

Practical Tools for Surviving and Thriving with Ongoing Loss: An Intervention Framework for Long-term Multiple Loss Survivors



"Before the retreat I had seen myself as pretty 'on-course' with my life. I'm HIV-positive. I've just come to accept this as my 'lot in life'. After the retreat my perspectives changed – I saw everything, including myself, differently. It has been a challenge to move from accepting this 'lot' - to a place where I actually take an active role and responsibility for my life. Since the retreat, I have felt angry, depressed, frustrated, elated, ecstatic, happy ... (at least I am feeling these emotions now!) ... I am, simply, a thousand times happier than before."

'Survive and Thrive' Retreat Participant

Many PLWHAs and affected individuals have experienced community devastation due to HIV/AIDS. Assessing and addressing the impact of AIDS-related multiple loss requires specific tools and unique models to support people at every stage, from loss to re-investment.

The AIDS Bereavement Project of Ontario conducted a community-based research project to develop an intervention framework with relevant theory and peer support strategies. It involved a series of 2-day retreats with 67 long-term survivors (LTS) of HIV/AIDS across four pilot sites.

Participants were:

- 67 long-term survivors, majority were males in their 40's
- 86% HIV-positive, with average 12 years with HIV
- average total number of AIDS-related deaths that individuals had experienced was 148
- 77% said that loss changed their belief system in some way

Tools in the Intervention Framework include:

1

Gathering Stories

- Multiple Loss Assessment Questionnaire
- 'The Tree of Life'

Pre-retreat Themes	3 Weeks Following Retreat	3 Months Following Retreat
MULTIPLE LOSS ASSESSMENT QUESTIONNAIRE • All retreat participants indicated that they have experienced Physical and Emotional Effects from their grief/loss, including either insomnia or fatigue. • The top 5 Emotional Effects participants relate to their grief/loss: Depression, Anxiety, Stress, Anger/ Frustration, Hopelessness	MEASURING RELATIVE FREQUENCY OF ATTITUDES AND EMOTIONAL STATES • Participants feel less depressed, less lonely, and less guilty for still being alive, less worried or concerned about their future, less like withdrawing from social activities. • Retreat participants also indicate that their grief/loss no longer affects their sex drive as much as before.	• Participants feel "happier about the way life is going" and continue to feel "less depressed"; "anxious/lonely"; "less guilty for still being alive"; "less afraid of dying"; and that "sex continues to be more important in their lives." • Participants also indicate the importance of "recognizing their losses" and "understanding their feelings."
'CLIMBING THE TREE OF LIFE' • Illness fatigue: some participants report being "worn down" and "fatigued" by living with a long-term, episodic and debilitating disease as described in HIV/AIDS research. • Coping and Multiple Loss: some participants report being "beaten by HIV", with isolation and withdrawal as a means of coping with effects of multiple loss; "watching life from a distance" and feeling "lonely, dependent and hopeless."	MEASURING SELF-PERCEPTION AND OVERALL REFLECTION • Many participants indicated that they felt like they had fallen from the tree and were now "struggling to get back on," some state that they were on an "emotional roller coaster" and were "feeling exhausted, less able to cope and fragile!" Quotes: - "Trying to cope, start the climb" - "Lost in the crowd of others in the background" - "Not sure if it's a good move" - "Holding on to what I can"	• Three months following the retreat participants described feeling "angry," "depressed/alone," "tired of life with HIV," and about so many losses" and "at least I am feeling these emotions now!" • Some participants described feeling "stuck" and "having trouble getting going," some identified "being at a crossroads in life," and some were "looking back and to the future to seek answers."

'Climbing the Tree of Life'



"Picture yourself as a child on this tree. Describe how this child represents where you feel you are at this moment in your life."

This qualitative exercise facilitates a reflective process for participants to express self-perception. Participant statements were pooled and analyzed for thematic content, generating the 'Helpful Indicators' below.

2

Normalizing Loss Experiences

with presentation and materials about AIDS-related multiple loss theory and facilitated group exercises and discussions.

Body Map Collage Exercise – Using the Body Map, make a collage depicting the impact of loss on you:

- **physically**
- **emotionally**
- **mentally**
- **spiritually**
- **sexually**
- **socially**

What They Showed Us



Depression Blues



I Can't Breathe



HIV Hideaway/
Angry Activist



A Bad Taste in
My Mouth

3

Identifying Coping Strategies

WHAT IS LOST?

- What gets you through?
- What more might help?

WHAT IS LEFT?

- Making meaning
- Legacy

WHAT IS POSSIBLE?

- New identity as a Long-term Survivor
- Imagining possibilities

Long-term Survivor Integration Process: Helpful Indicators

Elements of the process of integrating multiple loss with current identity may include people describing the following states of being:

"FALLEN"

- State of detachment from community.
- Opening to reconnection to life.

"STRUGGLING TO GET BACK ON"

- Active involvement towards reconnection.
- Opening to healing.

"EXHAUSTION/FATIGUE/FRAGILE"

- The physiological and psychological impact of doing healing work.
- Opening to change.

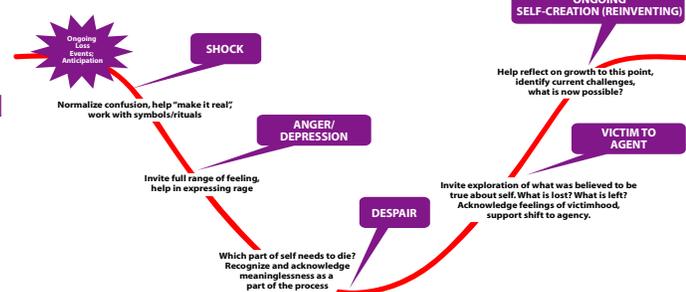
"LESS ABLE TO COPE"

- Result of changing coping strategies, a necessary stage.
- Opening to new expression.

"ON AN EMOTIONAL ROLLER-COASTER"

- Opening up to suppressed feelings and personal pain.
- Opening to learning of new coping and resiliency strategies.

Interventions in AIDS-related Multiple Loss



Legacy Work: Long-term Survivor Support = Nurturance of Living History

Community, organizational and individual recognition of the impact of multiple loss, in the context of HIV health promotion and prevention strategies, results in:

- Creating opportunities for Long-term Survivors to re-invest in themselves and each other.
- Improved appreciation of the role of multiple loss in depression; integrating strategies of resiliency in programs designed to improve quality of life.
- Better services to community members through addressing the impact of AIDS-related grief on a Long-term Survivor's ability to sustain practices related to health promotion and healthy sexuality.

It also builds bridges to members of marginalized communities, by recognizing that:

- Peer support is an essential mechanism for individuals to develop common language and meaning.
- Strong supportive group experiences can assist people to make personal changes and to develop purposeful engagement in the present and future.