

BEING HEARTFULLY ENGAGED

Creating Healthy Grief
Maintenance Strategies for
Workers in our AIDS Service
Organizations

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Why Grief and Loss and ASOs?

- Grief and Loss is central to our experience in coping with HIV
- Helpers are ill prepared with a knowledge of grief & loss
- ASO clients and caregivers (personal and professional) are experiencing multiple losses, disenfranchised grief and complicated mourning
- ASOs are experiencing the negative impact of multiple losses resulting in decreased organizational functioning- impaired communication, decreased organizational capacity outside ASO, and decreased capacity to maintain skilled staff (due to emotional exhaustion) within ASOs.
- These challenges are continuing to occur within ASOs at a time when ASOs are coping with transition, reduced funding, and more complex and diverse client populations.

Why Project Sustain?

- **Canadian Evidence**

- Cain (1993, 1994, 1995, 1997) documenting the history and challenges of ASOs.
- AIDS Bereavement Project of Ontario Evaluation (Gibson & Plotnick, 1997)
- Gervais (1998) Multiple Loss qualitative study within an ASO

- **Negative Impact on Organizational Functioning and Mental Health documented (ABPO, Gervais)**

- **Creative Coping Strategies observed in a climate of AIDS Multiple Losses within an ASO (Gervais)**

- **Organizational Interventions to assist in healing losses also assists with worker resiliency (ABPO)**

Project Sustain

- **Collaboration - ABPO & Researcher**
 - Vancouver, Winnipeg, Halifax-Atlantic
 - ACAP, Health Canada & MOH Ontario
- **Purpose & Activities**
- **Develop tools of assessment unique to ASO culture (February 1999 – April 2000)**

Quantitative and Qualitative assessment and comparison of multiple loss, organizational transition, and methods of resiliency within ASOs in 3 regions in the country
- **Develop tools of support and healing (February 1999 – present)**

Provide ASO organizational support through education and facilitation with individuals, staff groups, administration (executive and board members), community organizations.
- **Develop tools for sustained resiliency (April 2001 – March 2002)**

Identify and train local resource people from 4 regions in Canada, and develop training resources (manual)

Project Sustain Findings

- ASO workers across Canada are:

- Coping with complicated grief characterized by unresolved personal, professional and organizational losses because of AIDS grief and multiple loss
- Physically and socially experiencing isolation
- Fatigue and inadequate sleep as a primary symptom identified with grief
- Experiencing physical pain, especially headaches and back/neck pain
- Workers are exacerbating these problems by overworking as a coping strategy to avoid/cope with grief or deal with the endless demands where insufficient resources exist

Project Sustain Findings

- ASO workers across Canada report the Emotional Impact of grief and the energy demands of AIDS Work result in:
 - Sadness or Depression
 - Numbness
 - Anxiety
 - Anger
 - Tearfulness

Project Sustain Findings

- **Organizational characteristics:**
 - Staff Turnover and Burnout
 - Irritability
 - Emotional Outbursts
 - Co-workers are not used as frequently as expected
 - Grief has a negative impact on care and communication within an ASO
 - Denial of or unaware of impact of grief

Project Sustain Findings

- ASO Workers are coping with Additional Organizational Challenges:
- Uncertain program planning due to the fast changing, diverse, and non-homogeneous client population
- Ambivalent commitment of volunteers
- Uncertain provincial support and financial and skilled personnel resources
- Perpetual state of crisis while needs are more complex and diverse

Project Sustain Findings

- **AIDS Workers also identify:**
- **A Positive Impact of AIDS Work and**
- **Positive Coping Strategies**

Project Sustain Findings

- **Differences across regions:**
 - **Organizational size and current organizational and community challenges**
 - **Age and years of experience of workers**
 - **Primary population they were serving**
 - **Extent the organization was able or ready to create a strategic plan and locate resource people in their own communities**

Project Sustain Recommendations

- 1) ASO grief strategies need to be organizationally, community and culturally specific
- 2) Reduce the impaired communication patterns within ASOs
- 3) Create and maintain a healthy understanding and climate for the sharing of grief
- 4) Encourage and support creativity and a healthy, balanced commitment to the work

Project Sustain Recommendations

- 5) **Advocacy to secure funding to address and highlight the unique organizational and grief challenges**
- 6) **Future national collaboration and education or training**
- 7) **Development of organizational grief resource manual**
- 8) **Future research**

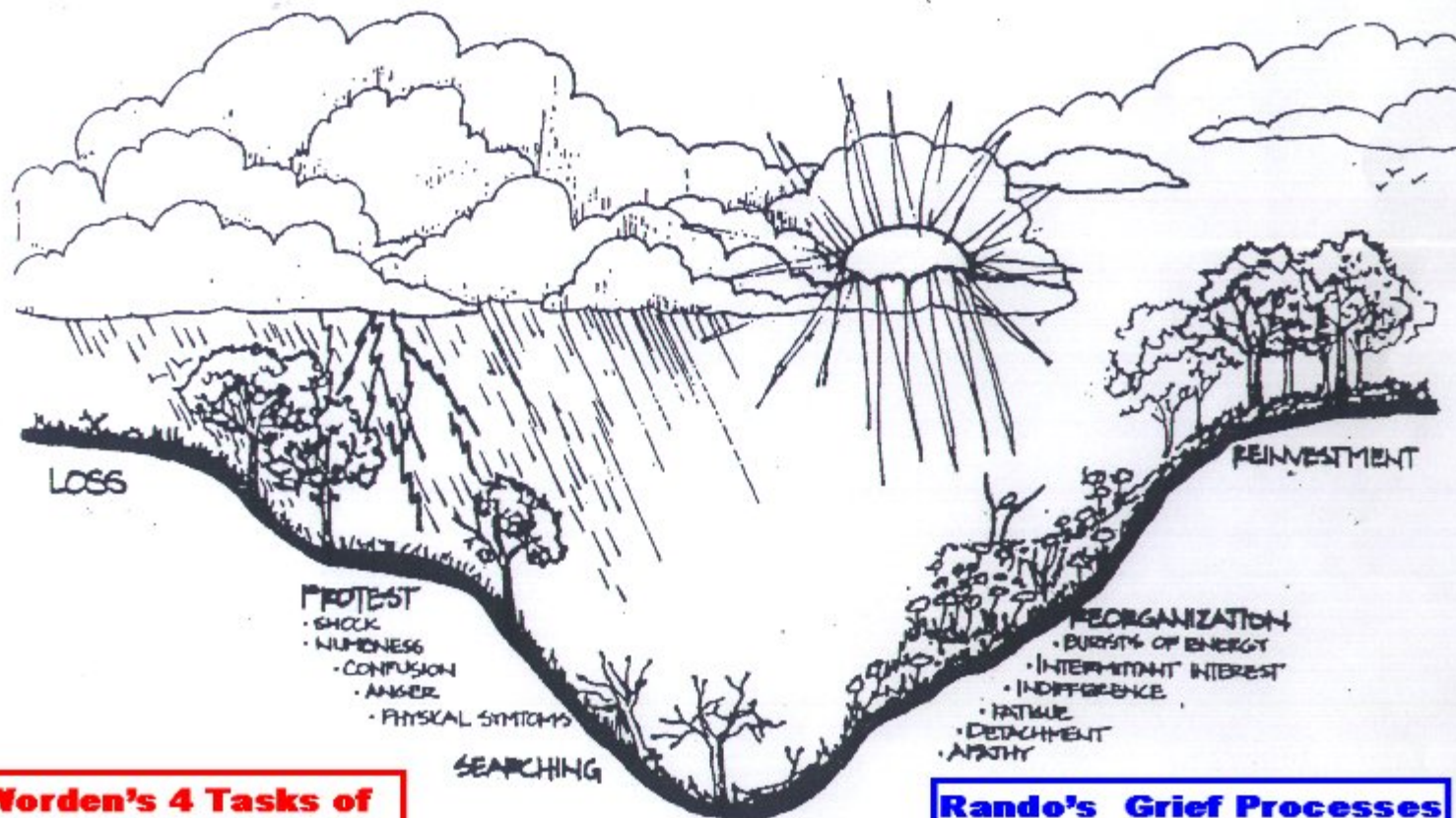
The Evolving Theory that Guides Us

- **Single Loss Theories**
- **Disenfranchised & Complicated Grief Concepts**
- **Trauma, Disaster, Stress & Coping Literature**
- **Social, Political and Cultural Context of HIV**
- **Multiple Loss Frameworks**

Single Loss Grief Theory

Worden's Four Tasks of Mourning	Bowlby's Phases	Theresa Rando's Grief Processes
<ol style="list-style-type: none">1. Accept the Reality of the Loss2. To Experience the Pain of Grief3. To Adjust to an Environment in which the deceased is missing4. To Withdraw Emotional Energy and Reinvest it in new relationships	<ul style="list-style-type: none">• Loss• Protest• Searching• Despair• Reorganization• Reinvestment	<ul style="list-style-type: none">• Avoidance• Confrontation• Reestablishment

THE JOURNEY OF GRIEF



Worden's 4 Tasks of Mourning

1. To Accept the Reality of the Loss
2. To Experience the Pain of Grief
3. To Adjust to an Environment in Which the Deceased is Missing
4. To Withdraw Emotional Energy and Reinvest in Another Relationship

Rando's Grief Processes

1. Avoidance – Shock, denial and disbelief
2. Confrontation – Highly emotional state where grief is the most intense
3. Reestablishment – Gradual decline of grief and beginning of an emotional and social reentry back into the everyday world.

Bowlby's Phases

SIGNS & SYMPTOMS of Grief – by William Worden (1991)

<p><u>Feelings</u></p> <p>Sadness/crying Anger/rage Helplessness Guilt Anxiety/panic Loneliness Tired Shock and numbness Longing Relief</p>	<p><u>Physical</u></p> <p>Hollowness in stomach Tightness in chest & throat Sensitivity to noises Sense of Depersonalization Disconnected Breathlessness Weakness Lack of Energy Dry Mouth</p>
<p><u>Thoughts</u></p> <p>Disbelief: not true Confusion Preoccupation Sense of presence of dead Hallucinations No hope Crisis of faith Obsessive review of details of death</p>	<p><u>Behaviors & Actions</u></p> <p>Sleep Disturbances Restlessness/ Over-activity Appetite disturbances Absent minded Social & Sexual Withdrawal Dreams of the dead Avoiding reminders of the dead Searching/ Visiting places Treasuring Objects</p>

Critique of Single Loss Grief Theory

- **Does not account for:**
 - **Complicated Mourning**
 - **Multiple Losses**
 - **Social, Political and Cultural Context of HIV**

Disenfranchised Grief

- **Grief that is not or cannot be openly acknowledged, publicly mourned or socially supported**
- **It complicates grief by reducing access to social supports or excluding mourners from roles that will assist with mourning**
- **It creates an intensifying of emotional reactions such as anger, guilt, and powerlessness**

Complicated Grief

- **Helps explain why an individual has not adjusted to a particular loss**
- **They are various types of complicated grief and various terms used to describe complicated grief**
- **Is related to the intensity or duration of a reaction**

Factors Associated with the development of Complicated Bereavement

- **Judgmentalness about the grieving process**
- **Lack of support from significant others and/or the community**
- **Past unresolved grief which influences the reaction to the current loss**
- **Restrictive values or beliefs about loss and/or grief**
- **Physiological or psychological illness**
- **Lack of information about normal grief**

Trauma, Disaster, Stress & Coping Literature

- Describes the impact where community trauma and devastation has occurred
- Describes the change in 'world view' that occurs
- Describes how people cope under stressful circumstances

Social, Political and Cultural Context of HIV

- Identifies the factors which contribute to discrimination, stigma, and social isolation
- Identifies the history and challenges of ASOs

Definition of Multiple AIDS – Related Loss

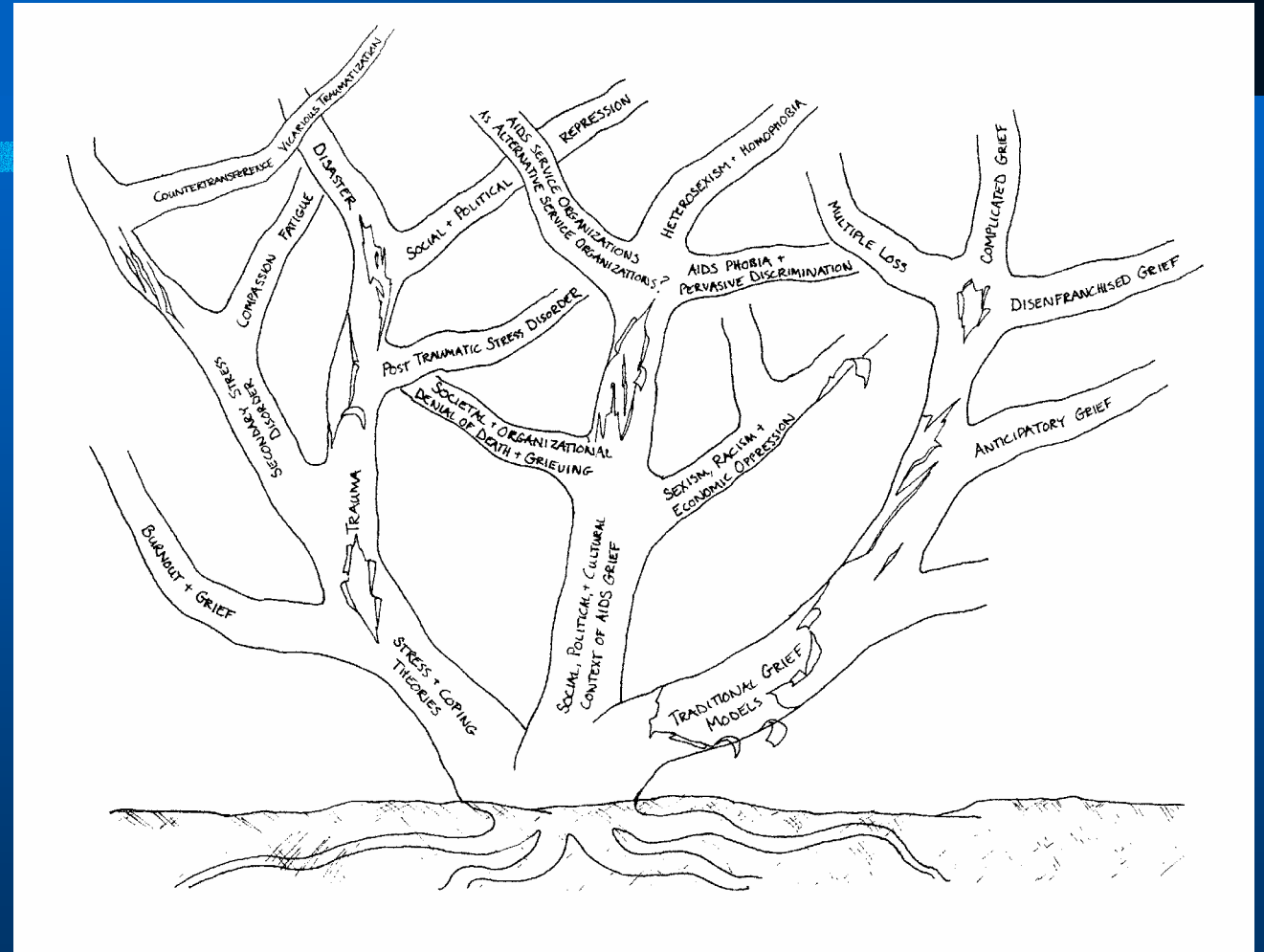
by David Nord

- **Deaths of Important People**
- **Loss of Social Support**
- **Loss of Future Plans**
- **Loss of Personal History**
- **Loss of Personality Characteristics**
- **Loss of a world that is not constantly overshadowed by death and dying**

AIDS MULTIPLE LOSS THEORY BRANCHES

At present our
Theoretical
Framework for
Multiple Loss is
Evolving from:

- Traditional Grief Theories
- Trauma, Disaster, Coping Literature
- The Social, Political, and Cultural Context of HIV



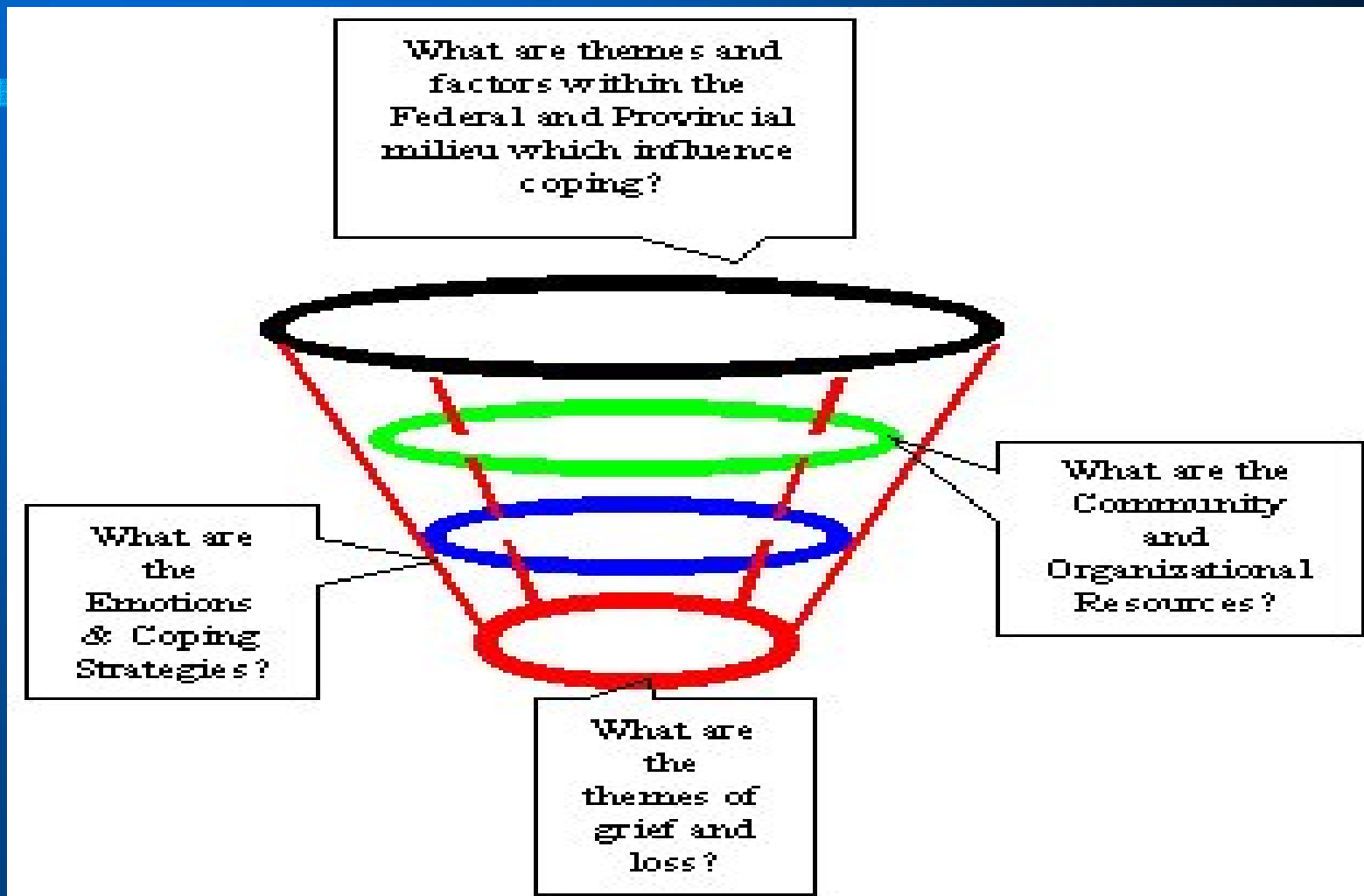
HIV-related Multiple Loss – Theoretical Grief

Cone – Gervais (1998)

- **Interconnected, Complex Layering that occurs with Multiple Loss**
- **Red Oval – The personal grief and losses**
- **Blue Oval – The Emotions & Coping Processes**
- **Green Oval – The Organizational and Community Resources**
- **Black Oval – The Social, Political and Cultural Context which contributes social Injustice & isolation, stigma, and discrimination**



HIV-related Multiple Loss – Theoretical Grief Cone



Negative Impact of HIV-related Multiple Loss

- Insufficient time to grieve before the next loss occurs creating ...
- Chronic and Compounded Grief
- “Bereavement Overload”
- “Death Imprint”

Negative Impact of HIV-related Multiple Loss

- **Negative Impact on Mental Health ...**
- **Increased Emotional Distress – Anxiety, and Anger, Survivor Guilt**
- **Depression, Suicidal Ideation, Sedative Use**
- **Increased Social Isolation & Social Stigma, and Reduction of Social Support**
- **Long Term Irreparable Effects on Mental Health**
- **Catastrophic Thinking & Change in World View**

Positive Impact of HIV-related Multiple Loss

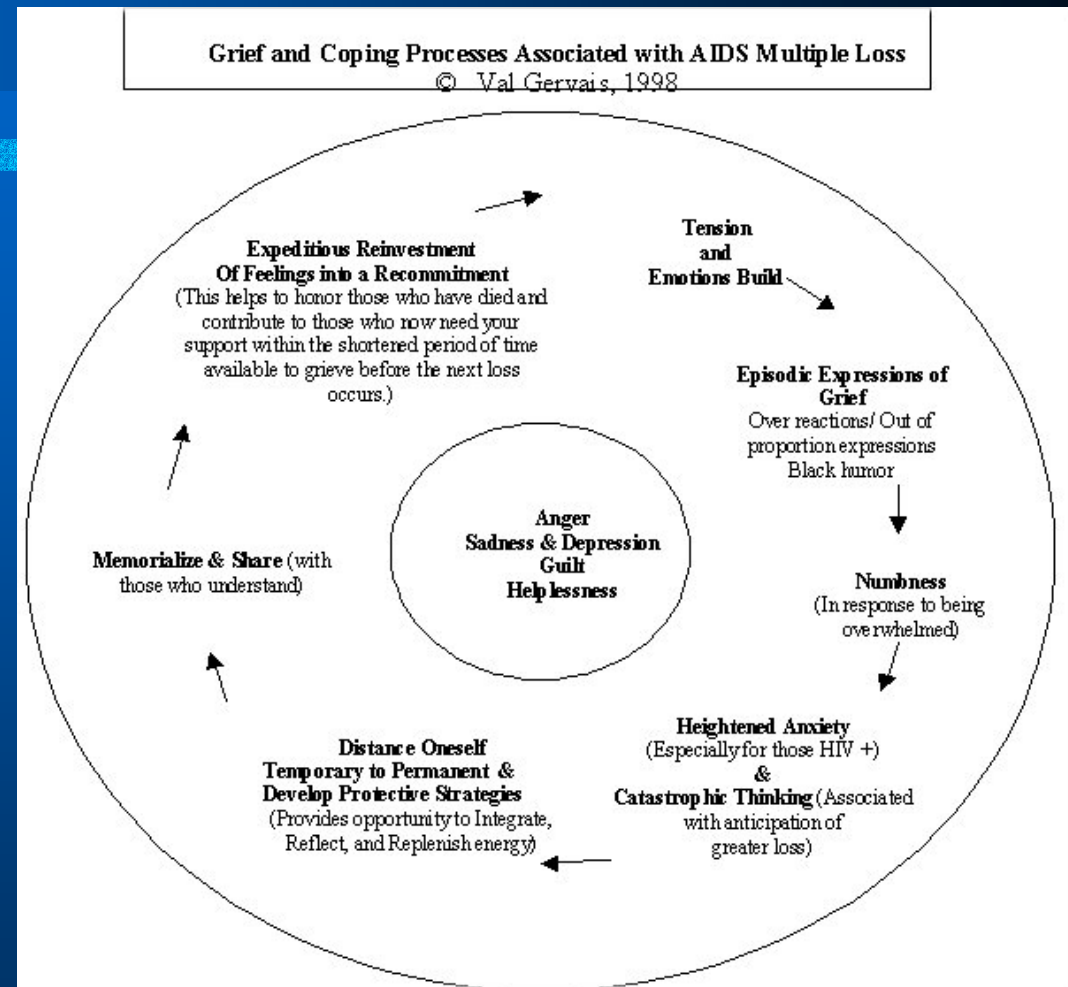
- Bereaved and Professionals working in a climate of multiple loss are known to be *“Resilient”*
- *“Adaptation”* to Multiple Loss is observed
- *“Creative Coping Strategies”* are identified

Resiliency to HIV-related Multiple Loss

- Multiple Loss Bereaved find *“meaning in their experience which helps honor their losses”*
- Multiple Loss Bereaved experience *“self discovery and personal growth”*, especially spiritual growth
- Multiple Loss Bereaved discover the *“importance of interpersonal relationships”*

Resiliency to HIV-related Multiple Loss

- **Multiple Loss bereaved have been known to have a “cyclical process of coping” by creatively investing their feelings into actions when there is insufficient time to grieve**



Resiliency to HIV-related Multiple Loss

- Multiple Loss bereaved need to *“build social supports”* and *“relate with at least one other person who has the lived experience”* of coping with multiple loss
- Ongoing and Consistent Self-Care

Resiliency to HIV-related Multiple Loss

- **Boundary Setting – Limit Activities and Roles that Provide Exposure to Multiple Loss**
- **Limiting or Being Selective in One's Participation in Grief Rituals**
- **Temporary to Permanent Forms of Emotional and Physical Distancing**

Resiliency to HIV-related Multiple Loss

- ***“Social Activism and Volunteerism”*** has helped both bereaved and professionals working with multiple loss find meaning in their experience
- ***“Personal and Community Rituals”*** assist in transforming the multiple losses

Resiliency to HIV-related Multiple Loss

- Bereaved achieve resiliency by focusing on coping strategies of ...
- *“Optimism”*
- *“Active Problem Solving”*
- *“Positive Reappraisal”*

Organizational Strategies for HIV-related Multiple Loss Resiliency

- An understanding of grief would be incorporated in all organizational policies, hiring practices & performance evaluations
- Informal and Formal Organizational Supports – Supervision, Counseling (EAP Program), Bereavement Workshops, Groups Supports, Individual and Community Rituals

Organizational Strategies for HIV-related Multiple Loss Resiliency

- **Ongoing Grief Education and Training**
- **Create Communal support with the Organization (shared mission and community of caring)**
- **Office design would incorporate connection with others and supportive environment for all bereaved with the ASO**
- **Use Research to document the impact of grief on ASO function and culture and as tool for further funding advocacy**

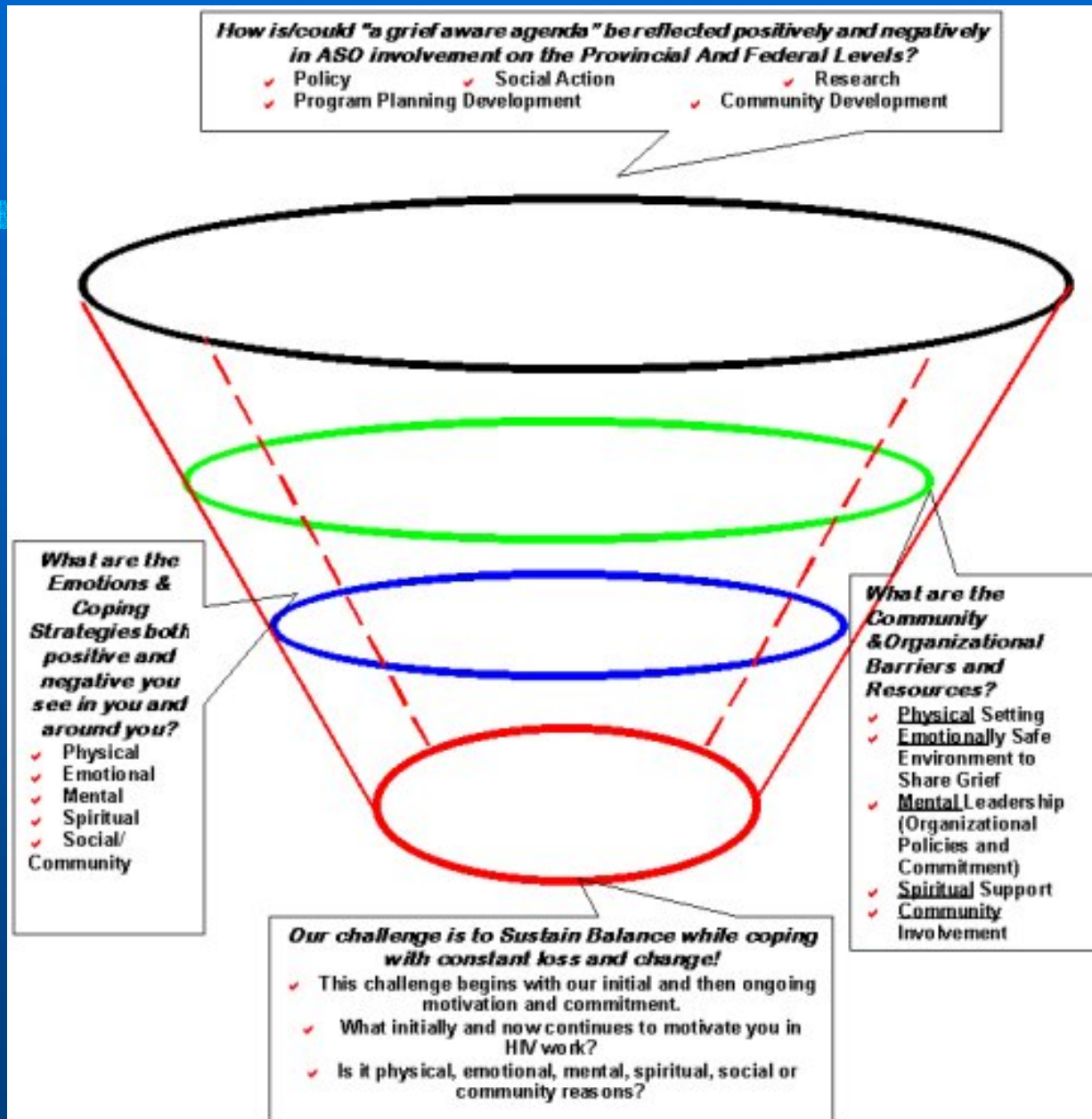
Project Sustain: Tools for Assessment and Resiliency

- **Organizational Readiness & Commitment**
- **Organizational Grief Assessment Cone**
- **Organizational Grief Facilitator**
- **Training and Workbook**

Organizational Readiness & Commitment

- **Assessing grief and loss manifestations (denial, crisis, saturation)**
- **Motivation and Participation**
- **Assessing group functionality, organizational capacity for change and stages of group development**
- **Previous experience in staff/team development**
- **‘Care for the Caregiver’ policies**

Organizational Grief Assessment Cone



This tool is based upon Gervais' 1998 Ethnographic Analysis of AIDS Grief and Multiple Loss within an AIDS Service Organization.

Roles and Tasks of Facilitators in Administering the Grief Cone Tool

- Identify the current individual, group and organizational responses
- Affirm and normalize the individual and organizational responses
- Identify the context barriers
- Identify on what level an intervention can occur
- Assist in identifying and set realistic collaborative practical individual and/or organizational strategies

Individual and Group Grief Assessment Tools

- **Assessing Impact of Loss**
- **What Sustains Workers? - Questionnaire**
- **Loss History Questionnaire**
- **Body Map**
- **Shifts in the Work**
- **Organizational Assessment Questionnaire**

Organizational Grief and Loss

Facilitator

- **Self-Awareness: Facilitator Questionnaire**
- **Knowledge of grief, multiple loss, facilitation, community-based orgs.**
- **Skills for integrating a holistic framework into both individual and organizational work**
- **Ability to develop interventions which identify and mitigate grief stressors and address depletion of workers**

Training and Workbook

- **Four-day facilitator's training in Toronto, Sept., 2001**
- **Fall, 2001 'Regional Resource People' from pilot regions will test SUSTAIN materials**
- **April, 2002, Workbook published: theory, intervention tools, workshop outlines & exercises, bibliography**

Tasks and Challenges for Caregivers and ASOs

- **Recognize that multiple loss bereaved may have a more familiar, intimate and comfortable relationship with dying and the dead than with the living**
- **Recognize that the central challenge for bereaved is to “balance the pain of loss with hope and commitment”**

Tasks and Challenges for Caregivers and ASOs

- ***“Normalize”*** the experience of the bereaved and ***“educate”*** them about grief and multiple loss
- Focus on current loss and assist bereaved in discovering the complex layering of multiple losses
- Encourage ***“peer support”***, ***“personal and community rituals”*** of healing

Tasks and Challenges for Caregivers and ASOs

- Help Bereaved “*link the loss*” to the social and political factors that have contributed to the pain (eg. Social Injustice, Stigma, Discrimination, Social Isolation)
- Explore “*Social Activism and Volunteerism*” with the bereaved which may help them invest their complicated feelings and experiences into meaningful activity

Tasks and Challenges for Caregivers and ASOs

- Assist bereaved in discovering ...
- Areas of “*personal growth and discovery*” created by their experiences with multiple loss
- “*Identify Self Care Strategies*”, “*Boundaries and Limit Setting*”
- “*Creative personal coping strategies*” which emphasize optimism, active problem solving and positive reappraisal

Tasks and Challenges for Caregivers and ASOs

- Provide Organizational Leadership and Commitment to incorporate an understanding of grief into policies and practices
- Listen attentively to our bereaved clients and Professionals working in a climate of multiple loss as they have much to teach us
- Remember Multiple Loss theory is evolving

The End

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WEB SITES

www.indiana.edu/~familygrf/units/culture.html

www.meb.uni-bonn.de/cancernet/306750.html

www.mhcs.health.nsw.gov.au/health-public-affairs/mhcs/publications/

www.talamasca.org/avatar/death-tasks.html

www.bereavement.org/

www.bam.on.ca/denning/grief.html

www.kirstimd.com/myths.html

www.mercer.edu/residence/griefand.html

www.rockies.net/~spirit/grief/griefA1.html

www.icomm.ca/ccvt/index.html

www.concentric.net.net/~Lismith/