was for them, that is, which part had the most impact, and invites them to make suggestions to improve the meeting.
- The facilitator tells the participants that they can now put their worksheets in their logbooks.

TIP

- The facilitator can write the participants’ comments on a piece of paper or a board as a reference for how to improve program content, structure or delivery.

IMPORTANT NOTES

- Give participants a few minutes to talk to you if they are not doing well. An appointment can be made for a later date if necessary.
- Remind participants that they can meet with you if they feel the need.
- Inform participants that the next meeting will focus on strategies for disclosing in various contexts. Give them a copy of “The allegory of the wise chameleon” so they can prepare for that meeting.
- At the next meeting, participants will continue to explore the same context that they chose for this meeting.
- Mention to participants that the first meetings will allow them to reflect on the the issue of disclosure while the same number of later meetings will deal with keeping their status private.

WEEKLY REFLECTION

- The participants are invited to reflect on or even incorporate into their daily lives what they learned in the meeting. This will be reviewed during the next meeting.

END OF THE MEETING

“THE PROS AND CONS SCALE” ACTIVITY SHEET

DISCLOSURE (already done, or anticipated) to X

Describe the context

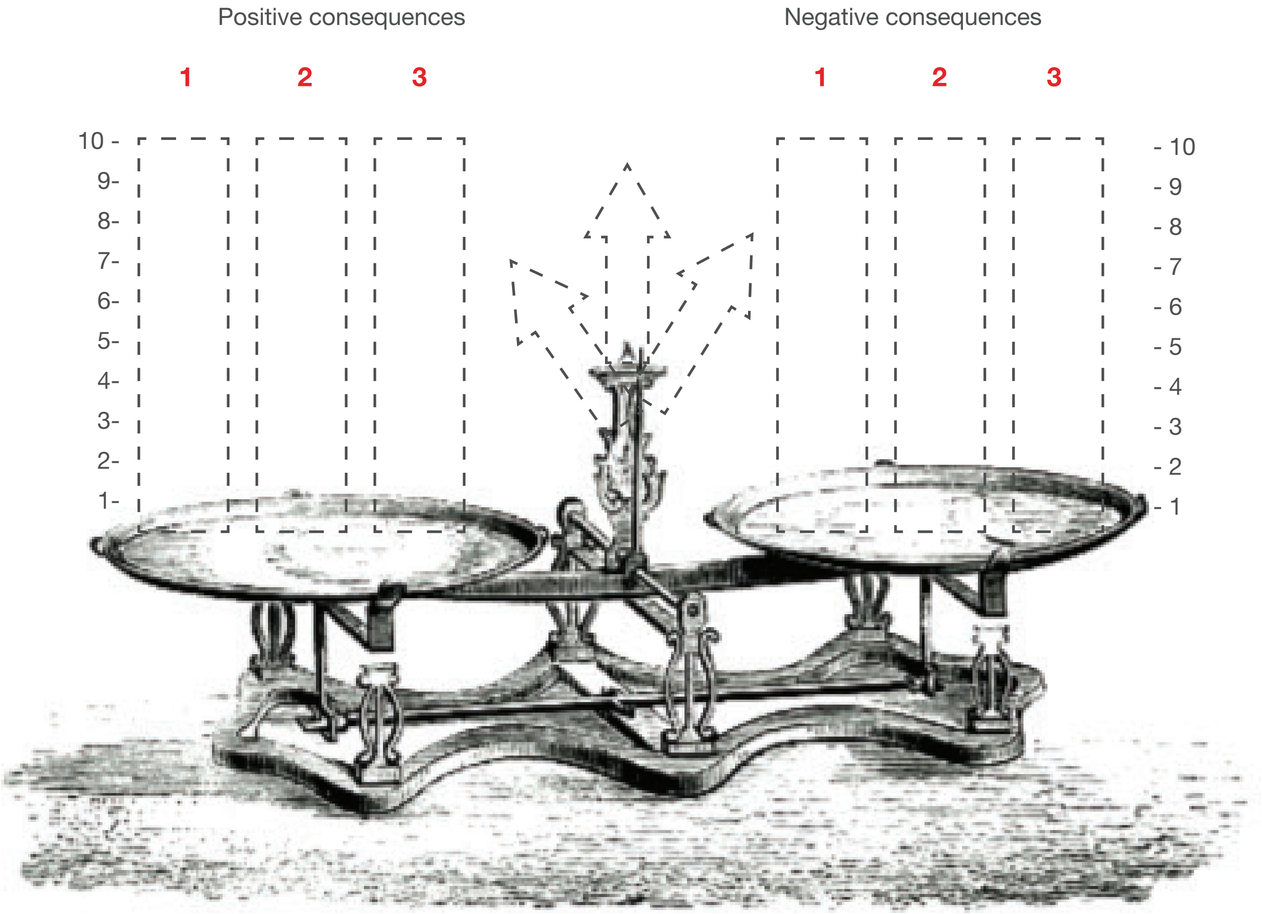


Fig. 3.

PROS	CONS
1.	1.
2.	2.
3.	3.

“THE PROS AND CONS SCALE” ACTIVITY SHEET: SAMPLE VERSION

DISCLOSURE (previous or anticipated) to X

Describe the context *To my children*

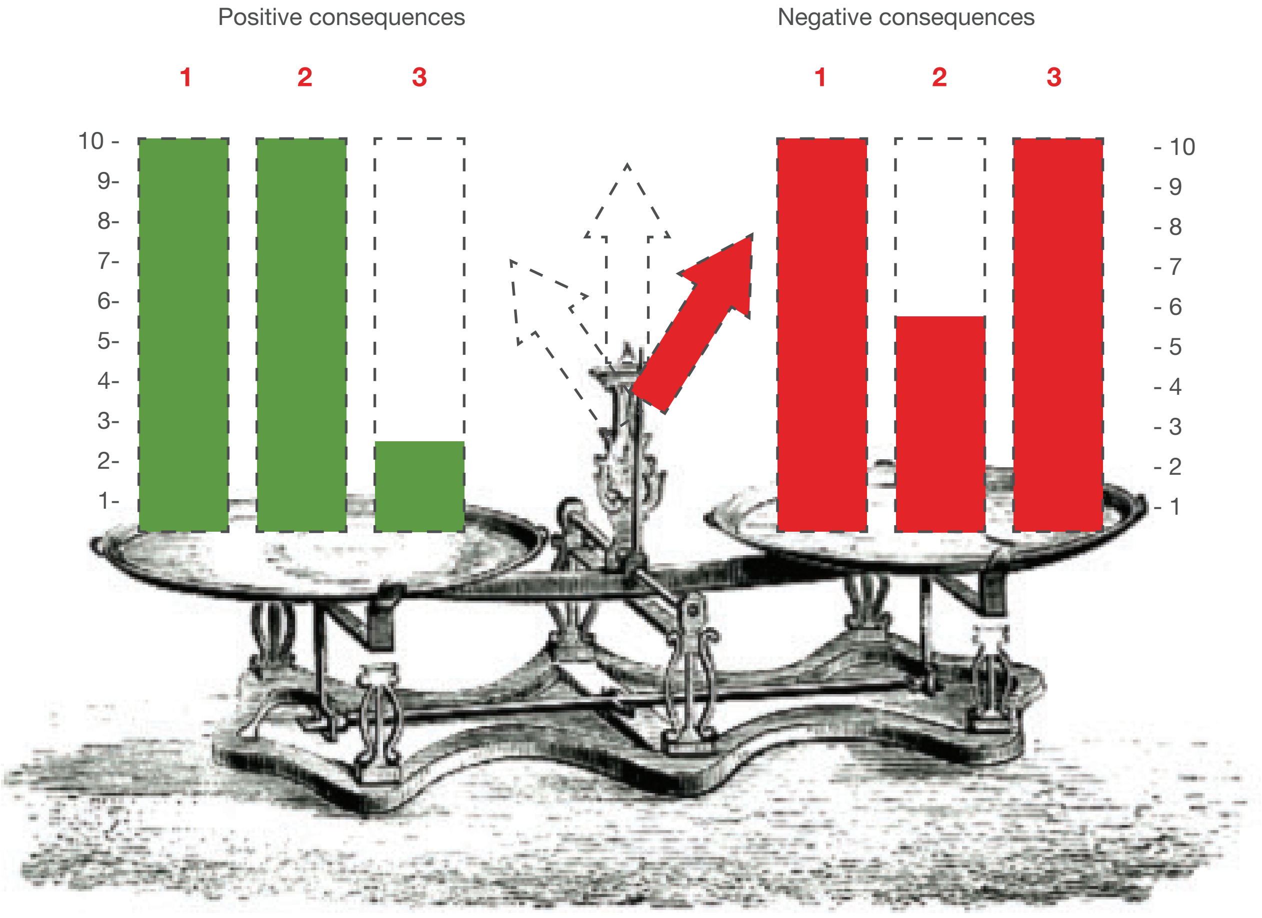


Fig. 3.

PROS

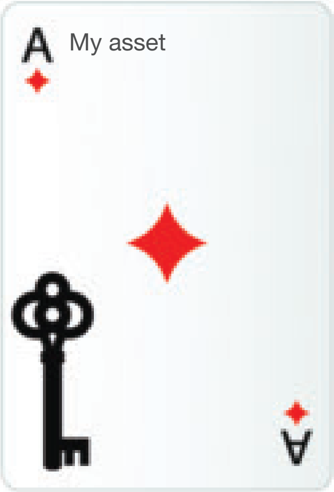
1. Being honest/not having to hide
2. Release, relief
3. I’m going to be able to inform them about HIV

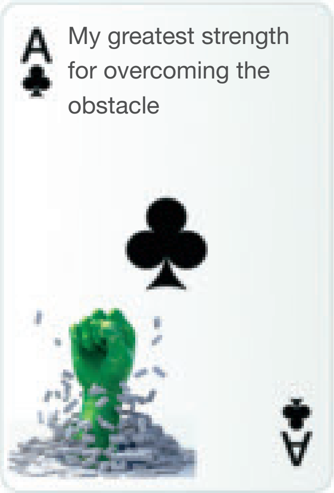
CONS

1. They’re going to be upset that I didn’t tell them before
2. It’s going to worry them (they’ll think I’m going to die)
3. I’m afraid they’ll tell others about my status

“MY WINNING HAND” ACTIVITY SHEET

Give each participant one card from each suit.





Rosa and Prudence: disclosure and its consequences

Rosa

Rosa's story

Rosa, 42, is from Quebec. She found out that she is HIV-positive 12 years ago. Rosa does not have children. She has been living with her partner for 10 years now. Her partner was the first person to whom Rosa decided to disclose her HIV status apart from her doctor and a nurse at the hospital. Furthermore, she maintains that she quit her job before being fired. To feel useful, Rosa sometimes visits schools to educate students about HIV.

The positive and negative consequences of **disclosure**

Partner

Rosa and her boyfriend had been seeing each other for a few months when she told him about her HIV status. At first, he was a little surprised, but he quickly realized that he was already attached to Rosa, that he did not want to leave her and that they could take steps to protect each other. Their relationship continued with no secrets between them.

Family

The second person to whom Rosa disclosed her status was her oldest brother. Before telling him, she worried that he would tell other people. Her fear proved to be justified when her brother told their three other brothers and their mother without asking for Rosa's permission. Rosa's mother did not believe the brother and asked Rosa if it was true. Rosa decided to deny it because her mother was very sick, and Rosa did not want the news to aggravate her mother's health condition.

Friend

Rosa also disclosed her status to a friend because she needed to share her secret with someone other than her partner and family. Rosa trusted that the friend would not tell other people they knew.

Prudence

The positive and negative consequences of **disclosure**

Prudence's story

Prudence, 32, is originally from Mali. She has known that she is HIV-positive for 3 years. She believes that she contracted the virus while having sex with her first husband, who is now deceased. Prudence has two children, a 7-year-old boy and a 3-year-old girl. Her children are both HIV-negative. Prudence found out about her status when she was pregnant with her daughter. She then married a man who is HIV-negative. When she told him about her status, he accused her of hiding it from him so she could marry him. Shortly afterwards, they separated.

Children

Prudence has not told her daughter about her HIV yet because she believes her daughter is too young and Prudence does not want to traumatize her. However, she told her son that she is sick, without telling him what she has. He is not sure if it is true or not because Prudence seems to be in good health. Sometimes he asks questions; she reassures him that she is taking care of herself and that everything is going well.

Family

Prudence has not disclosed her HIV status to other family members or friends because she worries that they would judge her. She is also afraid that her family would reject her. For now, she avoids the subject and when HIV comes up she does not talk about herself personally. She believes that one day she will tell people but is waiting for the right time.

Dentist

Prudence has disclosed her HIV-positive status to her dentist, who has been seeing her since she arrived in Canada. The news did not change her relationship with him—she believes that the care she is receiving from him is as good as before.

Friend

Prudence has also disclosed her status to one of her friends because it was important for her to know there was someone who would be able to take care of her children if she had any health problems. While not comfortable with the idea of disclosing, she sees that, in this case, it can be very useful.

The allegory of the wise chameleon[6]

Once upon a time, some people built their village at the foot of a mysterious hill. At the top of the hill there was only a crude hut and a very old apple tree.

That is where a wise chameleon lived. It had descended from several generations of prehistoric reptiles and was recognized for its wise advice. Its favourite place to relax was in the gigantic apple tree overlooking the valley.

Back then, a village custom when people had a problem was to go to the wise chameleon's hut to ask his advice. He always gave the villagers the same response:

There are four steps to resolving your problem:

- **First,** you have to turn yourself into a **detective** that is, you have to observe the situation and note all the important elements of the problem. You have to understand the basis of the problem before you can resolve it.

- **Second,** you have to act like an **architect** to analyze the problem. Illustrate it on paper, with some kind of diagram or drawing.

- **Third,** you have to be like a **carpenter**, to carry out the plan you produced when you were the architect. You will implement the solution you came up with in steps 1 and 2.

- **Fourth**, you will turn into a **referee** to verify all the data for the problem one last time and decide if the solution is suitable. If so, there you go! Otherwise, you will have to start the process over, and then you will certainly find the solution.

One day, the chief of the village, who had a serious conflict with his son, resolved it by following that wise advice. A village couple, who were having trouble finding the key to the mystery that was ruining their happiness, also followed the chameleon's recommendations and found happiness and harmony again.

Nearly all the residents of the village had consulted the wise chameleon at some time, and they all came back down the hill with shining faces because they had found their solutions, too.

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[6] Taken and adapted from Dufour, M. (1997). *Allégories II: croissance et harmonie.* Éditions JCL Inc., Chicoutimi, p. 166-168.

One day, however, lightning hit the giant apple tree, and the wise chameleon, who was lounging in the tree at the time, perished along with it. What misfortune!

Despite the loss of the wise chameleon, the villagers continued to go to the hut to attempt to resolve their problems and found their solutions by remembering those four steps.

One stormy night, the wise chameleon's hut fell down, and the people stopped going up there. When they encountered a problem, they only had to glance at the top of the hill to remember how effective the wise chameleon's four steps were.

That's how the wise chameleon's message was handed down from generation to generation. Every time a villager had a problem, he or she remembered the four steps and put them into action, and they were always successful.

THE END

MEETING 6

Sharing to better support each other

Overview

Meeting 6 | Sharing to better support each other

OBJECTIVE OF THE MEETING

To help participants to plan disclosure strategies

DURATION

▸ 3 hours

REQUIRED MATERIALS

+ Logbook for each participant
+ A board or flip chart and chalk or pencils
+ “My strategic plan” activity sheets
+ A disclosure strategy card for each participant
+ Scissors for each participant
+ Glue sticks
+ Coloured pencils, crayons and/or markers
+ Coloured poster board to make the cards
+ A pen for each participant

Optional:

+ Prudence and Rosa’s stories (“Disclosing with Prudence and Rosa” sheet)

MEETING PLAN

1. Welcome ▸ 15 minutes
2. Presentation of the theme and objective of the meeting ▸ 5 minutes
3. Activity: “Sharing knowledge and experience” ▸ 40 minutes

   Break ▸ 15 minutes
4. Activity: “My strategic plan” ▸ 1 hour
5. Activity: “Encouragement card” ▸ 30 minutes
6. Thoughts on the meeting ▸ 15 minutes

   End of the meeting

Meeting 6 | Sharing to better support each other

OBJECTIVE OF THE MEETING

To help participants to plan disclosure strategies

DURATION

- 3 hours

REQUIRED MATERIALS

- Logbook for each participant
- A board or flip chart and chalk or pencils
- “My strategic plan” activity sheets
- A disclosure strategy card for each participant
- Scissors for each participant
- Glue sticks
- Coloured pencils, crayons and/or markers
- Coloured poster board to make the cards
- A pen for each participant

Optional:

- Prudence and Rosa’s stories (“Disclosing with Prudence and Rosa” sheet)

MEETING PLAN

15

1. WELCOME

REVIEW OF THE PREVIOUS MEETING

- The facilitator invites the participants to reflect on the last meeting and asks them to answer the following question:
  - *How did the last meeting help you to evaluate the negative and positive consequences of disclosure?*

5 2. PRESENTATION OF THE THEME AND OBJECTIVE OF THE MEETING

- The facilitator introduces the theme of the meeting: **Sharing to better support each other**
- **Objective**:
  - to plan disclosure strategies

NOTE TO FACILITATOR

Throughout the meeting, the facilitator should:

- support the participants in their process of disclosing or not disclosing
- ask the participants to support each other in their respective processes
- place equal value on both disclosing one's HIV-positive status and keeping it secret

40 3. ACTIVITY: "SHARING KNOWLEDGE AND EXPERIENCE"

3.1 DISCLOSURE TYPES ▸ 10 minutes

- The facilitator introduces the idea that there are four approaches to disclosing one's HIV status.

+ *Can you name the four approaches to disclosure?*

CONTENT DETAILS: FOUR APPROACHES TO DISCLOSURE

Women living with HIV approach disclosure in various ways. Four approaches are reported in the literature:

1. **Secret disclosure:** This involves disclosure to only a few people from whom complete confidentiality is required—for example, the woman's partner and mother.
2. **Selective disclosure**: Women evaluate the situation before disclosing and open up to those with whom they have quality relationships, who can keep the secret, or who can help them with their health. Other factors may encourage selective disclosure, such as the risk of sexual transmission to a partner.
3. **Complete disclosure (rare):** Women consider it important to disclose their status without taking into consideration the people to whom they are disclosing and do not require complete confidentiality. The women disclosing in this way do so for social, political or educational reasons.
4. **Unwanted disclosure:** Although rarely documented, this phenomenon of someone disclosing another person's status without their consent is real. The breach of confidentiality often comes from family members and healthcare professionals.

CONTENT DETAILS: FOUR APPROACHES TO DISCLOSURE (CONTINUED)

Sources:

Black, B.P., and Miles, M.S. (2002). “Calculating the risks and benefits of disclosure in African- American women who have HIV.” *Journal of Obstetric, Gynecologic, and Neonatal Nursing,* 31(6), 688-97.

Sowell, R.L., Seals, B.F., Phillips, K.D., and Julious, C.H. (2003). “Disclosure of HIV infection: How do women decide to tell?” *Health Education Research,* 18 (1), 32-44.

3.2 SHARING ▸ 20 minutes

- The facilitator invites the participants to share their disclosure experiences (it is recommended that a person who has had a positive experience and a person who has had a more difficult one be selected).
  - + *Does anyone want to share a disclosure experience that went well? Has anyone had a more difficult experience?*

VARIATION

+ The facilitator can introduce this exercise by reading “Disclosing with Rosa and Prudence.” Participants can be asked to idenitfy the disclosure strategies used by Rosa and Prudence.

3.3 DISCLOSURE STRATEGIES ▸ 10 minutes

- The facilitator can next ask the participants to point out the disclosure strategies used by the participants who shared their experiences or those used by Rosa and Prudence or to describe other disclosure strategies they know of.

- The facilitator sections off the board or flip chart into three categories :
  1. Preparing to disclose
  2. Strategies
  3. After disclosure

- As the faciliator poses questions to the participants, she writes down what they say in the appropriate category. The facilitator fills in the table with items from the box below.
  - + *How can we prepare for disclosure?*
  - + *What were the disclosure strategies used by those who shared their experience? What disclosure strategies did Rosa and Prudence use? Do you know of, or can you imagine, any other disclosure strategies?*

- The facilitator then asks the participants how they can prepare for people's reactions
  - *Have you considered the reaction of the person to whom you would like to disclose?*
  - *How are you going to respond/how have you responded to that reaction?*
  - *How can you protect yourself emotionally or take care of yourself if it does not go well?*

VARIATIONS

- The facilitator can provide participants with references from several HIV resources in Canada (see Appendix 2).
- Other leaflets and brochures on disclosure may also be given to participants (see Appendix 1).

CONTENT DETAILS: DISCLOSURE STRATEGIES

Disclosure strategies (here is a possible list):

- decide on the person to whom you want to disclose
- ask for support from your social worker, the psychosocial team at the hospital or another healthcare professional.
- participate in support groups
- read up on the subject
- give yourself time to prepare emotionally
- test the attitude of people close to you about people living with HIV and about HIV
- write a letter
- disclose over the phone
- leave your HIV medications out
- make presentations in schools or to your community to raise people's awareness about HIV
- disclose individually to each of your family members
- continue relationships only with those who accept you
- get physically active and work on reducing the stress of disclosure
- call a friend to talk about the disclosure experience
- engage in an activity you especially like to get your mind off it
- give the person to whom you disclose time to digest the news
- refer that person to a healthcare professional
- be available to answer questions from the person

CONTENT DETAILS: DISCLOSURE STRATEGIES (CONTINUED)

Example:

Preparing to disclose

- decide whom you want to tell in your family
- ask for support from a social worker, hospital psychosocial team, etc.)
- participate in support groups
- test people's attitudes
- read up on the subject
- give yourself time to prepare emotionally

Disclosure strategies

- write a letter
- disclose over the telephone
- leave your HIV medications out
- talk about your experience in schools or community to raise awareness
- disclose individually to each family member, etc.

After disclosure

- continue relationships only with those who accept you
- get physically active and work on relaxation to reduce the stress of disclosing
- call a friend
- engage in an activity you especially like to get your mind off it
- give the person to whom you are disclosing time to digest the news
- refer that person to a healthcare professional
- be available to answer questions from that person

BREAK ▸ 15 minutes ◂

4. ACTIVITY: "MY STRATEGIC PLAN"

- The facilitator and the group read the activity sheet "My strategic plan." Afterwards, the facilitator asks each participant to complete their strategic plan. Participants complete version 1 of the strategic plan ("Treasure map") for an anticipated disclosure and version 2 ("Chess match") for a previous disclosure.

- For anticipated disclosures, the participants are asked to answer the following questions while completing "their strategic plan."

Disclosure context

1. To whom am I going to disclose my HIV status? (Choose the person and determine whether or not that person's characteristics are influencing your decision to disclose—for example, their gender, age, health condition.)

2. Why do you want to disclose? (Clarify your intended objective of and motivation for disclosing.)

3. When do you want to do it? (What is the best time?)

4. Where do you want to do it? (What is the best place?)

Decision/support/certainty

5. Where are you in terms of your decision to disclose? (e.g., I have not thought about it yet, I am thinking about it, or I have almost decided)

6. Are you feeling pressure from others to disclose?

7. Are you getting enough support from others in making the decision?

8. Are you sure it's the best choice for you?

Skills/knowledge

9. Do you feel equipped to answer questions about your health?

10. Are you prepared and do you have enough information to disclose?

  10.1 What question(s) do you anticipate from the person you want to tell?

11. What is your plan if disclosure does not go well?

Strategies/experience

12. What disclosure strategies do you intend to use?

13. How do you use this strategy to assess the feasibility of disclosing in this particular context?

14. Have you disclosed your HIV status to others? If so, what strategies did you use? Would those strategies be useful in this context?

- For previous disclosures, the participants are asked to answer the following questions while completing "their strategic plan."

Disclosure context

1. To whom did you disclose? Why did you choose to disclose to this person?

2. Why did you decide to disclose your HIV status? (What was your objective and motivation for disclosing?)

3. When did you think the best time for disclosing was?

4. Where did you think the best place for disclosing was?

Decision/support/certainty

5. What were you thinking at the moment you disclosed?

6. Did you get support from others beforehand?

7. Did you decide to disclose under pressure from others?

8. Were you sure it was the best choice for you?

Skills/knowledge

9. Did you feel informed enough to disclose?

  9.1 What question(s) did you anticipate from the person you told?

10. Did you feel you were equipped to answer questions about your health?

11. Did you have a plan in case the disclosure did not go well?

Strategies/experience

12. What disclosure strategies did you use?

13. How did you use this strategy to assess the feasibility of disclosing or not disclosing in this particular context?

14. Have you disclosed your HIV status to others? If so, what strategies did you use? Would those strategies be useful for this exercise?

- The facilitator invites the participants to share their answers to questions 11 and 12 of their strategic plan with the group.

TIP

- The faciliatator can give each participant a strategy card to fill out after the other participants have described the strategies they used. The goal of this exercise is to help each participant think about strategies that could be used in other contexts.

- In closing, the facilitator reviews the exercise with participants.
  - *After completing your strategic plan, are you thinking about disclosure differently?*
  - *Considering your "winning hand" (from Meeting 5) and your strategic plan for an anticipated disclosure, when do you think you will be ready to disclose?*
  - *Considering an experience you may have already had disclosing, how do you think it went?*

VARIATIONS

- This exercise may also be done in pairs of one participant who has already disclosed their HIV status and one participant who has not disclosed in the same context.
- The exercise may also be done in a one-on-one session with an individual participant, if you provide that type of support.

30

5. CLOSING ACTIVITY: "ENCOURAGEMENT CARD"

- To encourage participants to support each other in the delicate process of planning to tell people about their HIV status, the facilitator invites them to make cards with encouraging messages for each other.
- The cards might contain advice or a word of encouragement or hope about the reactions participants can expect after disclosing.
- The facilitator hands out cards to participants at random.
- Those who wish to can respond to the cards they receive.

VARIATION

- The facilitator can ask the participants to make a card in which each participant highlights a strength or quality they see in the recipient that could be useful for facing or overcoming obstacles to disclosure.

15

6. THOUGHTS ON THE MEETING

- The facilitator asks the participants how they feel. Participants should be given approximately 2 minutes each to express themselves.

VARIATION

- **Impact technique using expression**

A word, an emotion, a colour or a number

+ The facilitator asks the participants to describe how they are feeling using one word, a short sentence, an emotion, a colour or a number (e.g., a number on a scale of 0 to 10, with 10 meaning that you are doing very well). The participants can then be invited to comment on their answer if they wish.

Source: Beaulieu, D. (2006). *Techniques d'impact en psychothérapie, relation d'aide et santé mentale.* Québec, Québec. Impacts! Éditions, 310 pages, © 1997.

NOTE TO FACILITATOR

+ This exercise gives participants the opportunity to express how they are feeling. It also allows the facilitator to understand each participant's state of mind and to offer them support after the meeting if needed or make individual appointments for further discussion.

- The facilitator asks the participants what they liked the most and what they did not like as much.

What was the high point of the meeting for you? Which part had the most impact on you? How could the meeting be improved?

- The facilitator lets the participants know that they can now put their worksheets in their logbooks.

TIP

+ The facilitator can write down the participants' feedback on a piece of paper or on the board to refer to them later when planning how to improve the meeting.

IMPORTANT NOTES

- If participants are not doing well, leave time for further discussion. You may need to schedule a subsequent appointment.
- Remind participants that, if they would like, you can meet with them individually.
- Mention that at the next meeting, the group will explore the theme of not disclosing (keeping one's HIV status private) in various contexts.
- Explain that the first meetings will allow them to reflect on the issue of disclosure and the same number of subsequent meetings will deal with keeping one's HIV status private.

WEEKLY REFLECTIONS

- The participants are invited to think of one person with whom they want to share their secret. If participants do not have a context in mind, they can be invited to reflect on a situation in which they hesitated before disclosing their HIV-positive status.
- The participants are invited to reflect on or even incorporate into their daily lives what they learned in the meeting. There will be an opportunity to discuss this more at the next meeting.

END OF THE MEETING

My strategic plan: Should I disclose?

For an anticipated disclosure (version 1)

Treasure Map

ABILITIES / KNOWLEDGE

9 Do I feel like I have adequate tools to deal with questions about my health or about HIV ?

☐ Yes ☐ No

10 Do I have enough information to disclose ?

☐ Yes ☐ No

11 What is my plan if my disclosure does not go well or if the person has a negative reaction ?

STRATEGIES / EXPERIENCES

12 **HOW?**

(Wath are my strategies ?)

14 Do I have other disclosure experiences ?

☐ Yes ☐ No

15 Could strategies used in the past be useful in this situation ?

☐ Yes ☐ No

13 **Feasibility ?**

On scale of **1 to 5,** assess the feasibility of each of the proposed strategies

Not at all feasible				Very feasible
1	2	3	4	5

THE DECISION

5 How much I have thought about this decision ?

☐ No decision

☐ Reflection underway

☐ Almost ready to know where I stand

☐ My decision is made

6 Am I making this decision because of pressure from other people ?

☐ Yes ☐ No

SUPPORT / CERTAINTY

7 Am I supported in this decision ?

☐ Yes ☐ No

8 Am I certain that this is the best choice for me ?

☐ Yes ☐ No

THE SITUATION

1 **To whom am I considering disclosing ?**

Is there anything about this person I could consider prior to disclosing ?

2 **WHY ?**

3 **WHEN ?**

4 **WHERE ?**

MY STRATEGIC PLAN

For a previous disclosure (version 2)

Chess match

NO ☐		NO ☐					
9 WAS I INFORMED ENOUGH ?		10 WAS I EQUIPPED?		11 RESPONSES TO REACTION		12 HOW? STRATEGIES	
YES ☐		YES ☐					
	My decision in progress ☐		NO ☐		NO ☐		NO ☐
No decision ☐	5 MY REFLECTIONS	About to be sure ☐	6 DID I HAVE SUPPORT ?		7 WAS I UNDER PRESSURE?		8 DID I MAKE THE RIGHT DECISION ?
	Decision made ☐		YES ☐		YES ☐		YES ☐
1 TO WHOM ?		2 WHY ?		3 WHEN?		4 WHERE?	

Source: O'Connor, Stacey, Jacobson. (2004). *Ottawa Personal Decision Guide*. Ottawa Hospital Research Institute. Online: http://decisionaid.ohri.ca/decguide.html

MY STRATEGY CARD

Cut out a copy of this card for each participant

Strategy Card

- ✓ Write a letter
- ✓ Disclose on the telephone
- ✓ Leave medications out
- ✓ Disclose to each loved one individually
- ✓ ...

Disclosing with Rosaand Prudence

Rosa

Reminder of Rosa's story

Rosa, 42, is from Quebec. She found out she is HIV-positive 12 years ago. Rosa has no children. She has been living with her partner, to whom she is not married, for 10 years now. Her partner was the first person to whom Rosa decided to disclose her HIV-positive status besides her doctor and a nurse at the hospital. Furthermore, she maintains that she quit her job before being fired. To feel useful, Rosa sometimes gives talks about her status to student audiences

Disclosure strategies

Partner

After being with her partner for 6 months, Rosa felt that their relationship was serious and that she could trust him. She had asked him if he knew anything about HIV and whether he knew people who had it, to test his attitude toward HIV and people living with the disease. Because he had seemed very open, she felt comfortable enough to tell him her secret. Rosa decided to do it over the telephone, because she thought that distance would allow her to be less emotional and allow her to explain everything she planned to say.

Brother

Later, Rosa decided to disclose her HIV status to her oldest brother. Because they were very close, she felt obligated to tell him. Unfortunately, her brother did not keep the secret with which Rosa had entrusted him and told their 3 other brothers and their mother without asking Rosa's permission.

Family

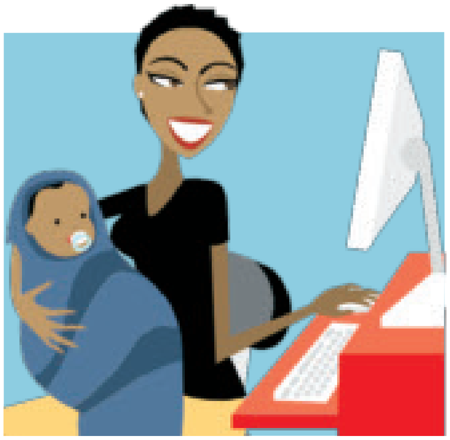
Then Rosa met with all of her brothers so she could tell them herself. She told herself that, in some way, her oldest brother had broken the ice and that it was all for the best. After the experience with that brother, Rosa also realized that it might be very difficult for her other brothers to keep a secret like that. So, when she spoke to them, she put a lot of emphasis on the fact that she trusted them and needed them to be discreet. Although things went faster than she thought they would, she reacted calmly by reflecting on the positive aspects of the situation.

Now Rosa can talk about her health with all four of her brothers without fearing that her secret will be discovered.

Friend

Rosa also decided to disclose her status to her closest friend. One evening when they were alone at her place, chatting about anything and everything, Rosa decided to put a leaflet on antiretroviral treatments on the living room table. She thought that her friend would bring up the subject or ask her why she was reading that type of thing and then it would be easier for Rosa to talk about it. She was hesitant about using the leaflet because she could also bring up the subject by relating it to a movie or the news. Recently, she had the idea of disclosing her status to another friend by inviting her to join her in a walk for the Farha Foundation, which raises money every year for people living with HIV.

Prudence



Disclosure strategies

Reminder of Prudence's story

Prudence, 32, is originally from Mali. She has known that she is HIV-positive for 3 years. She believes that she contracted the virus while having sex with her first husband, who is now deceased.

Prudence has two children, a 7-year-old boy and a 3-year-old girl. Her children are both HIV-negative. Prudence found out about her status when she was pregnant with her daughter. She then married a man who is HIV-negative. When she told him about her status, he accused her of hiding it from him so she could marry him. Shortly afterwards, they separated.

Children

Prudence felt that the time had come to talk to her kids about her HIV status. She felt ready and well-prepared, but she decided to take her children to meet with her social worker so someone else could explain things to them. She believed that her children had the right to know what was going on but that it was important to choose the right time. To prepare herself, she thought about the questions and concerns her children might have by putting herself in their position. She thought, "What if my mother had revealed such a secret to me when I was only seven ! "

Friend

Prudence also had to manage the question of disclosure with a friend with whom she lived after her separation. This friend had asked a lot of questions about Prudence's medications but, at that time, Prudence was pregnant and told her they were for her pregnancy. However, after having her baby, she continued to take the same medications. Prudence found the situation awkward and was tired of always having to hide what was going on. At first, Prudence thought about getting a babysitter for the children and the two of them having a girls' night out. She told herself that by choosing the right time and place and by thinking through how she would tell her friend, she would feel more in control of the situation. However, when it came down to it, the idea of the disclosure made Prudence too anxious, so she decided to tell her about her HIV in a long letter in which she explained how her friendship was important to her and that she regretted

Family

Prudence did not disclose her status to her family members, some of whom are living in Quebec, because she is afraid that some of them would reveal it to people in her community. She does not want her children or her to be the subject of rumours or finger-pointing. She also knows that there is lots her family does not know about HIV and she has heard them express prejudiced views towards people living with HIV. For now, she has decided to not disclose to her family, but to discuss the subject in a less personal way. Sometimes, she comments on a report or an article about HIV and tries to raise their awareness. This way, when she is ready to disclose, it will be less difficult. She is waiting to be ready herself but also for her family members to be ready.

Mother who is far away

With time, she is gradually warming up to the idea of disclosing to her mother, who lives in Mali. Prudence would like to be able to talk to her about her concerns regarding her status and her children. She believes that her mother can support her despite the many kilometres between them. However, she vacillates between the possibility of returning to Africa before telling her and telling her over the phone. Her next trip might not be for several years, but she believes that her mother would understand better if Prudence could tell her in person. So Prudence will only tell her over the phone if it is an emergency.

MEETING 7

Secrets to keeping your secret

Overview

Meeting 7 | Secrets to keeping your secret

OBJECTIVE OF THE MEETING

To get the participants to use what they have learned to assess the possible consequences of keeping their secret in various contexts.

DURATION

- 3 hours

REQUIRED MATERIALS

- A logbook for each participant
- A blackboard or flip chart and chalk or markers
- "My savings account" activity sheet
- A pen for each participant
- Monopoly money in all denominations ($30 for each participant)
- "My secret code" activity sheet
- A box containing feathers

Optional:

- The stories of Prudence and Rosa ("Rosa and Prudence, secrets and their consequences" activity sheet)
- A ball

MEETING PLAN

1. Welcome ▸ 15 minutes
2. Presentation of the theme and objective of the meeting ▸ 5 minutes
3. Activity: "Pros and cons" ▸ 25 minutes
4. Activity: "My savings account" ▸ 40 minutes

   Break ▸ 15 minutes
5. Activity: "My secret code" ▸ 40 minutes
6. Closing activity: "My box of secrets" ▸ 25 minutes
7. Thoughts on the meeting ▸ 15 minutes

   End of the meeting

Meeting 7 | Secrets to keeping your secret

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Optional:

- The stories of Prudence and Rosa (“Rosa and Prudence: secrets and their consequences” activity sheet)
- A ball

MEETING PLAN

15

1. WELCOME

REVIEW OF THE PREVIOUS MEETING

- The facilitator asks the participants to review the previous meeting. The following question is asked and the participants are invited to share their answers:
  - *“How did the last meeting help you create strategies related to the disclosure of your HIV status?”*

5 2. PRESENTATION OF THE THEME AND OBJECTIVE OF THE MEETING

- The facilitator tells the participants the title of the meeting: **Secrets to keeping your secret**.
- **Objective**:
  - to assess the possible consequences of keeping one’s secret in various contexts.

*

NOTE TO FACILITATOR

Throughout the meeting, the facilitator should:

- support the participants along their journey to disclose or not disclose their HIV-positive status
- encourage the participants to support each other’s journeys
- place no value judgements on participants’ decisions, be it to disclose or not

25 3. ACTIVITY: “PROS AND CONS”

- **Brainstorming session:** From their personal history, the participants determine the “pros” (positive consequences) and “cons” (negative consequences) of keeping their status a secret.

* **The “pros” and “cons” of keeping their status a secret will have been discussed in previous meetings.**

- *Can you list some advantages of keeping your status a secret?*
- *Can you list some disadvantages of keeping your status a secret?*

- The facilitator writes the participants’ responses on the board. The facilitator should refer to the “Content details: ‘Pros and cons’” box below.

VARIATION

- To facilitate this exercise, write different categories on the board (e.g. work life, family life, etc.). For each, participants can list the pros and cons of keeping their status a secret.

CONTENT DETAILS: “PROS AND CONS”

BRAINSTORMING SESSION

The “pros” of keeping my secret (here is a possible list)

+ to keep my kids from being stigmatized and socially discriminated against, to avoid rejection, to safeguard the health of a loved one, to keep my job, to avoid being stigmatized and socially discriminated against, etc.

Example of where these pros can fit into different categories:

Work-related

- keeping my job
- to avoid being stigmatized and socially discriminated against

Family-related

- to avoid rejection
- to keep my kids from being stigmatized and socially discriminated against

Relationship-related

- to safeguard the health of a loved one

The “cons” of keeping my secret (here is a possible list)

+ feeling isolated, the fear of being “outed” by others, the burden of keeping my secret, always having to hide or lie about my health, having to lead a double life, etc.

Example of where these cons can fit into different categories:

Work-related

- always having to hide
- being discriminated against
- having to lie about my health, etc.

Family-related

- the fear of being “outed” by others
- the fear of being rejected
- the burden of keeping my secret
- always having to hide
- having to lie about my health, etc.

Relationship-related

- feeling isolated
- the burden of keeping my secret
- rejection/separation
- always having to hide
- damaging my relationships
- having to lie about my health
- leading a double life
- potential criminal prosecution, etc.

VARIATION

- Before having the participants list the “pros” and “cons” of keeping their secret, the facilitator can introduce this exercise by reading the stories of Rosa and Prudence (“Rosa and Prudence, secrets and their consequences” activity sheet) for inspiration.

40

4. ACTIVITY: “MY SAVINGS ACCOUNT”

- Using their “The people in my orbit” worksheet (see Meeting 4), each participant should choose a scenario in which the issue of keeping their HIV-positive status a secret can come up (a past or anticipated situation).
- For the scenario they have chosen, the participants should list the “pros” and “cons” of keeping their secret on the “My savings account” activity sheet (a maximum of three “pros and “cons” is suggested).
- On a scale of 0 to 10, the participants should determine what each “pro” contributes to their well-being and what each “con” costs them in terms of energy.
- The idea is for them to add up their deposits (benefits) and withdrawals (energy spent) when it comes to keeping their secret in a given context, or in other words, to determine whether it is worth it to keep the secret in that context.

CONTENT DETAILS: “MY SAVINGS ACCOUNT”

Complete the “My savings account” activity sheet using the “Example” version

Instructions:

- The participants should choose a non-disclosure scenario and write it in the designated space **(step 1)**.

PROS

- The participants write three PROS related to the non-disclosure scenario **(step 2).**
- In the DEPOSITS column, they assign a number from 0 to 10 to each PRO. This number allows them to quantify the benefits of keeping their secret **(step 3).**
- The participants add up all these numbers to obtain their TOTAL PROS score **(step 4).**
- On the basis of this score (0 to 30), the facilitator (banker) then gives each participant the equivalent amount of Monopoly money.

CONS

- The participants write three CONS related to the non-disclosure scenario **(step 5)**.
- In the WITHDRAWALS column, they assign a number from 0 to 10 to each CON. This number allows them to quantify the amount of energy it takes to keep their secret **(step 6).**
- The participants add up all these numbers to obtain their TOTAL CONS score **(step 7)**.

CONTENT DETAILS: “MY SAVINGS ACCOUNT” (CONTINUED)

BALANCE

- The participants calculate their grand total by performing the following calculation: TOTAL PRO SCORE – TOTAL CON SCORE = GRAND TOTAL (the result can be positive (x) or negative (-x) **(step 8).**
- If the GRAND TOTAL is positive (x), then keeping their secret benefits them more than it costs them in terms of energy. So for now, it’s better for them to keep their secret.
- If the GRAND TOTAL is negative (-x), then keeping their secret costs them more in terms of energy than it benefits them. So it may be better for them to reveal their secret.
- On the basis of the score obtained (0 to 30), each participant should give back the equivalent cash amount to the facilitator (banker). If the total is more than what the participant has in the bank, then she gives the banker all of her money.
- To end this exercise, the facilitator (banker) asks the participants if they saved money ($) or spent more than they had in their savings account. *Do your results validate your decision to keep your secret?*

TIPS

- Organizing one’s thoughts by theme and putting them on paper can promote critical thinking and inspire people to make positive changes.
- The goal is to shed light on the positive and negative consequences for the participants of keeping their HIV-positive status a secret and to create strategies that will benefit them. This process can help the participants reflect and may shed light on changes they need to make or factors they need to consider.

BREAK ▸ 15 minutes ◂

40

5. ACTIVITY: “MY SECRET CODE”

- The facilitator asks the participants what the word “secret” means to them and writes their answers on the board.
  + *When you think of the word “secret” what words come to mind?*

CONTENT DETAILS: WHAT THE WORD “SECRET” MEANS TO THE PARTICIPANTS

Words associated with keeping a secret (here is a possible list)

+ burden
+ weight
+ fear of being discovered
+ shame
+ feeling like a liar
+ distress
+ isolation
+ protection (for themselves and their kids)
+ etc.

The picture painted by this activity can be both positive and negative. Not everyone has the same experience when it comes to their secret. Some participants in the group may have decided to never keep their HIV-positive status a secret. Some may see negative consequences in doing so, while others may see positive consequences. The idea is to make the participants see that keeping their status a secret may be necessary in some situations and may not be a bad thing in other situations. It can be difficult to tell in some situations, leading participants not to disclose, even though they may want to. It can also be difficult for participants not to tell, even when this is their choice. It could be that various obstacles are making it difficult for them to disclose, although there are ways to minimize the negative consequences of disclosing and to overcome these obstacles.

- The facilitator then asks the participants to think of situations where it is best for them to keep their HIV-positive status a secret. Next, the facilitator asks them to think of obstacles that might prevent them from keeping their secret. The participants can use their own situation and/or experiences (or use short stories, if applicable).

  + *In what situations or contexts is it best for you to keep your HIV-positive status a secret?*
  + *In these situations or contexts, what do you do to keep your status a secret (ideal conditions)?*
  + *What could you do that would make it easier for you to keep your status a secret (assets)?*
  + *What might prevent you or what does prevent you from keeping your status a secret (obstacles)?*
  + *What has helped you overcome obstacles that you encountered in trying to keep your status a secret? What could help you?*

- The facilitator divides the board into five categories and writes the participants' answers to the above questions in the appropriate category. The facilitator completes the board using the content details in the box below:

CONTENT DETAILS: : FAVOURABLE FACTORS AND UNFAVOURABLE FACTORS

SITUATIONS WHERE IT MAY BE BEST TO KEEP THE SECRET
- during a job interview
- at work
- when my kids are young
- when my safety may be compromised

WINNING CONDITIONS (which favour keeping the secret)
- hiding my medications
- lying about the types of medications I am taking
- having people in my life who respect my desire not to talk about it
- not telling my young kids to make sure they don't reveal my status
- following my treatment as prescribed
- keeping certain people at a distance, etc.

ASSETS
- controlling my reactions to people's discriminatory comments or attitudes about people living with HIV
- knowing my rights
- not talking about the side effects of my treatment
- staying active to avoid suspicion, etc.

OBSTACLES (which do not favour keeping the secret)
- rumours or doubts about me
- being "outed" by someone close to me
- broken confidentiality by a health professional
- disease, hospitalization
- taking my medications
- lipodystrophy/lipoatrophy
- not breastfeeding, early weaning of my baby
- situations where there is a realistic possibility of sexual transmission (where the person is legally required to disclose their status under threat of criminal prosecution)
- the fear and stress of being discovered
- feeling like I have to tell
- not being able to work as I did before because of my health, etc.

STRENGTHS
- inventing another disease
- ignoring the rumours and doubts being spread about me
- demanding that people stop spreading gossip about my status or face action from the human rights commission
- taking my medication in private
- feeling ok about keeping my secret, etc.

- The facilitator distributes the "My secret code" activity sheet and asks the participants to complete it, indicating the numbers corresponding to the ideal conditions, assets, obstacles and strengths in the appropriate fields.
- The facilitator tells the participants that they can refer to the factors favouring and not favouring keeping their secret indicated on the activity sheet and add others afterwards, taking care to assign a number to them.

6. CLOSING ACTIVITY: “MY BOX OF SECRETS”

- This activity is done with a small box filled with a dozen medium-sized feathers. The facilitator explains to the participants that the box represents the secret of their HIV-positive status.
- To illustrate, the facilitator asks a participant to take their “My box of secrets,” give it to another participant and ask them not to open it. Meanwhile, the facilitator explains that this gesture symbolizes the participant sharing their secret with another person and asking them to keep it. The facilitator then asks the participant with the “My box of secrets” to open it and flip it over so that the feathers fly all over the place. The facilitator explains that this gesture symbolizes that the person did not respect the participant’s request to keep their secret.
- The facilitator then asks the other participants to pick up the feathers that fell to the ground.
- Finally, the facilitator asks the participants their interpretation of this exercise: *“What did this exercise say about the challenges involved in keeping your HIV-positive status a secret?*
- The facilitator adds to the participants’ feedback using the information presented in the box below.

CONTENT DETAILS: “MY BOX OF SECRETS”

+ No matter how strong their “secret code” may be, the participants should understand that choosing to share their secret with someone could lead to others finding out, whether they want this or not. The participants should understand that even if they take every precaution to keep their status a secret, others could find out. It’s therefore important for them to be careful whom they tell, to think about the person’s ability to keep their secret, to determine if this information may be too big a burden for them, to listen and support the person or to refer them to other contacts or resources, if necessary. Finally, the participants should understand that once they share their secret, it is more difficult to control and can be a heavy burden for some people to bear.

VARIATION

+ This activity can also be done with a ball. Instead of asking a participant to cause the feathers to scatter, the facilitator asks a participant to throw a ball to another participant. In this case, the ball represents the secret.

7. THOUGHTS ON THE MEETING

- After the meeting, the facilitator asks the participants how they feel and gives each participant about 2 minutes to express their feelings.

VARIATION

Impact technique using expression

A word, feeling, colour or number

+ The participants can be asked to answer the question using a word, feeling, colour or number (e.g., on a scale of 0 to 10, where 10 means they feel very good). The facilitator can then ask the participants to elaborate if they feel this would be helpful and appropriate.

SOURCE: Beaulieu, D. (2006). *Techniques d'impact en psychothérapie, relation d'aide et santé mentale*. Québec, Québec. Impacts! Éditions, 310 pages, © 1997.

NOTE TO THE FACILITATOR

+ This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, if appropriate, or schedule an individual meeting to talk.

- The facilitator asks the participants what they liked about the meeting and what they didn't like as much. Where applicable, they can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.
- The facilitator tells the participants they can put their activity sheets in their logbooks.

TIP

+ The facilitator can write what the participants said on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.

IMPORTANT NOTES

- Give the participants a few minutes to talk if they feel uneasy. A subsequent meeting can be scheduled, if needed.
- If required, tell the participants about contact(s) who would be happy to meet with them if they feel the need.
- Inform the participants that the theme of the next meeting will be **strategies related to keeping their secret** in various contexts. During this meeting, the participants will use the same non-disclosure scenarios as those used for this meeting.
- Mention to the participants that the first meetings are dedicated to the issue of disclosure and that the same number of meetings is dedicated to the issue of non-disclosure.

WEEKLY REFLECTION

- The participants are asked to think about what they learned during the meeting and to integrate it into their daily lives. The group will talk about how things went at the next meeting.

END OF THE MEETING

Rosa and Prudence: secrets and their consequences

Rosa

The positive and negative consequences of **not disclosing**

Recap of Rosa's situation

Rosa, a 42-year-old woman born in Quebec, has known that she is HIV-positive for 12 years. Rosa has no kids and has lived with her common-law spouse for 10 years. They aren't married. He was the first person she told about her HIV status, after her doctor and a nurse at the hospital. She maintains that she quit her job before being fired. To feel useful, Rosa sometimes speaks at schools.

Mom

When Rosa's brother told their mother, she didn't believe him and asked Rosa if it was true that she had HIV. Rosa denied it because her mother was very ill and she didn't want the news to make her condition worse. In this situation, Rosa truly believed that not telling her mother was the right decision, even though there are times when she wishes she could lean on her mother for support. Still, she knows that there are other people in her life who are there for her and that maybe, someday, if her mother's health improves, she can have a long talk with her.

Daily life

Rosa generally finds it easy to keep her HIV-positive status a secret. However, she admits that it can be difficult at times, like when she has to make excuses with certain people to explain her frequent visits to the hospital. This makes her feel like she isn't being authentic—like a part of her is hiding, living in the shadows, unable to express itself. On the other hand, she feels that this is personal information and that she is hardly the only one with secrets. What bothers her is why she should even have to hide her condition. It's not like she has anything to be ashamed about...but she knows that not everyone is as open and understanding as her husband and friend.

Prudence

The positive and negative consequences of **not disclosing**

Prudence's story

Prudence, a 32-year-old woman originally from Africa, has known that she is HIV-positive for 3 years. She thinks she became infected through sex with her first husband, who has since passed away. Prudence has two children, a 7-year-old son and a 3-year-old daughter. Both kids are HIV-negative. Prudence knew she was HIV-positive when she was pregnant with her daughter. She had remarried, to a man who didn't have the virus. When he found out she was HIV positive, he accused her of hiding her status so she could marry him. They separated and no longer live together.

Family

Prudence hasn't told anyone in her family and hardly any of her friends about her status, fearing they will reject her, so she just avoids the subject. Maybe she will tell them the truth someday but not until people with HIV aren't so discriminated against. For now, she finds the secret a heavy burden to bear. She sometimes feels isolated despite having joined HIV support groups and attending a few meetings. The problem is, every time she goes to one, she fears that people from the community will recognize her and tell people in her family, some of whom still live in Africa. It would be awful if her mother found out from someone other than her. Basically, Prudence feels like if she reveals her status, she won't be embraced and encouraged, so why bother?

The office

Prudence also has a part-time job, and her boss has no idea that she is HIV-positive. She believes that there's no point in him knowing since her condition hasn't affected her job performance. Plus, if she tells him, he might judge her and she could lose her job. Besides, this is personal information and it's not like they're close. One of her co-workers has seen a therapist for years and she has never told their boss. The only thing that worries Prudence is her insurance. She hopes her boss doesn't have access to her medical records.

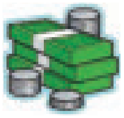
"My savings account"

Scenario

Indicate the non-disclosure scenario you have chosen

PROS	DEPOSITS (in terms of well-being)		
			+
			+
			+
			+
Total **PROS**			
CONS	WITHDRAWALS (in terms of energy)		
			+
			+
			+
			+
Total **CONS**			
GRAND TOTAL (Total **PROS** - total **CONS**)			

Well-being ← → Energy spent



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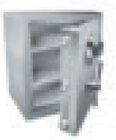
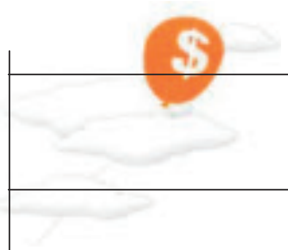




“My savings account”(example)

Scenario

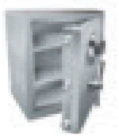
Indicate the non-disclosure scenario you have chosen

Not telling my kids

PROS	DEPOSITS (in terms of well-being)	
To keep them from being stigmatized	10	10
So they won’t be sad	10	10
	Total **PROS**	20
CONS	WITHDRAWALS (in terms of energy)	
Having to lie about my situation	6	6
Having to hide my medication	8	8
	Total **CONS**	14
GRAND TOTAL (Total **PROS** - total **CONS**)		6

Well-being ← → Energy spent

+ 10 0 10 -



MY SECRET CODE

- The participant should write their non-disclosure scenario on the line below.
- For each factor that favours and does not favour keeping their secret, the participant should select a winning condition, an asset, an obstacle and a strength. The participant then writes the number corresponding to each of these in the designated space to create their secret code.

Scenario

- **WINNING CONDITIONS** (conditions that favour keeping the secret)

1 Hiding my medications

2 Lying about the types of medications I take

3 Having people in my life who respect my desire not to talk about it

4 Not telling my young kids to make sure they don't reveal my status

5 Following my treatment as prescribed

6 Keeping certain people at a distance, etc.

7 ...

8 ...

- **ASSETS** (things that can make it easier to keep the secret)

1 Controlling my reactions to people's discriminatory comments or attitudes about HIV or people with HIV

2 Knowing my rights

3 Not talking about the side effects of my treatment

4 Staying active to avoid suspicion, etc.

5 ...

6 ...

- **OBSTACLES** (things that do not favour keeping the secret)

1 Rumours or doubts about me

2 Being "outed" by someone close to me

3 Broken confidentiality by a health professional

4 Disease, hospitalization

5 Taking medication

6 Lipodystrophy or lipoatrophy

7 Not breastfeeding, early weaning of my baby

8 Situations where there is a realistic possibility of sexual transmission (where the person has a legal duty to disclose their status under threat of criminal prosecution)

9 Situations where there is a possibility of transmission through blood

10 The fear and stress of being discovered

11 Feeling like I have to tell

12 No longer being able to work as I did before because of my health, etc.

13 ...

14 ...

- **STRENGTHS** (things that can be done to overcome the obstacles preventing you from keeping your secret)

1 Inventing another disease

2 Denying the rumours and doubts being spread about me

3 Ignoring the rumours and doubts being spread about me

4 Demanding that people stop spreading gossip about my status or face action from the human rights commission

5 Hiding when I take my medication

6 Telling people I have to take antibiotics if anyone sees me taking my medication and questions me

7 Feeling ok about keeping my secret, etc.

8 ...

9 ...

MY SECRET CODE

Indicate the number corresponding to each of the elements below.

MEETING 8

One, two, three, HUSH!

Overview

Meeting 8 | One, two, three, HUSH!

OBJECTIVE OF THE MEETING

To get the participants to use what they have learned to develop strategies for keeping their secret.

DURATION

‣ 3 hours

REQUIRED MATERIALS

+ A logbook for each participant
+ A blackboard or flip chart, plus chalk or markers
+ “My secret recipe!” activity sheet
+ An index card of strategies that can be used to keep the secret for each participant (“My strategies card”)
+ Scissors for each participant
+ Glue sticks
+ Coloured pencils, crayons or markers
+ A pen for each participant

Optional:

+ The stories of Prudence and Rosa (“And sometimes Rosa and Prudence don’t tell” activity sheet)

MEETING PLAN

1. Welcome ‣ 15 minutes
2. Presentation of the theme and objective of the meeting ‣ 5 minutes
3. Activity: “Let’s share our secrets” ‣ 40 minutes

   Break ‣ 15 minutes
4. Activity: “My secret recipe” ‣ 1 hour
5. Closing activity: “I can live with my secret” ‣ 30 minutes
6. Thoughts on the meeting ‣ 15 minutes

   End of the meeting

Meeting 8 | One, two, three, HUSH!

OBJECTIVE OF THE MEETING

To get the participants to use what they have learned to develop strategies for keeping their secret.

DURATION

- 3 hours

REQUIRED MATERIALS

- A logbook for each participant
- A blackboard or flip chart, plus chalk or markers
- “My secret recipe!” activity sheet
- An index card of strategies that can be used to keep the secret for each participant
- Scissors for each participant
- Glue sticks
- Coloured pencils, wax crayons or felt markers
- A pen for each participant

Optional:

- The stories of Prudence and Rosa (“And sometimes Rosa and Prudence don’t tell” activity sheet)

MEETING PLAN

15

1. WELCOME

REVIEW OF THE PREVIOUS MEETING

- The facilitator asks the participants to reflect on the previous meeting. The following question is asked and the participants are invited to share their answers:
  - *“How did the last meeting help you assess the possible consequences of keeping your secret in various situations?”*

5

2. PRESENTATION OF THE THEME AND OBJECTIVE OF THE MEETING

- The facilitator tells the participants the title of the meeting: One, two, three, HUSH!
- **Objective**
  + to use what they have learned to develop strategies for keeping their secret

NOTE TO FACILITATOR

Throughout the meeting, the facilitator should:

+ support the participants along their journey to disclose or not disclose their HIV-positive status
+ encourage the participants to support each other's journeys
+ not place value judgements on participants' decisions, be it to disclose or not disclose their HIV-positive status

40

3. ACTIVITY: "LET'S SHARE OUR SECRETS"

3.1 SHARING ▸ 30 minutes

- The facilitator encourages the participants to share a past or present experience related to keeping their secret (it would be best to include a person who is having or has had a positive experience and one who is having or has had a more difficult experience).
  + *Can you tell us about the downsides of keeping your secret?*
  + *Is there someone who would like to share a positive experience related to keeping their secret?*
  + *Is there someone who would like to share a negative experience related to keeping their secret?*

VARIATION

+ The facilitator can introduce this exercise by reading the stories of Rosa and Prudence ("And sometimes Rosa and Prudence don't tell" activity sheet) and can then ask the participants to list the "pros" and "cons" for Rosa and Prudence of keeping their secrets.

3.2 MANAGING YOUR SECRET ▸ 10 minutes

- Next, the facilitator asks the participants to share some of the strategies they have used to keep their secret (or to discuss the strategies used in the stories of Rosa and Prudence, where applicable) as well as other strategies they have heard about.
- The facilitator divides the board into three categories:

  1- Managing the secret of your HIV status
  2- Managing the issue of your medications
  3- How to react after you have been "outed"

The facilitator asks the participants the following questions and writes their responses in the appropriate category. The facilitator completes the board with the content elements in the box below.

- *What are the secret-keeping strategies used by the participants who shared their experiences?*
- *Do you know of or intend to use other secret-keeping strategies?*

- Finally, the facilitator asks the participants about the ways in which they can prepare themselves for being "outed" and writes their responses in the appropriate category. The facilitator completes the board with the content details in the box below.
  - *How can you prepare yourself for being "outed"? What is the best way to react if someone reveals your status without your consent?*

CONTENT DETAILS: MANAGING YOUR SECRET

Strategies for keeping your secret (here is a possible list)

- looking into people's attitudes about HIV and people living with HIV; asking a social worker, the hospital's psychosocial team or a health professional for guidance about your decision; hiding your medications; taking your medications in private; saying you have another disease, etc.

Example of strategies grouped into three categories:

Managing the secret of your HIV status

- Looking into people's attitudes about HIV and people living with HIV
- Asking a social worker, the hospital's psychosocial team or a health professional for guidance on your decision
- Telling white lies
- Talking to someone you trust about your secret, etc.

Managing the issue of your medications

- Hiding your medications
- Taking your medications in private
- Saying you have another disease, etc.

How to react after being "outed"

- Filing a complaint with the human rights commission
- Contacting HIV advocacy and defence groups
- Asking the person to respect the confidentiality of your medical status
- Reacting calmly and coolly
- Not fearing the worst
- Getting support
- Speaking to those concerned
- Denying it, etc.

VARIATIONS

- The facilitator hands out information that participants can use to get help in the event that their status has been disclosed (for a list of publications, see Appendix 1).
- Other brochures and resources addressing the non-disclosure issue can also be given to the participants (for a list of publications, see Appendix 1).

BREAK ▸ 15 minutes ◂

60

4. ACTIVITY: “MY SECRET RECIPE”

- The facilitator reads the “My secret recipe” activity sheet to the group and then asks the participants to create their secret recipe individually.
- The participants are asked to answer the following questions:

1. *With whom and in what situations do you feel it is best to keep your secret?* (Identify the specific person(s) or scenario(s).)
2. *Why do you prefer not telling these people or not disclosing in these situations?* (Specify your reasons and motivations for not telling.)
3. *Do you intend to tell these people or disclose in these situations at some point?* (If so, indicate when and where you might do this.)
4. *Are you sure that this is the best decision for you?*
5. *What, if any, of these people’s personal characteristics influenced your decision to not tell them?* (Determine the characteristics that influenced your decision to not tell them.)
6. *Do you feel equipped to deal with people’s suspicions that you are HIV-positive?*
7. *How would you react to being “outed”?*
8. *Has anyone ever pressured you to make this decision?*
9. *How will you go about keeping your secret?* (What strategies do you plan to use to keep your secret?)
10. *To what extent do you think it is possible for you to keep these people from finding out about your status if you use these strategies?*
11. *Does keeping your secret affect you in your daily life?*
12. *How do you cope with your secret? How do you minimize its effects on you in your daily life?*

- The facilitator then invites the participants to share their answers to questions 9 and 12.

TIP

+ The facilitator gives each participant a card listing various secret-keeping strategies. This card will allow them to create alternate strategies they can use in other situations where they wish to keep their secret.

▸ Finally, the facilitator reviews the exercise with the participants.

+ *What ingredients do you have in your recipe? What ingredients are you missing? Do you think you could add other ingredients to your recipe?*
+ *Now that you've created your secret recipe, do you see things differently when it comes to keeping your secret?*
+ *Now that you have a secret code (see Meeting 7) and a secret recipe, to what extent do you feel equipped and comfortable keeping your HIV-positive status a secret?*

VARIATIONS

+ This exercise can also done in groups of two. Ideally, a participant who is keeping their status a secret in one context should be paired with another participant who is keeping their status a secret in the same situation.
+ This exercise can also be done individually with the facilitator if participants are offered individual support.

30 5. CLOSING ACTIVITY: "I CAN LIVE WITH MY SECRET"

▸ Using their logbook, the participants illustrate or write how they can lighten the burden of their secret or better manage it by being more comfortable with their HIV-positive status.

TIPS

+ The participants are encouraged to use their imagination.
+ Ideally, the participants should have access to magazines, newspapers, stickers, cardboard, scissors, etc.

▸ The facilitator invites the participants to share their thoughts on tools they can use to manage their secret.

VARIATION

+ If there isn't much time left for the review activity, the facilitator can ask the participants to give just one word that stuck with them during the exercise.

15

6. THOUGHTS ON THE MEETING

- The participants are asked how they felt about the meeting and are each given around 2 minutes to express themselves.

VARIATION

▸ Impact technique using expression

A word, feeling, colour or number

+ The participants can be asked to answer the question using a word, feeling, colour or number (e.g., on a scale of 0 to 10, where 10 means they feel very good). The facilitator can then ask the participants to elaborate if they feel this would be helpful and appropriate.

source: Beaulieu, D. (2006). *Techniques d'impact en psychothérapie, relation d'aide et santé mentale*. Québec, Québec. Impacts! Éditions, 310 pages, © 1997.

- The facilitator asks the participants what they liked about the meeting and what they didn't like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions to improve the meeting.
- The facilitator tells the participants that they can put their activity sheets in their logbooks.

TIP

+ The facilitator can write what the participants said on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.

IMPORTANT NOTES

- Give the participants a few minutes to talk if they feel uneasy. A subsequent meeting can be scheduled, if needed.
- If required, tell the participants about supportive contacts who would be happy to meet with them if they feel the need.
- Inform the participants that the next meeting will be the last group meeting. The facilitator can state the theme of the meeting (what message they would share with other people living with HIV when it comes to the issue of disclosure), without revealing the surprise activity (group mural).
- Mention to the participants that the meeting might go over 3 hours and that they should plan accordingly.
- Tell them that there will be a potluck and ask everyone to bring a cold dish. Ask the participants who will bring what and if anyone has food allergies or foods they do not eat.
- Finally, if the venue permits, offer to bring music that the participants can listen to during the surprise activity.

WEEKLY REFECTION

- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives. The group will talk about how things went at the next meeting.

END OF THE MEETING

My secret recipe !

Here are the main ingredients needed to make your secret recipe a success!

Create your recipe by indicating the amount of each ingredient you have on hand and other ingredients that you could get later.

NOTE: Answer the questions on the following pages before making a list of the ingredients you have.

Feel free to be creative and to add other ingredients to make YOUR recipe unique!

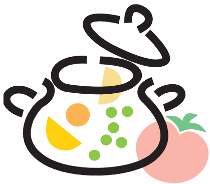
I made the decision to not reveal my HIV-positive status in this situation:

____.

Ingredients	amount on hand	buys later
Decision	____________	☐
Motivation	____________	☐
Certainty	____________	☐
Knowledge	____________	☐
Skills	____________	☐
Abilities	____________	☐
Support	____________	☐
Strategies	____________	☐
_ _ _ _ _ _	____________	☐
_ _ _ _ _ _	____________	☐
_ _ _ _ _ _	____________	☐
_ _ _ _ _ _	____________	☐
_ _ _ _ _ _	____________	☐

The amount you indicate is fictitious and is only used to determine whether or not you have this ingredient.

Motivations



- **Why do you intend not to reveal your HIV-positive status to these people?**

____

____

____.

- **Do you intend to tell these people at some point?**

  ☐ Yes ☐ No

- **If so, when and where do you intend to tell these people?**

____.

Certainty

- **Are you sure this is the best decision for you**? ☐ Yes ☐ No

Knowledge

- **What, if any, of these people's personal characteristics influenced your decision to <u>not tell</u> them?**

☐ Age ☐ Health status ☐ Proximity (lives far from me), etc.

Others characteristics:

____

____

____

____

____.

Skills

- **Do you feel equipped to deal with these people's questions or suspicions about your HIV status?**

  ☐ Yes ☐ No

- **If these people were to "out" you, would you react to this breach of confidentiality?**

  ☐ **Yes** ☐ **No**

If so, how?

____

____

____.

Support

- **Did anyone pressure you to make this decision?**

  ☐ **Yes** ☐ **No**

Strategies

- **What strategies do you use to keep your secret from these people?**
- **It is feasible for you to keep your secret from these people if you use these strategies? On a scale of 1 to 5, indicate to what extent you feel that each of these strategies is feasible.**

Strategies	Not at all feasible				Very feasible
1.	1	2	3	4	5
2.	1	2	3	4	5
3.	1	2	3	4	5
4.	1	2	3	4	5
5.	1	2	3	4	5

Well-being

- **How do you live with your secret?**

- **How does keeping your HIV status affect you in your daily life?**

- **How do you cope with your secret? What are your tricks?**

- **Indicate other ingredients that you think you should add to your recipe.**

Source: O'Connor, Stacey, Jacobson. (2004). *Guide personnel pour la prise de décision*. Ottawa Hospital Research Institute. Website: http://decisionaid.ohri.ca/francais/index.html

MY STRATEGY CARD

Cut out a copy of this card for each participant

Strategy Card

- ✓ Hiding your medications
- ✓ Taking your medications in private
- ✓ Checking into people's attitudes about HIV and people living with HIV
- ✓ Asking a social worker, the hospital's psychosocial team or a health professional for guidance on your decision
- ✓ Telling white lies
- ✓ Talking to someone you trust about your secret
- ✓ …

And sometimes Rosa and Prudence don't tell

Rosa

Non-disclosure strategies

Recap of Rosa's situation

Rosa, a 42-year-old woman born in Quebec, has known that she is HIV-positive for 12 years. Rosa has no kids and has lived with her common-law spouse for 10 years. They aren't married. He was the first person she told about her HIV status, after her doctor and a nurse at the hospital. She maintains that she quit her job before being fired. To feel useful, Rosa sometimes speaks at school.

Common-law spouse

Although Rosa's common-law spouse was the first person she told about being HIV-positive, it took 6 months for her to share the news with him. At first, she told him that she had tuberculosis and had to take medication because her immune system was weak. During that time, she would find any excuse to avoid having sex with him. Since she didn't want to tell her mother either, she was relieved to hear that her mother didn't believe her brother when he told her that Rosa was HIV-positive. From that point on, she became very careful around family and friends and stuck to the code of conduct she created for herself. For example, she takes her medications in private and is careful never to leave pamphlets on HIV lying around. Whenever her mother visits, she inspects her home first. And she feels free to call upon her brothers to help her deal with trickier situations.

Mom

Prudence

Recap of Prudence's situation

Prudence, a 32-year-old woman originally from Africa, has known that she is HIV-positive for 3 years. She thinks she became HIV-positive through sex with her first husband, who has since passed away. Prudence has two children, a 7-year-old son and a 3-year-old daughter. Both kids are HIV-negative. Prudence knew she was HIV-positive when she was pregnant with her daughter. She had remarried, to a man who didn't have the virus. When he found out she was HIV-positive, he accused her of hiding her status so she could marry him. They are now separated and no longer live together.

Non-disclosure strategies

Family

Prudence hasn't told her family that she is HIV-positive. She prefers to not talk about the subject except in general terms and even then she checks herself, taking care not to react too personally. On the other hand, she sometimes talks about having a "friend" with the disease to gauge her family's reactions. It's sort of her way of talking about it without revealing that she has HIV herself. Recently, she bumped into someone from her community while at an appointment at the hospital and the person asked her what she was doing there. She said she was visiting a friend, which was sort of true because one of the nurses has almost become a friend after all the time she has spent there. These situations always make her uncomfortable, but fortunately she's quick on her feet and has lines prepared in case she bumps into someone she knows

Community

A mother who lives far away

Prudence also has a few tricks she uses when she calls her mother. For example, when she feels the need to talk about her health, she talks about her symptoms in a more general way because HIV symptoms can mirror those of other conditions and talking about her health in this way allows her to be comforted by her mother.

MEETING 9

Participants’ messages

Overview

Meeting 9 | Participants' messages

OBJECTIVE OF THE MEETING

To encourage the participants to reflect on what they got out of the program and to express their solidarity with other people living with HIV

DURATION

- 3 ½ hours (may vary by group)

REQUIRED MATERIALS

- A logbook for each participant
- A large piece of cardboard or a large piece of fabric (to make the mural)
- Scissors for each participant
- Glue sticks
- Coloured pencils, crayons or markers
- Various magazines
- A device to play music
- A selection of music

MEETING PLAN

1. Welcome ▸ 15 minutes
2. Presentation of the theme and objective of the meeting ▸ 5 minutes
3. Review of "My first page" ▸ 40 minutes
4. Activity: "Participants' messages" ▸ 1 hour 30 minutes, variable duration
5. Closing activity: "Potluck and final thoughts on the program" ▸ 1 hour

End of the meeting

Meeting 9 | Participants' messages

OBJECTIVE OF THE MEETING

To encourage the participants to reflect on what they got out of the program and to express their solidarity with other people living with HIV

DURATION

- 3 ½ hours (may vary by group)

REQUIRED MATERIALS

- A logbook for each participant
- A large piece of cardboard or a large piece of fabric (to make the mural)
- Scissors for each participant
- Glue sticks
- Coloured pencils, crayons or markers
- Various magazines
- A device to play music
- A selection of music

MEETING PLAN

15

1. WELCOME

REVIEW OF THE PREVIOUS MEETING

- The facilitator asks the participants to review the previous meeting. The following question is asked and the participants are invited to share their answers:
  - *"How did the last meeting help you plan strategies related to keeping your secret?"*

5

2. PRESENTATION OF THE THEME AND OBJECTIVE OF THE MEETING

- The facilitator tells the participants the title of the meeting: **Participants' messages.**
- **Objective**:
  - To see what the participants gained from the program and for them to express their solidarity with other people living with HIV

*

NOTE TO FACILITATOR

Throughout the meeting, the facilitator should:

- support the participants along their journey to disclose or not disclose their HIV-positive status.
- encourage the participants to support each other's journeys
- place no value judgements on their decisions, be it to disclose or not disclose their HIV-positive status

40

3. REVIEW OF "MY FIRST PAGE"

- The facilitator asks the participants to take out their "first page," which they completed during the first meeting of the program (the welcome meeting).
- The facilitator asks the participants to take turns sharing what they learned during the program and how this ties into what they wrote on their first page (what they hoped to get out of the program).
  - *What did you get out the program?*
  - *Would you say that the program met your expectations?*

IMPORTANT NOTE

- Given the nature of the activities involved in this final meeting, let the participants know there will be no scheduled break but that each participant can take a short break at some point if they feel the need.

4. ACTIVITY: “PARTICIPANTS’ MESSAGES”

* This activity may vary depending on the number of participants and the amount of time the participants spend on it.

4.1 GROUP MURAL ▸ 1 hour

- The facilitator asks the participants to think about the question below. The participants then draw and write down their thoughts or messages using the materials provided by the facilitator (cardboard, fabric, canvas, etc.):
  - + *What message would you give to other women living with HIV who have concerns surrounding the disclosure of their status?*
- The idea is for the participants to COLLECTIVELY create a message of solidarity with other women living with HIV.

TIPS

+ For this exercise, it would be helpful to guide the participants as they create the group mural. The facilitator can draw inspiration from the content details in the box below.

+ The facilitator can also play music to create a more relaxing and creative atmosphere.

CONTENT DETAILS: GROUP MURAL

Guiding the participants in their creation of the group mural:

What are the objectives of the group mural?

1. To develop a positive sense of belonging within the group.

2. To allow the participants to express their message of solidarity through art.

How can group artwork be created?

To make this effort successful, the facilitator should encourage the participants to:

+ use their imagination

+ work together and respect others’ ideas and ability to do this type of creative exercise

+ come up with strategies that will promote teamwork (e.g., one person can write, another can draw, another can look for images from the magazines provided, etc.)

The facilitator should emphasize to participants that they don’t need to be artistic to work on this activity and that everyone’s contribution is essential.

CONTENT DETAILS: GROUP MURAL (CONTINUED)

The steps involved in making the mural:

Step 1: Inspiration

+ The participants should reflect on the theme of the mural (messages to women living with HIV who have concerns surrounding the disclosure of their status) and think of a message they would like to convey.
+ For this step, the participants should determine the message as a group.
+ Once they determine the message, they find words, colours, shapes or images from magazines that they can use to express this message.

Step 2: Development

+ The participants draw, write, colour or paint the message they want to express using markers, paint and images.

Step 3: Observation

+ The participants look at the mural to ensure that the people they are creating it for will intuitively understand their message and know that they are supported.

Step 4: Final touches

+ If they wish, the participants can choose a background colour. While some of the participants work on part of the mural, others can paint the background or help those who have not finished their part.

Fifteen minutes before the end of the activity, the facilitator tells the participants how much time is left to complete the mural.

* **The facilitator can also work on the mural with the participants.**

4.2 REVIEW ▸ 30 minutes

- The facilitator asks the participants what they think of the group mural.
- Where applicable, the facilitator can ask the participants' permission to take a few pictures of the mural, which may be published on the organization's website to promote the program.
- With the participants' help, the facilitator hangs the mural on a wall.

5. CLOSING ACTIVITY: “POTLUCK AND FINAL THOUGHTS ON THE PROGRAM”

- While the participants share the potluck meal, the facilitator asks them to express what each group member has taught them.

- In closing, the facilitator asks the participants to suggest other themes they would have enjoyed exploring.

TIPS

- The facilitator can write the participants’ statements on a piece of paper or on the board. This exercise allows the participants to talk about the new skills, beliefs and attitudes they learned from each other.
- The additional themes the participants suggest could also guide program improvements or could be considered as subjects to be explored in future group meetings.
- If the organization and its resources permit, tell the participants they can continue to meet whenever they wish. They could create an informal support group where they could get together over coffee to chat or further explore subjects discussed during the program meetings.

IMPORTANT NOTES

- The facilitator suggests that the participants stay in touch so they can support each other in the future.
- The participants can also assign one of themselves to serve as a resource person that the others can call on for support and comfort, if they need it.
- Finally, the facilitator suggests that the participants exchange contact information so they can stay in touch.

END OF THE PROGRAM

EXAMPLES OF GROUP MURALS

APPENDICES

Documents to share with participants

APPENDIX 1

Documents to share with participants

The resources in this list may be out of date. Please consult reliable sources and www.catie.ca for the most up-to-date resources and information.

MEETING 3: LEARNING TO LIVE WITH HIV

HIV and Pregnancy

BROCHURES

- Health and Social Services. (2012). *Enceinte ou vous pensez le devenir*. [Dépliant]. s.d, Government of Quebec. (French only)
- CATIE. (2012). *You can have a health pregnancy if you are HIV positive*. Toronto: CATIE. Available online: http://orders.catie.ca/product_info.php?products_id=25424
- Women's College Hospital. (2010). *Information for women who are diagnosed with HIV during pregnancy.* Toronto: CATIE. Available online: http://orders.catie.ca/product_info.php?products_id=25774
- Women's College Hospital. (2010). *Information for HIV+ new moms*. Toronto: CATIE. Available online: http://orders.catie.ca/product_info.php?products_id=25776
- Women's College Hospital. (2010). *Pregnancy planning information for HIV+ women and their partners*. Toronto : CATIE. Available online: http://orders.catie.ca/product_info.php?products_id=25772

HIV and Women

BOOKLETS

- Positive Women's Network. (2011). Pocket guide for women living with HIV. Vancouver: PWN. Available online: http://orders.catie.ca/product_info.php?products_id=25878
- Positive Women's Network. (2013). Pocket guide on aging for women living with HIV. Vancouver: PWN. Available online: http://orders.catie.ca/product_info.php?products_id=25989

MEETING 4: LIFE SITUATIONS

BROCHURES

- COCQ-SIDA. (2010). Folder « *Nous vivons avec le VIH/sida et nous sommes des personnes à part entière avec des besoins, des rêves, des ambitions et … Les mêmes droits que vous* ». (French only) Available online: http://www.cocqsida.com/mediatheque/publications/les-memes-droits-que-vous.html
- Jobin, Catherine pour Aide Suisse contre le Sida. (2002). *Protection des données – protection de la sphère privée : une brochure destinée aux personnes vivant avec le VIH/sida, aux employeurs, assureurs et médecins*.

Switzerland: Aide Suisse contre le Sida et Office fédéral de la santé publique 2009. (French only)

Available online: http://www.sida-vs.ch/prevention/protection-donnees-protection-sphere-privee.html

- Terrence Higgins Trust. (2007). *Making decisions about telling people you have HIV: Your decision.*

  London: Terrence Higgins Trust.

  Available online:

  http://www.aidsmap.com/v634467753923330000/file/1050135/Your_decision_October_2007_pdf.pdf

- Southern African AIDS Training Programme (SAT). (2004). *Counselling guidelines on disclosure of HIV status*. Zimbabwe: Canadian International Development Agency. Available online: http://catalogue.safaids.net/sites/default/files/publications/counselling%20guidelines%20disclosure.pdf

FACT SHEETS

- Canadian HIV/AIDS Legal Network. (2012). *HIV disclosure and the law*: A resource kit for service providers Available online: http://www.aidslaw.ca/site/hiv-disclosure-and-the-law-a-resource-kit-for-service-providers/

MEETING 6: SHARING TO BETTER SUPPORT EACH OTHER

Information on HIV/AIDS and available treatment

- CATIE practical guides and booklets. Available online: http://www.catie.ca

PRACTICAL GUIDES

- Managing your Health: A Guide for People Living with HIV
- A Practical Guide to Complementary Therapies
- A Practical Guide to HIV Drug Side Effects
- A Practical Guide to HIV Drug Treatment for People Living with HIV
- A Practical Guide to Nutrition for People Living with HIV

BOOKLETS

- HIV & AIDS Basic Facts
- HIV disclosure: A Legal Guide for Gay Men in Canada
- HIV and Emotional Wellness
- Just Diagnosed with HIV
- Living with HIV and Hepatitis C Co-infection
- Living with HIV: Starting Points
- Pozitively Healthy: A Gay Man’s Guide to Sex and Health in Canada

- Pre-fix: Guide for People with Hep C or HIV Who Inject Drugs
- You Can Have a Healthy Pregnancy if You are HIV Positive

MEETING 8: ONE, TWO, THREE, HUSH!

Information on Disclosure

BROCHURE

- Perinatal HIV Research Unit. (n.d.). *Telling others that I am HIV positive*. Johhannesburg, South Africa: Perinatal HIV Research Unit. Available online: http://www.womenchildrenhiv.org/pdf/p05-vc/vc-03-04.pdf

Information to help participants access support in case of a breach of confidentiality of their HIV status

SERVICES AND WEBSITES

- COCQ-SIDA. (2010). *VIH info droits*. Montreal: COCQ-SIDA. Please see: http://www.cocqsida.com/ressources/ vih-info-droits.html or contact COCQ-SIDA in the Montreal area: 514-844-2477 ext.34, outside of Montreal (toll-free): 1-866-535-0481 ext. 34 or by email vih-infodroits@cocqsida.com

- Commission des droits de la personne et des droits de la jeunesse. (n.d.). Filing a complaint Government of Quebec . Please see: http://www.cdpdj.qc.ca/en/plainte/Pages/default.aspx

- Government of Quebec (2011). Charter of Human Rights and Freedoms. Available online: http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/C_12/C12.html

- Canadian HIV/AIDS Legal Network. (2012). *HIV Disclosure and the Law: A Resource Kit for Service Providers* Available online: http://www.aidslaw.ca/site/hiv-disclosure-and-the-law-a-resource-kit-for-service-providers/

- Canadian HIV/AIDS Legal Network. (2014). *Know Your Rights brochures series*. Available online: http://www.aidslaw.ca/site/kyr/

APPENDIX 2

Canadian Resources on HIV/AIDS

For information on HIV services across Canada, visit www.HIV411.ca
or contact CATIE:

CATIE
555 Richmond Street West, box 1104
Toronto, Ontario
M5V 3B1
Tel: 1800-263-1638
Email: info@catie.ca
Web: www.catie.ca