



AIDS Bereavement Project of Ontario

“Survive & Thrive”

Long-term Multiple Loss Survivor Retreats

Practical tools for *surviving and thriving with Ongoing Loss*

2002-2005: Phase I and II - Participant Evaluation Report

October 2005



Acknowledgements

“Survive & Thrive”

Practical Tools for Surviving and Thriving with Ongoing Loss

The AIDS Bereavement Project of Ontario would like to thank the regional AIDS Service Organizations who participated in the organization of the local “Survive & Thrive” weekend retreats and follow-up sessions. We would also like to acknowledge the courage and strength of retreat participants who so beautifully opened themselves to this experience and took the time to complete evaluation materials, contributing the comprehensiveness of this evaluation.

In addition, we would like to thank members of the Provincial “Survive & Thrive” working group; and retreat facilitators for their invaluable contributions and support for this important initiative.

We gratefully acknowledge the financial support of the Ontario Regional, AIDS Community Action Program and the Ontario AIDS Bureau, Ministry of Health and Long Term Care whose funding made this project possible.

Lastly, we would like to thank Chad Leaver for the design and implementation of the 2005 evaluation initiative.

CONTACT US:

Yvette Perreault, Director
AIDS Bereavement Project of Ontario
571 Jarvis St., 2nd flr.
Toronto, M4Y 2J1

T: 416-205-9888 ext.24
E: yperreault@fifehouse.org



Table of Contents

TABLE OF CONTENTS

Background & Retreat Format	5
Evaluation Approach	6
Evaluation Results	8
The Collective LTS Experience	9
Evidence-based impact of “Survive & Thrive” Retreats	10
Retreat Impact by Community	12
Phase I & II Results - A Comparative Look	13
The Tree of Life	16
The Tree of Life - Retreat Impact - <i>The Changes</i>	17
Implications of Findings	20
Participant Evaluation - Graphs	22-52
Facilitation & Venue Rankings - Phase I & II	53
Overall Experience - Phase II	58
Constructive Comments	60
Constructive Enhancements	61
A Message to Facilitators	62
Participant Acknowledgements	63



Background - Retreat Format

“Survive & Thrive” Retreat Format

Recruitment and Participant Preparation Session

A community forum about multiple AIDS-related loss was organized by the host agency, held 2- 4 weeks prior to the scheduled retreat. It was essential that workers did personal outreach to community members to encourage participation.

Retreat Agenda - DAY ONE

Welcome:

Participants arrived to a full breakfast

Check-Ins:

Names and intent for attending this retreat, concerns about the event, establishing safety and security

Building the Container:

Introduced the premise of the ‘Survive and Thrive’ grant; reviewed housekeeping items and developed Group Guidelines.

Evaluation Component:

Introduction and informed consent of ‘Survive and Thrive’ evaluation surveys and an invitation to participants to complete questionnaires.

Presentation of Loss Theory:

Single Loss Journey and Interventions and Experience of AIDS-related Multiple Loss

Key Exercise:

Making A Collage - *Assessing the Impact of Multiple Loss.*

Checkouts:

Facilitators led a breathing exercise and brief visualization to help close the big feelings from the day.



Background - Retreat Format

“Survive & Thrive” Retreat Format - *Continued*

Retreat Agenda - DAY TWO

Welcome/Check-In:

How was your evening? What was your response to beginning to open to the reality of losses yesterday?

Collage Presentation:

Facilitator invited participants to present their collage and tell their story.

Debriefing:

How was it to do this exercise, to speak, to listen, to check-out?

Closure:

Retreat weekend closed with a breathing/centering exercise to help people reflect on their gains and connections with themselves and one another. Angel cards were offered as parting gifts. Participants were given a reminder of the 2 follow-up evaluation sessions.

Overall Participant Evaluation Exercise

This report presents overall participant evaluation from both Phase I and Phase II of the ‘Survive and Thrive’ weekend retreats, held through 2003 - 2005. In Phase I of the project we were interested in understanding the sustained impact of the retreat experience for participants. We thus developed an embedded longitudinal quantitative evaluation plan examining participant ratings across time, measuring participant ratings at baseline (before the retreat, immediately after the retreat; and at 3-weeks; and 3-months following the retreat).

Embedded Longitudinal Evaluation

3 Week (Post 1) and 3 Month (Post 2) Evaluation Sessions

An evening session for participants was held at 3 weeks and 3 months following the initial retreat. Participants took time to debrief/contribute to group session and complete the survey instrument. Follow-up evaluation documents and postage-paid return envelope were mailed to individual participants who were not in attendance at the follow-up sessions or for those locations where an in-person follow-up session was not possible.

Evaluation follow-up session components included:

- Meal for Participants followed by Check-In
- Check-in - ‘Reflections from the 2 days’
- Evaluation questionnaires completed



Evaluation Approach

Evaluation Approach

The retreat allows participants to explore more deeply emotional aspects of grief, loss and ongoing healing in a safe space with community peers. Retreats spanned two days and were conducted in four regional sites across Ontario, Canada. On-site accommodation and/or local travel costs were covered where appropriate.

We were interested in understanding the overall retreat experience and the initial and sustained impact of the “Survive & Thrive” retreats on persons attending; and subsequently designed a comprehensive evaluation plan that consisted of a self-complete questionnaire and qualitative reflection tool (Tree of Life) conducted at three intervals: 1) prior to the retreat, 2) three weeks; and 3) three months following the retreat.

Response Rate - Phase I & 2

Among the 70 persons who attended the retreats across Ontario, 67 completed the first phase of evaluation materials. Across the evaluation follow-up period Ottawa retained a 100% response rate; approximately 50% of participants were lost to follow-up in Toronto, London/Windsor and Guelph.

The overall provincial response-rate, from pre-retreat to three weeks following the retreat (80.5%) is sufficient for meaningful analyses. The second follow up period, 3 months enjoyed an overall response rate of 58%, still sufficient for a meaningful matched-pair analyses.

Similarly, for phase II, 68 participants completed participant evaluation forms.

Analysis Methodology

Descriptive statistics and pre/post matched pair (wilcoxon) analysis examined the impact of the Retreat on selected attitudinal and knowledge indicators. Analyses were conducted in SAS V8.12 and SPSS V.11. Evaluation findings are considered in the context of HIV and multiple loss and are summarized by region and province where sample sizes allowed for stratification. Phase II was not analyzed by region, due to small sample sizes of Long-Term Survivors within each regional area.



Evaluation Approach - *continued*

Evaluation Instruments

Quantitative Survey Design

- Personal background/characteristics (age, sex, gender, HIV Status)
- Community attachment
- HIV and Non-HIV related losses
- Physical and Emotional effects of grief and loss
- Counseling/Support/Therapy background and networks
- Involvement with AIDS Service Organization (ASO)
- Retreat and facilitator evaluation
- Grief / Loss Issues:
 - *blame, fear of dying, guilt, length of time grieving, support networks, understanding feelings, perspectives on sex and sexual well-being, alcohol and recreational drug use, emotional well-being, coping, community involvement, self-care.*

Qualitative Reflection Tool - “Climbing the Tree of Life”

- As an evaluation tool, the ‘Tree of Life’ is designed to engage participants in a reflective process about where they see themselves in their lives right now.
- Though the Tree of Life exercise was utilized as part of the broader pre-post evaluation protocol, the data are not subjected to a before and after analysis like the objective measures of the survey tool. Instead, the data are pooled at each testing interval and read for thematic content.
- It is not the intent of the Tree of Life exercise then to see if participants got ‘better’ or ‘worse’ after the retreat; instead, we were interested in the various ways that participants reflect on their lives at the beginning of the retreat, and at three weeks and three months following.



Evaluation Results

- ≈ **Overall Evaluation Findings:**
The Collective LTS Experience

- ≈ **Evidence-based Impact of ‘Survive & Thrive’ Retreats**
3 weeks (Post1)
3 months (Post2)

- ≈ **A Comparative Look at Phase I & II Participant Evaluation Findings**

- ≈ **Sociodemographic and Attitudes - Graphs and Data**

- ≈ **Retreat Facilitation and Venue Rankings**
Qualitative Summary and Rating Graphs



The Collective LTS Experience

The Collective LTS Experience

*Understanding Grief and Loss Among
Long-term Survivors (LTS) of HIV in Ontario*

In Phase I, the majority of “Survive & Thrive” retreat participants were male (79%), HIV positive (86%), and self-identified as gay (64%) or straight (19%). On average participants were 40 years of age (range: 34-63); and among HIV positive persons, have been living with HIV for approximately 12 years (range: 6-18). In addition, 56% of participants volunteered at their local AIDS Service Organization, with a small proportion (9%) currently employed as ASO staff.

In our evaluations we were interested in documenting the loss-history among Long-term Survivors (LTS). Across Ontario retreat sites, participants indicated experiencing, on average: 157 deaths related to HIV in their lifetime; and 76 deaths not related to HIV. Participants also indicated having experienced a number of ‘significant’ losses throughout their lifetime, such as: male relationships, partners/lovers, friends, family, career, income, health, body image, privacy, independence and pets, to name a few.

All retreat participants indicated that they have experienced Physical and Emotional effects from their grief/loss. While physical Effects from grief/loss are difficult to discern due to the likely high-correlation with side effects from HIV treatments, all participants indicate they have experienced “insomnia and/or, fatigue” that they personally associate as related to their grief and/or loss. The top 5 Emotional effects participants relate to their grief/loss include: Depression, Anxiety, Stress, Anger/Frustration and Hopelessness.

A total of 88% indicate having received professional support in the past for issues related to HIV status, sexuality, relationships, family and grief and/or bereavement. Among those receiving support, 84% receive support from such sources as: ASOs, friends, counselor or psychologist.

The vast majority, 86% of participants report having a ‘personal faith/belief system’ of some kind (we did not ask religious or spiritual denominations or affiliations). Among those indicating they have a personal faith/belief system, 77% indicated that their grief/loss related to HIV has changed their belief system in some way (i.e. heightened, shattered, sought new faith/belief system).



Evidence-based Retreat Impact

Evidence-based Impact of ‘Survive & Thrive’ retreats:

In the interest of understanding the initial and sustained impact of the retreat we asked participants to complete evaluation materials three weeks and three months following the initial retreat in Phase I. These evaluation materials consisted of the same questions that were asked prior to the retreat inclusive of the reflective ‘Tree of Life’ exercise. The ‘Tree of life’ exercise engages participants in a reflective process, composing written statements about where they see themselves in their lives right now.

In essence, the child chosen on the tree allows participants to compose their present perception of ‘self’ - or **self-perception**. Participant ‘Tree of Life’ statements were analyzed for thematic content at three weeks and three months following the retreat. Combined with the **attitudinal measures** from the questionnaire, our evaluation findings demonstrate a balanced understanding of the ‘grief-journey’ for those who attended the ‘Survive & Thrive’ weekend retreats.

Prior to the retreat participant’s tended to perceive themselves as ‘isolated’ and ‘withdrawn’ as a means of coping with the effects of worry, grief, loss, financial stress, etc, as though they were ‘watching life from a distance’ feeling ‘lonely, despondent and hopeless.’ A number of participants indicated that they had ‘illness fatigue,’ described in the literature as being worn-down emotionally, physically and psychologically from living with a long term, episodic, debilitating disease, many indicated that they saw this as ‘coming to terms with living with HIV’. Others indicated feeling ‘beaten by HIV’ yet wrote about the necessity of a ‘positive attitude’, or ‘taking one day at a time’.

Participant statements convey the understanding that while living with HIV has Long-term Survivors feeling on the periphery of community, family or social networks and results in them feeling lonely, despondent or hopeless, they have nevertheless come to accept this as the reality of living with HIV.



Evidence-based Retreat Impact

Evidence-based Impact of ‘Survive & Thrive’ retreats:

Three weeks following the retreat participants report feeling less depressed, less lonely, and less guilty for still being alive, less worried or concerned about their future; and less like withdrawing from social activities. In addition, participants also indicate that their grief/loss no longer affects their sex drive as much as before. Considering how participants perceived themselves 3 weeks after the retreat, 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.’ These responses are not surprising and are in accordance with the ‘grief-journey’ outlined above. At this stage, participants have begun a process of change and reflection.

Three months following the retreat participants report feeling ‘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’. Considering how participants perceived themselves 3 months following the retreat, most participants described feeling ‘angry.’ ‘depressed’ ‘alone’ and ‘tired of life with HIV’ and ‘sad about so many losses.’ Some described feeling ‘stuck’, ‘having trouble getting going’, ‘being at a cross-roads in life’, where they were ‘looking back and to the future to seek answers.’ Again, these responses continue to validate the experience of participants in the context of the ‘grief-journey’ and highlight the importance of continued support as Long-term Survivors increase community-engagement as a result of the retreat.

Summative Statement:

“Before the retreat I had seen myself as pretty ‘on-course’ with my life. I’m positive, and this affects every aspect of my life and relationship I have with others. I do not really see myself as a part of any ‘community’ or ‘circle’ per se. 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.”



Retreat Impact by Community - Phase I

	3 weeks following retreat	3 months following retreat
Ottawa	Participants feel less depressed; less worried or concerned about their future; and indicate that sex is more important to them.	Participants continue to feel less depressed and also feel anxious, lonely, less guilty for being alive; and less afraid of dying. Participants also indicate that their grief/loss no longer affects their sex drive, sex has become more important in their lives; and they feel like having sex more often.
Toronto	Participants feel less sad; less frustration with others; and indicate an increased ability to make new friends.	Participants increase volunteerism at local ASO. <i>Note: Very small Post2 sample size.</i>
London/ Windsor	Participants feel less like they should 'get on with it'; and less like withdrawing from social activities. Participants also indicate that their grief/loss does not affect their sex drive as much as before and they feel happier about the way life is going.	Participants feel less worried or concerned about their future.
Guelph	Participants feel slightly more sad 3 weeks following the retreat; however, participants also report feeling less like their grief/loss affects their ability to conduct their day to day activities.	Participants feel happier about the way life is going, less sad, lonely and depressed and less like there are not enough supports in their life. Participants also indicate the importance of recognizing their losses and more like they understand their feelings.



Phase I & II Results - *Comparative Look*

“Survive & Thrive”

A Comparative Look at Phase I and Phase II Participant Evaluation Results

The following section presents findings from Phase I and Phase II of the AIDS Bereavement Project of Ontario, Long-Term Survivor (LTS) weekend retreat sessions. Phase I includes sessions held between 2002 and 2004; and Phase II includes sessions held between 2004 and 2005. Long-Term Survivors were represented from all five Ontario Health Planning Regions: Northern; Central East; Central; Southwest; and Southern.

Note on evaluation instruments in Phase I and Phase II: Evaluation forms changed slightly between Phase I and Phase II, whereby a few questions were omitted from Phase II based on participant feedback from the Phase I form and the overall relevancy of the questions. In addition, overall retreat and facilitator evaluation sections were also slightly modified from Phase I and II.

A Comparative Look at Phase I & II - RESULTS

Selected Characteristics of Phase I & II Retreat Participants

The majority of Phase I and II participants were HIV-positive, were male and identified as Gay and had lived in their current city of residence for at least five years or more. Phase II had a greater proportion of HIV-Negative participants, primarily due to one retreat session focused entirely on Provincial AIDS Service Organization workers. There were also a greater proportion of women who participated in the Phase II retreats. The average age of participants increased from Phase I to II (40 to 44, respectively). The average number of years HIV positive participants had lived with HIV remained the same between Phase I and II participants, at 12yrs. One survivor has been living with HIV for, now, over 22yrs. In Phase II, half as many participants identify as Gay (64% vs. 32.4%). There was a significant increase from Phase I to II survivors who identify as Straight (5% vs. 44%); and more participants in Phase II identify as Queer. Cultural diversity was substantial in both Phases.

Participants from both Phases were highly identified with their PHA community; and gay communities. Phase II participants indicated a higher degree of connection to the women's community, this is likely due to a greater proportion of women who participated in the Phase II retreats.



Phase I & II Results - *Comparative Look*

Phase I & II Results - *Continued*

Multiple Losses

Phase I retreat participants indicated a very high number of losses in their life from HIV. This was largely due to many participants genuinely having more than 200 deaths that they were able to recall, and also a number of participants who indicated that there was “just too many for them to count”. In Phase II, it appears that provincial workers have experienced more deaths related to HIV than community-members. This is of course expected.

Non-HIV related losses are also substantial for participants from both phases, and range from losses of such things as trust, autonomy, faith, job, profession, vision and home. Emotional effects from loss were similar for participants from both phases, namely, depression, anxiety, stress, anger, frustration and hopelessness. Similarly, physical effects participants relate to their grief/loss or sorrow were also similar for survivors from both Phases, namely insomnia and fatigue. Other effects from loss included social and sexual withdrawal and difficulties creating friendships.

Attitudes towards Grief/Loss related to HIV

Phase I participants were slightly less likely than Phase II participants to feel that they should just get on with it (their life); and that their losses were somehow not real. Phase II participants were, however, more likely to feel like withdrawing from social activities than Phase I participants as an affect from their grief/loss; and that they were less able to take care of themselves and to believe that their grief/losses affected their use of alcohol or use of drugs for recreational purposes.

Phase I and II participants did not differ with respect to feeling like they have been grieving too long, that their losses are not important, adequacy of supports in their life, and their understanding of their own feelings. There was also no difference in Phase I and II participant ratings of how their grief/loss affects survivor sex life, ability to conduct their day-to-day activities, frustration with other or their ability to make new friends.

General frequency of feeling was also similar for participants from both Phases of the retreats, Phase II participants were no more likely than Phase I participants to feel sad, lonely depressed, unhappy about the way life is going. Phase II participants, however, were less likely than Phase I participants to be frustrated with sexual relationships.



Phase I & II Results - *Comparative Look*

Findings - Continued

Support Service History and Sources of Current Support

In total, 88% of Phase I participants had ever received support services in the past. Eighty-four percent of Phase I participants have received support in the past for issues related to HIV, 54% had received support for Bereavement or grief issues, 52% for relationship difficulties, and 51% for relationship difficulties. Additional past support had been received by Phase I retreat participants on issues with sexuality, work/career, and drug and alcohol use. This question was not asked to Phase II respondents.

Fifty-seven percent of Phase II participants report that they feel they do not have enough supports in their life; 26.5% report that they occasionally feel they do not have enough supports in their life; and only 13.2% acknowledged that they feel that they have enough supports in their life. Current support, for participants from both Phases was primarily the local AIDS Service Organization, friends, family and Counselor. Phase II participants were less likely to currently be receiving support from their friends, a psychologist, or a private therapist than Phase I participants; and more likely to be receiving support from their local ASO.



Tree of Life - *Phase I & II*



The “Tree of Life” is a qualitative exercise, facilitating a reflective process for participants to express their present **perceptions** of ‘self’ at the present moment.



Phase I Retreat Impact -The Changes

Pre-Retreat - Tree of Life Themes

Contentment: life is 'full' and 'complete' and participants have 'come to terms with living with HIV.'

Illness Fatigue: 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: participants report being 'beaten' by HIV, isolation/ withdrawal as a means of coping with effects of multiple loss (e.g.: worry, grief, financial stress); "watching life from a distance" and feeling "lonely, despondent and hopeless."

Post 1: Three Weeks - Quantitative Measures

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.

Post 1: Tree of life themes

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"*



Phase I Retreat Impact -The Changes

Post 2: Three Months - Quantitative Measures

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'.

- **Post 2: Tree of life themes:**
- Three months following the retreat participants described feeling "angry" "depressed" "alone" and "tired of life with HIV" and "sad about so many losses".
- Some described feeling "stuck", "having trouble getting going", "being at a cross-roads in life", where they were "looking back and to the future to seek answers."



Tree of Life - Phase I & II

The “Tree of Life” assessment tool data provided general thematic areas with which to better understand people’s lived experience of multiple loss. Elements of the LTS healing process 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.

I just choose to sleep it all away. (PH II - survivor)

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.



Implications of Findings

Implications for Support Workers & Volunteers

When working with LTS Clients:

Maintain an awareness of the process that is happening for them as they do multiple loss work

Recognize that the process of going deeper is an expected and natural outcome of multiple loss work, in the context of HIV/AIDS.

Awareness of LTS healing stages are the result of changing support structures and coping strategies.

Improve awareness and familiarity of effective ways to support people as they are changing their personal and community support structures and coping strategies. (i.e. supporting people feeling “Stuck”).

Improve awareness and familiarity models of support that can strengthen individual’s resiliency strategies and help people sustain changes over time.

Transference: conscious awareness to disconnect from grief/loss of clients and consider personal coping strategies and contributions to healing, growth, and understanding of individual grief/loss issues.



Implications of Findings - *Continued*

Helpful Indicators

Elements of the LTS healing process may include people describing the following stages:

“Fallen”

Detachment from community: Where life activity is.

“Struggling to get back on”

Doing the ‘work’ towards resiliency: Where healing is.

“Exhaustion/fatigue/fragile”

Impact of doing the ‘work’: The physiological and psychological impact of doing the ‘work’.

“Less able to cope”

Changing coping strategies: A necessary stage.

“On an emotional roller-coaster”

Opening up to suppressed feelings: Modes to release them.

Implications for Community

Understanding and recognition of multiple loss in the context of HIV on individuals.

Understanding and recognition of the emotional process of ‘doing this work’ for LTS.

Addressing the experience of isolation among Long Term Survivors through increased opportunity for community involvement.

Depression and Quality of live

LTS the nurturance of living history - we need to know ourselves.

In terms of resliency - pre - and is shaped by diagnosis = legacy work.

Getting people together to share discussions - social support, meaning ful contact, meaning from pain - helpful

Peer support - detachment - changing coping strategies - revolutionary , transformative

Specific areas information



Implications of Findings - *Continued*

“Legacy Work”

Long-term Survivor Support = Nurturance of Living History

Community, organizational and individual understanding and recognition of multiple loss in the context of HIV on individuals; and the emotional impact of doing this work.

- Better services to community members through strengthening of loss awareness and coping strategies
- Addressing the experience of isolation among Long-term Survivors through increased opportunity for community involvement.
- Creating opportunities for people’s re-investment in themselves and each other.
- Improved understandings of depression and strategies towards improved quality of life. legacy work.

Builds bridges to members of marginalized communities and to the broader community.

- Getting people together to share living histories provides social support and meaningful peer contact, facilitating language and meaning from pain from which ongoing healing occurs.
- Peer support is essential to individual’s processes of the transformative experience of changing coping strategies.



Participant Evaluations - *Graphs*

Participant Evaluation

Long-Term Survivors
- Weekend Retreat Experience

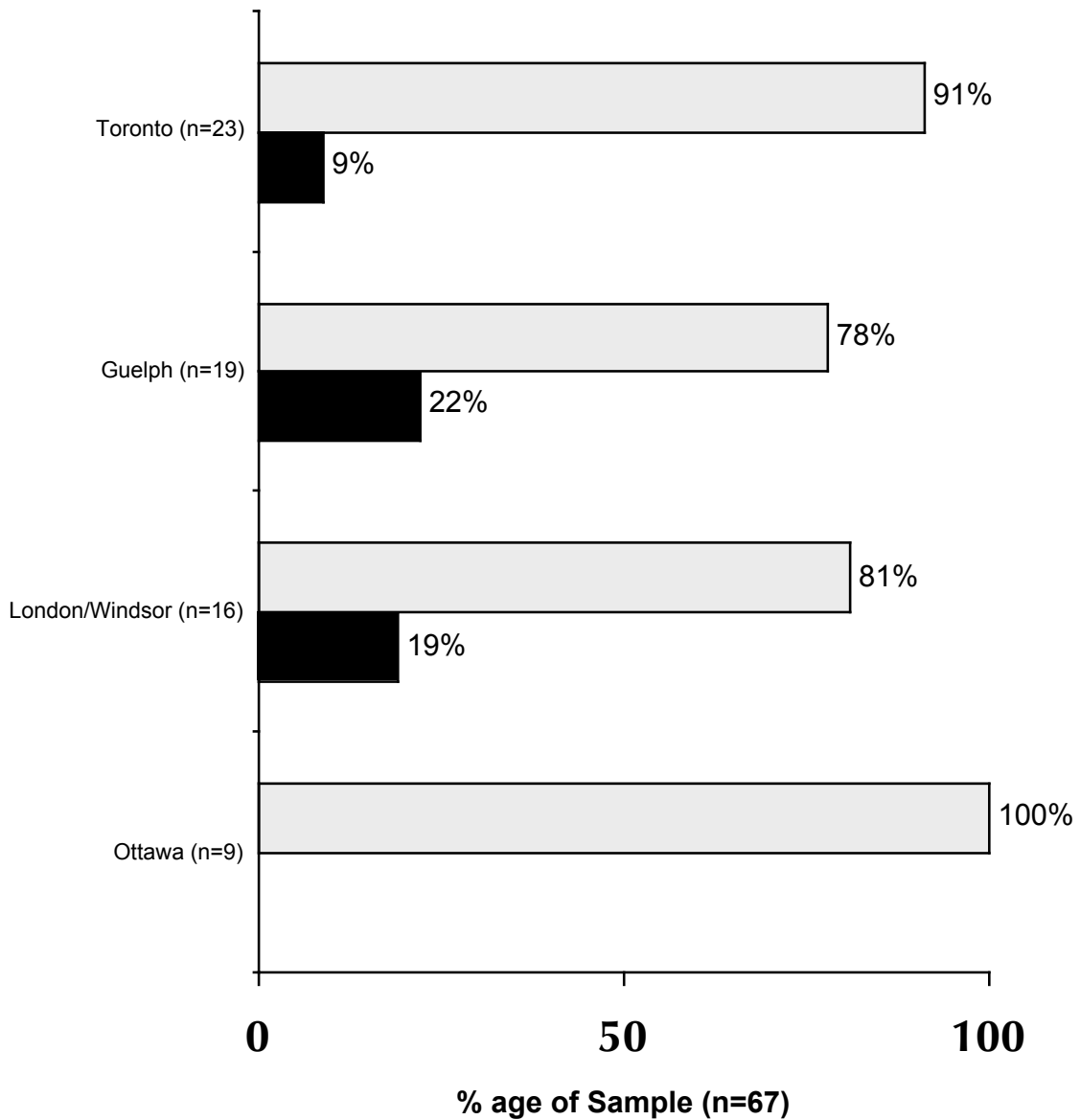
GRAPHS

- *PHASE I & II*



HIV Status by Retreat Site - Phase I

HIV Status by Retreat Site

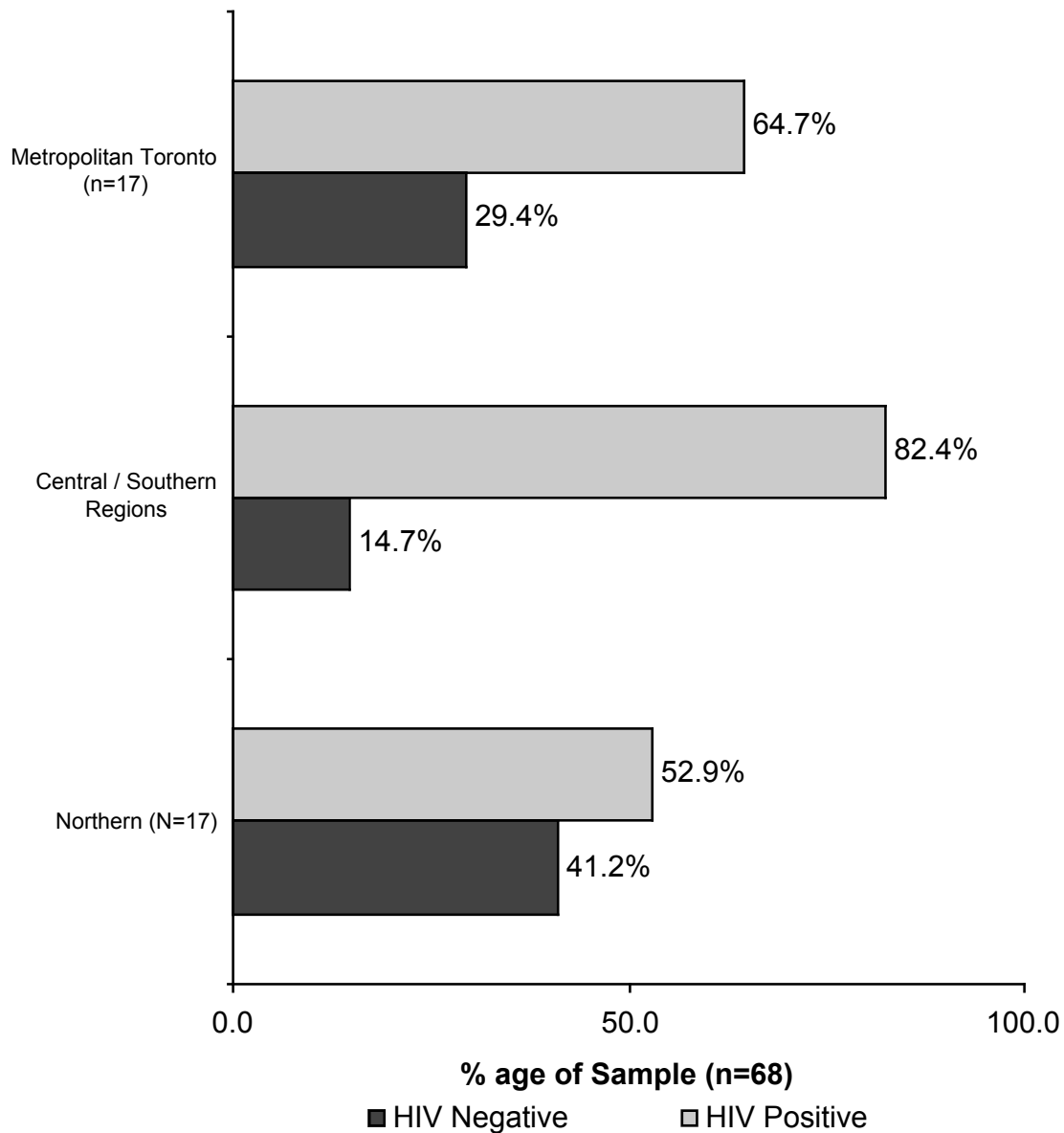


DQ1. Please indicate your HIV Status: HIV Positive, HIV Negative, Don't Know



HIV Status by Retreat Site - Phase II

HIV Status by Retreat Region



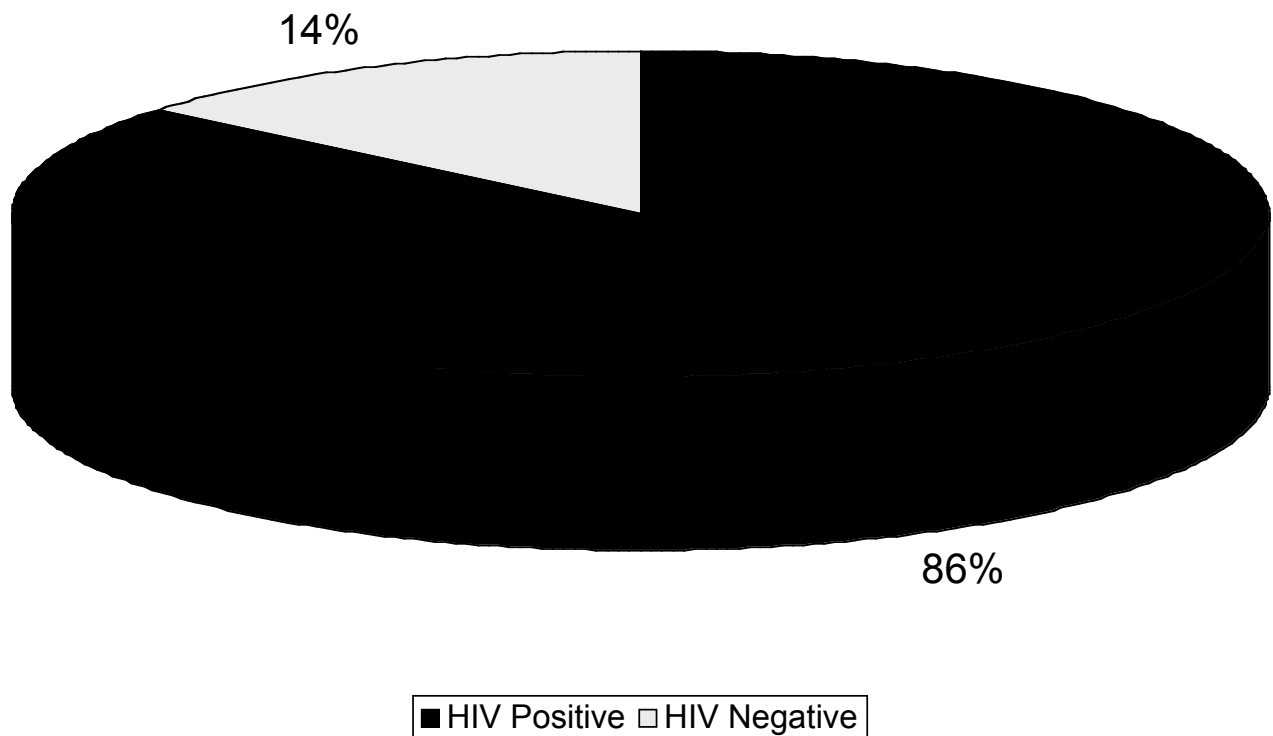
Q1. Please indicate your HIV Status: HIV Positive, HIV Negative, Don't Know

Note: One participant in Metropolitan Toronto and 1 participant in Central / Southern Ontario did not know their HIV Status at the time of the retreat. One person in the Northern region did not report their HIV Status.



HIV Status - Ontario - Phase I

HIV Status - Ontario



Average # of Years living with HIV/AIDS: 12 [range: 6-18]

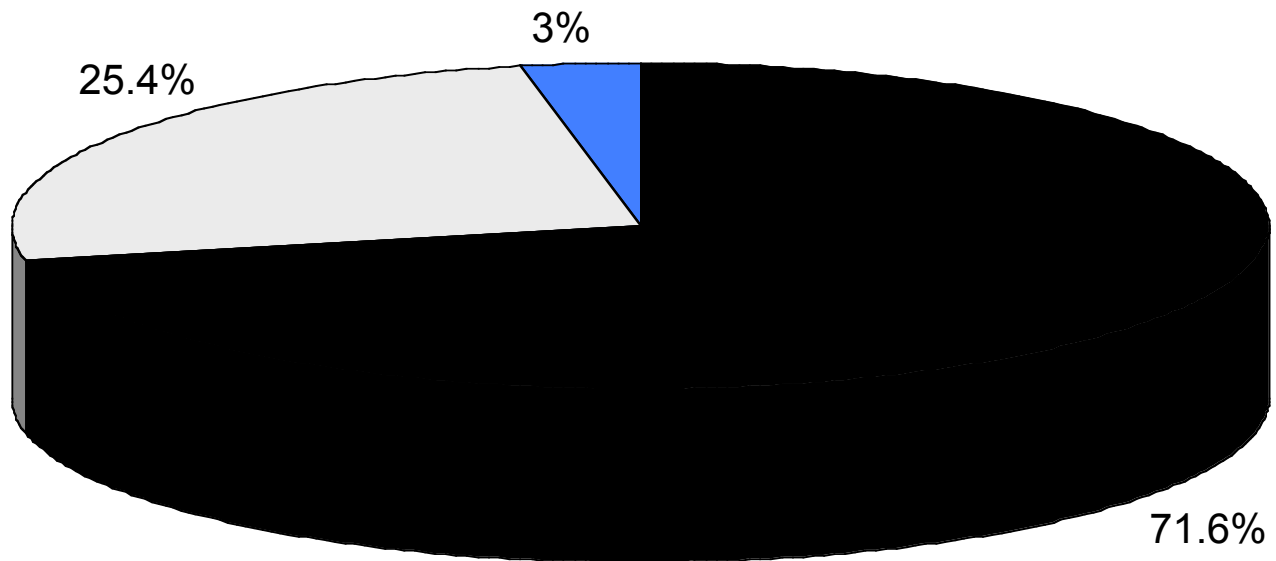
DQ1. Please indicate your HIV Status: HIV Positive, HIV Negative, Don't Know

DQ2. When were you diagnosed with HIV? (month/year)



HIV Status - Ontario - Phase II

HIV Status - Ontario



■ HIV Positive □ HIV Negative ■ Don't Know

Average # of Years living with HIV/AIDS: 12yrs

[range: 1-22 years]

Q1. Please indicate your HIV Status: HIV Positive, HIV Negative, Don't Know

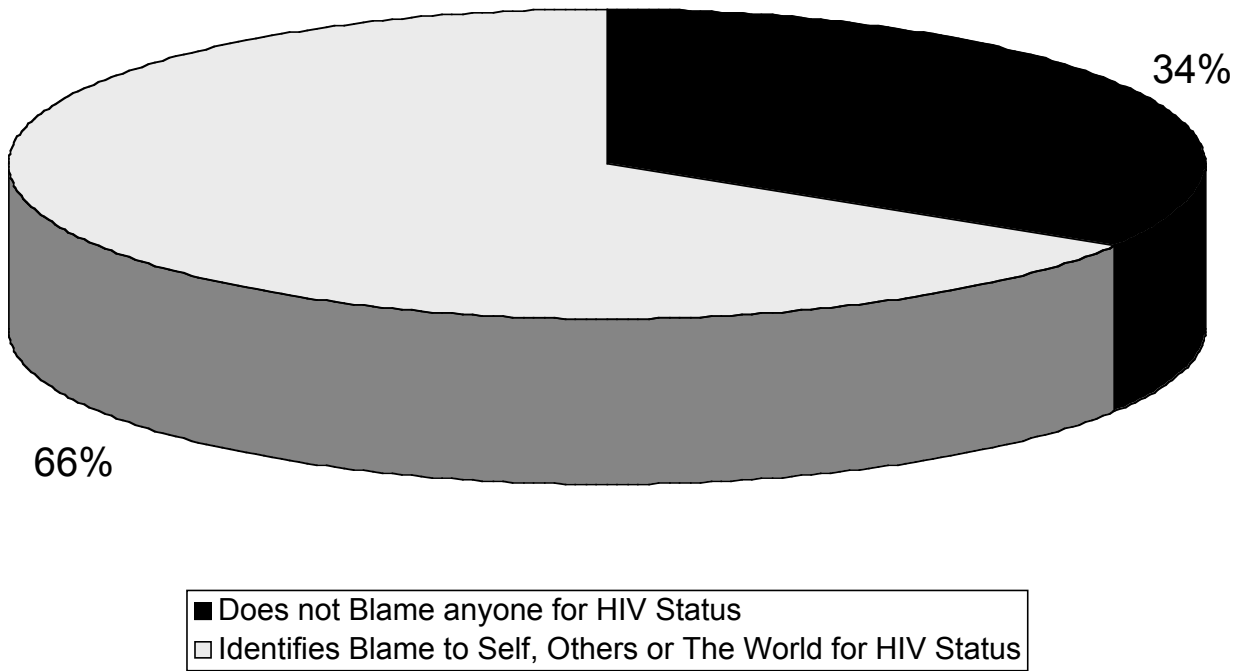
Q2. When were you diagnosed with HIV? (month/year)

(n=67)



HIV Status & Feelings of Blame - Phase I

HIV Status & Feelings of Blame



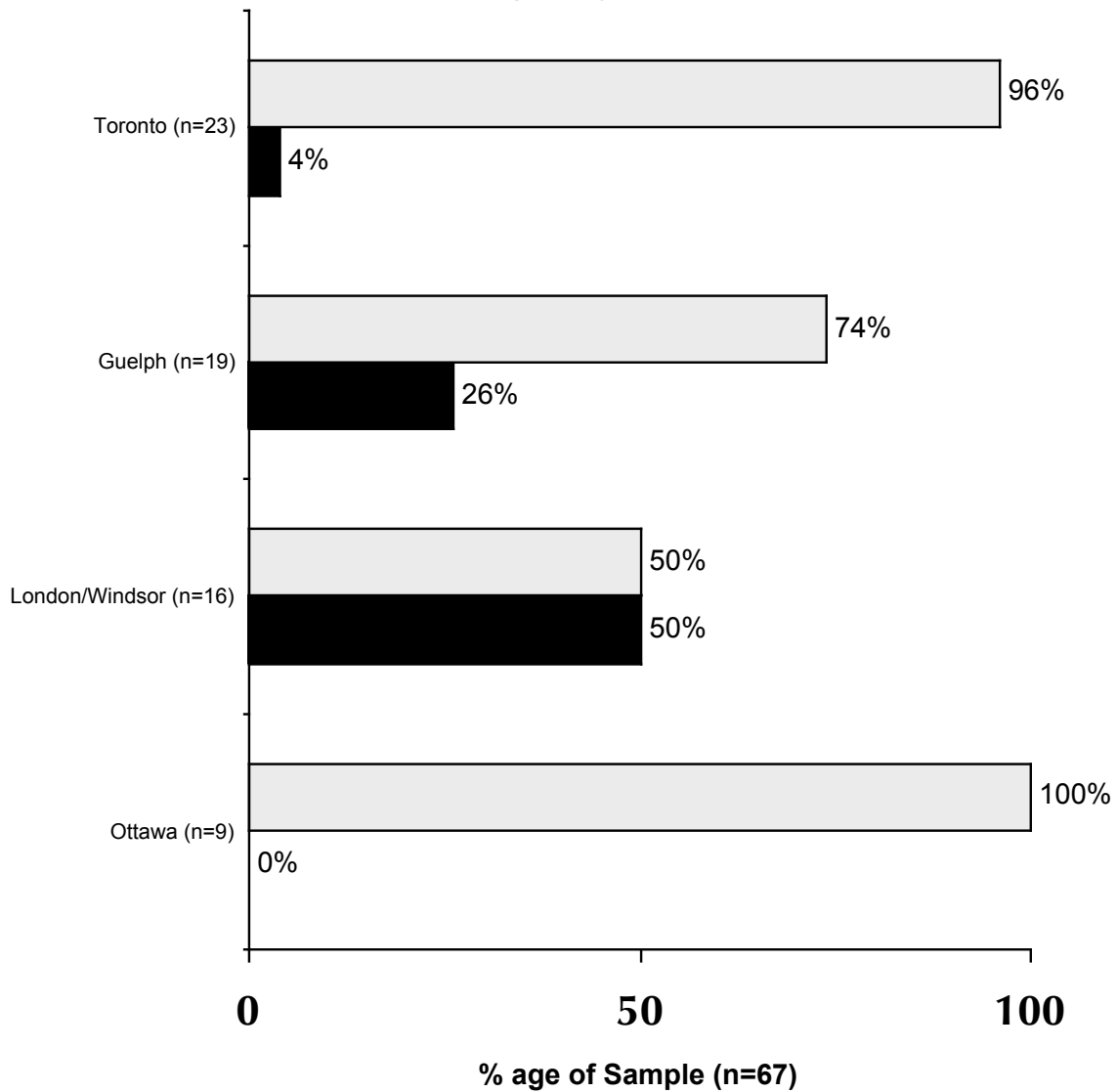
		<u>Mean (1-10)</u>
Average degree HIV+ve participants blame	Self	6.1
	Others	2.5
	The world	2.4

Pre/Post1&2 Q1. For persons living with HIV: On a scale of 1 to 10 where 1 is 'Never/Not at all' and 10 is 'All of the time/Entirely', when thinking about your HIV Status to what degree to you blame ...



Gender and Age - Phase I

Gender & Age by Retreat Site



Average Age of Retreat Participants: 40 [range:34-63]

Overall Ontario Gender: 71.9% Male
20.9% Female

DQ3a. How old are you?

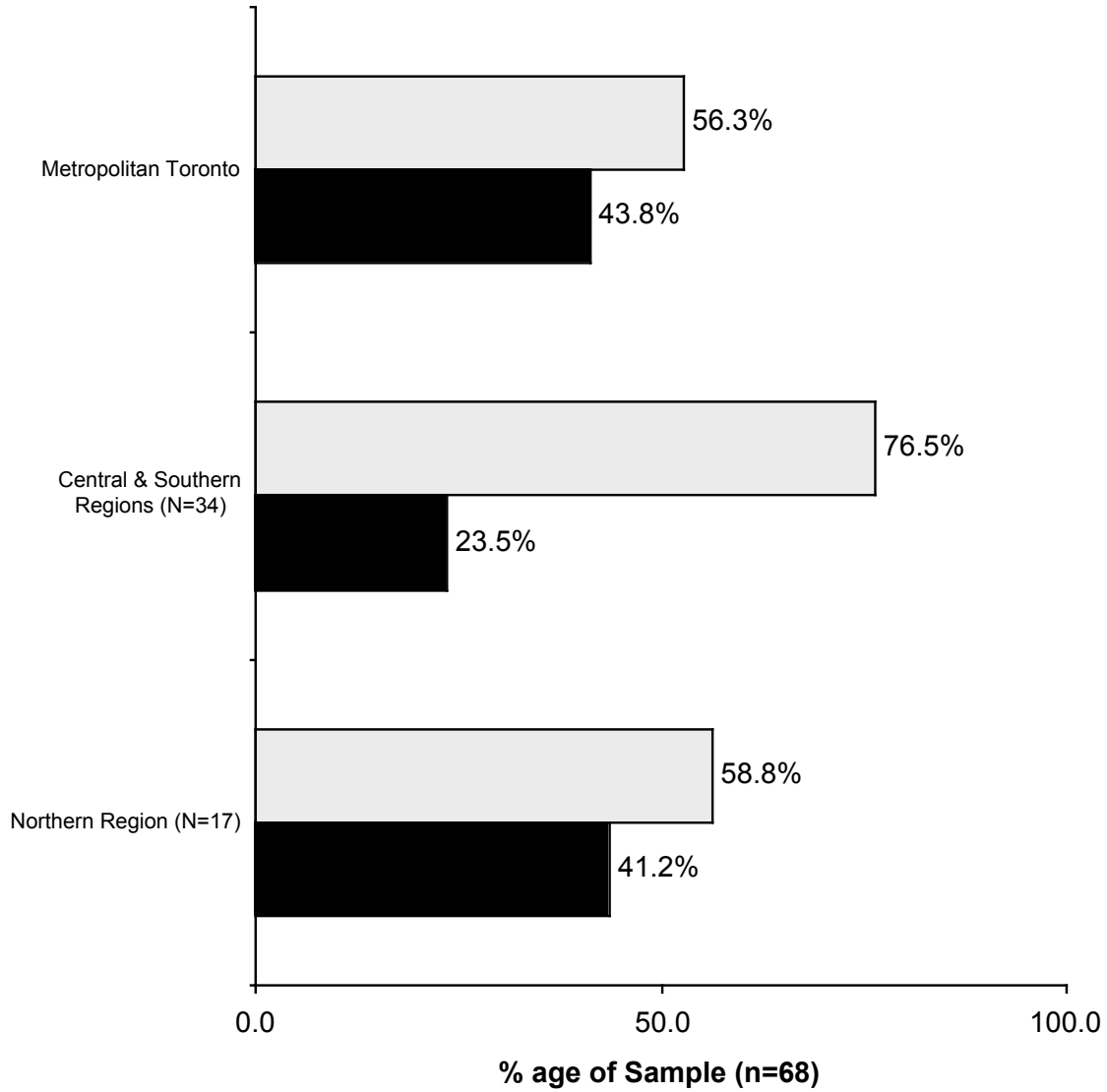
DQ3. Are you: Male? Female?

DQ4: Are you also; Transgender? Transsexual? Note: Ottawa includes 1 transgendered



Gender and Age - Phase II

Gender & Age by Retreat Region



■ Female □ Male

Average Age of Retreat Participants: 44 [Range: 22 - 65]

Overall Ontario Gender: 63.2% Male
35.3% Female

Q3a. How old are you?

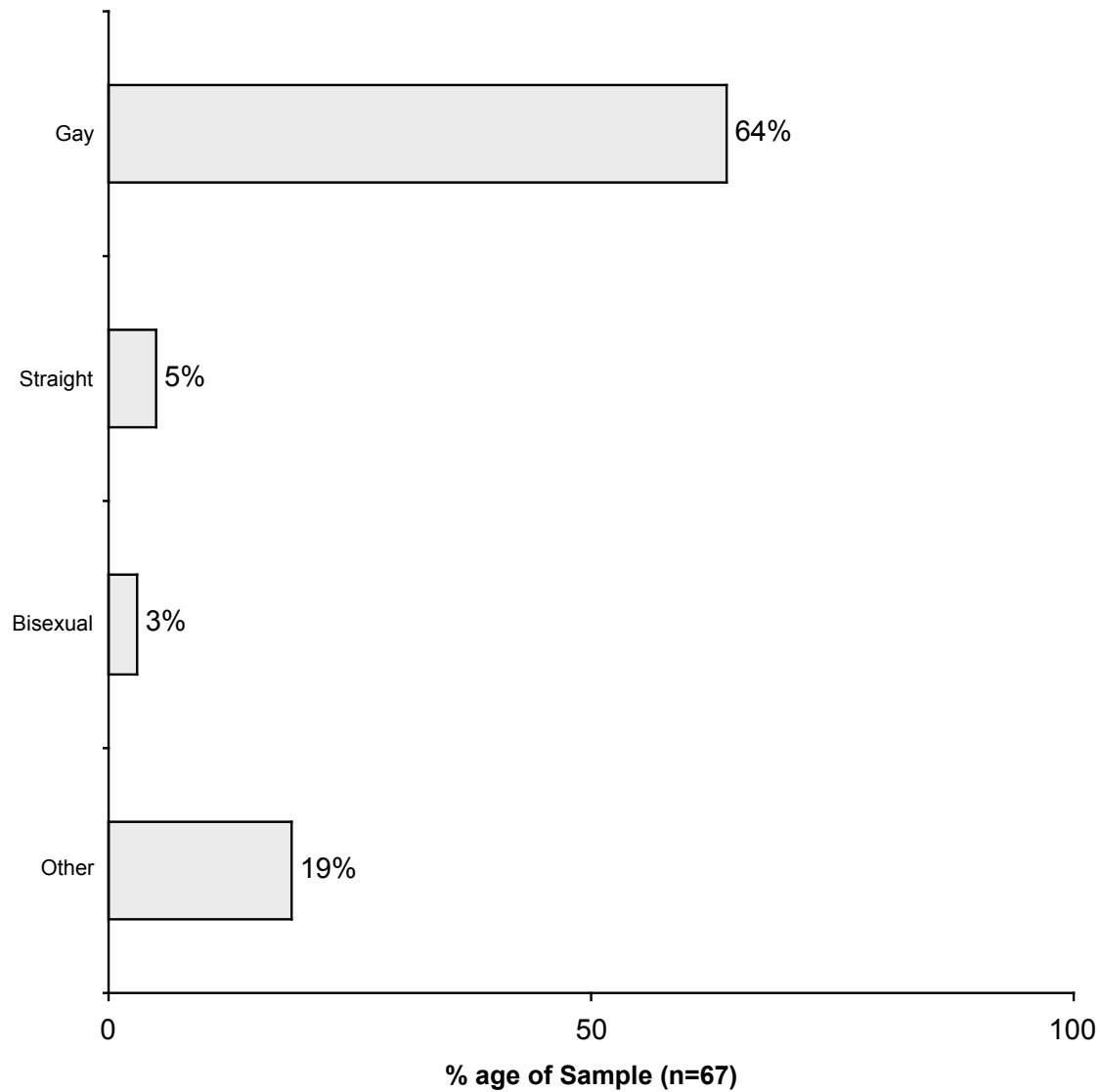
Q3. Are you: Male? Female?

Q4: Are you also; Transgender? Transsexual?



Sexual Orientation - Phase I

Sexual Orientation - all Ontario



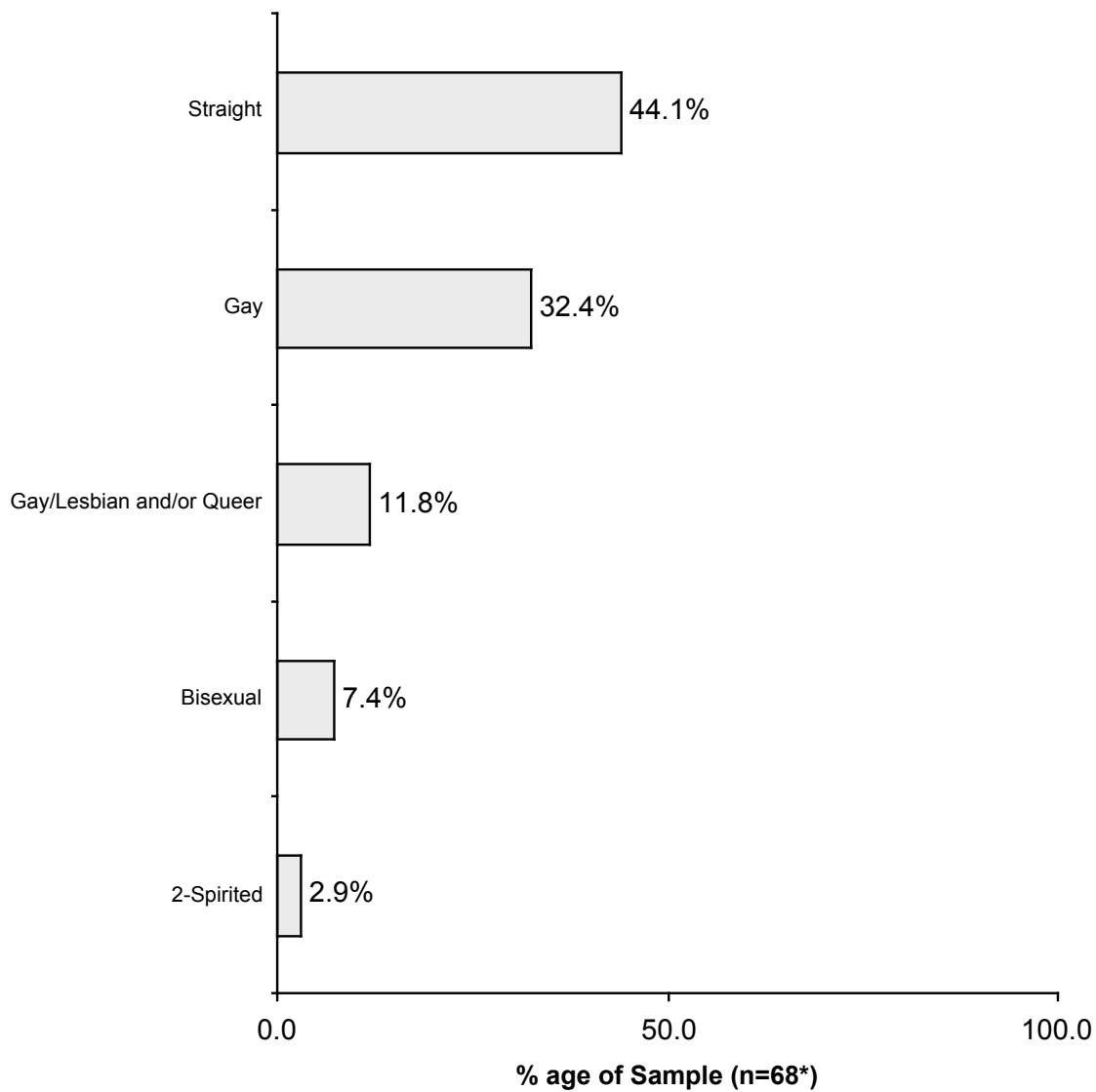
DQ5. Do you identify as: Gay, Straight, Lesbian, Bisexual, Queer, Other?

Note: Due to small sample sizes percentage breakdown of Sexual Orientation are not presented by retreat site.



Sexual Orientation - Phase II

Sexual Orientation - all Ontario



Q5. Do you identify as: Gay, Straight, Lesbian, Bisexual, Queer, Other?

* 1 missing



Cultural Self-Identification - *Phase I & II*

2003/4 Retreat participants culturally identify as:

- African
- Arab
- British
- Caucasian /White
- Christian
- Canadian
- English
- French Canadian
- Latin
- Portuguese
- Scottish
- Trinidadian
- WASP

2004/5 Retreat participants culturally identify as:

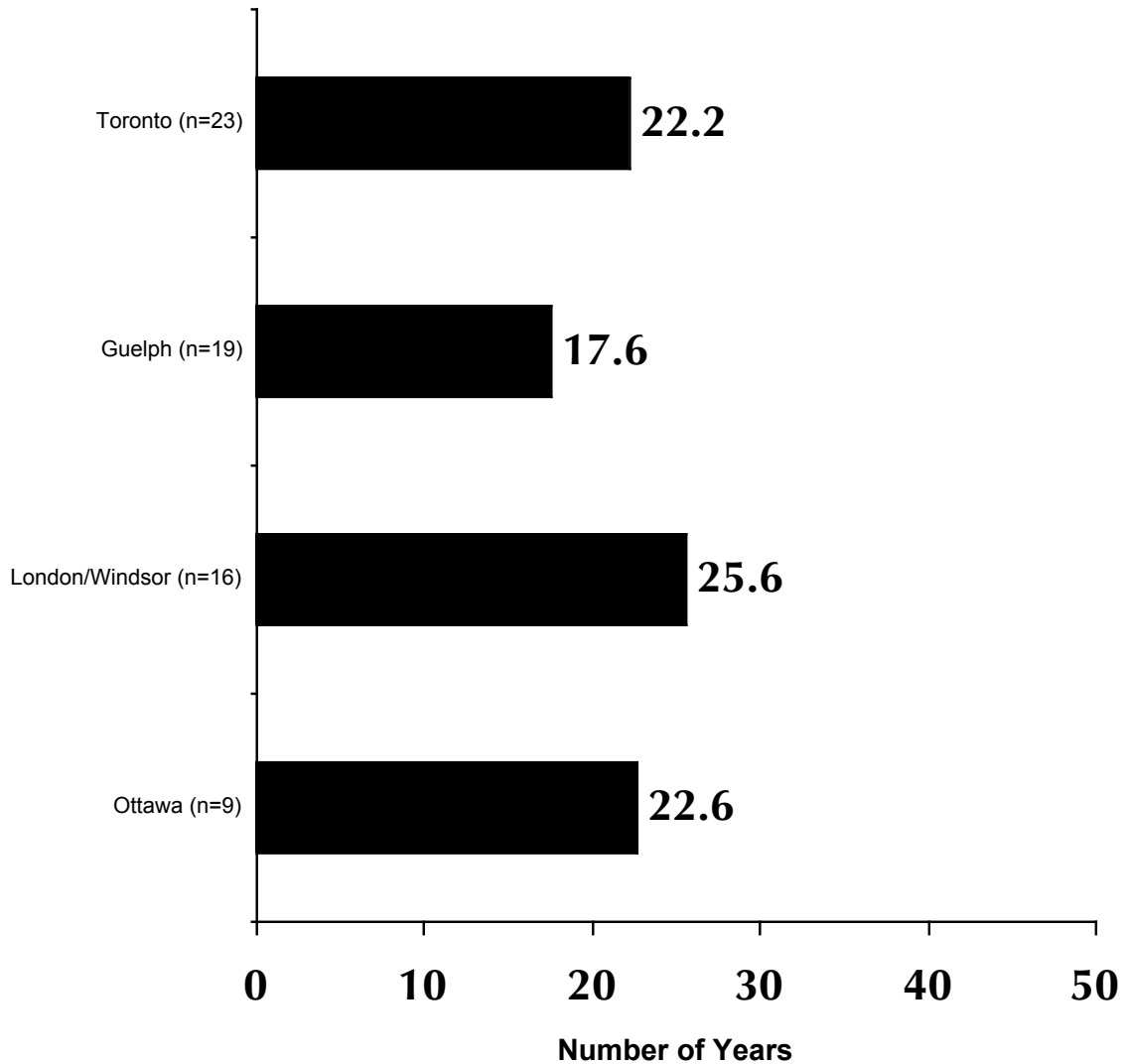
- Aboriginal
- African
- Black
- Caribbean
- Caucasian
- Canadian
- French Canadian
- Jewish
- Latin

Q6. How do you identify culturally?



Years in City of Residence - Phase I

Average # of Years in City of Residence



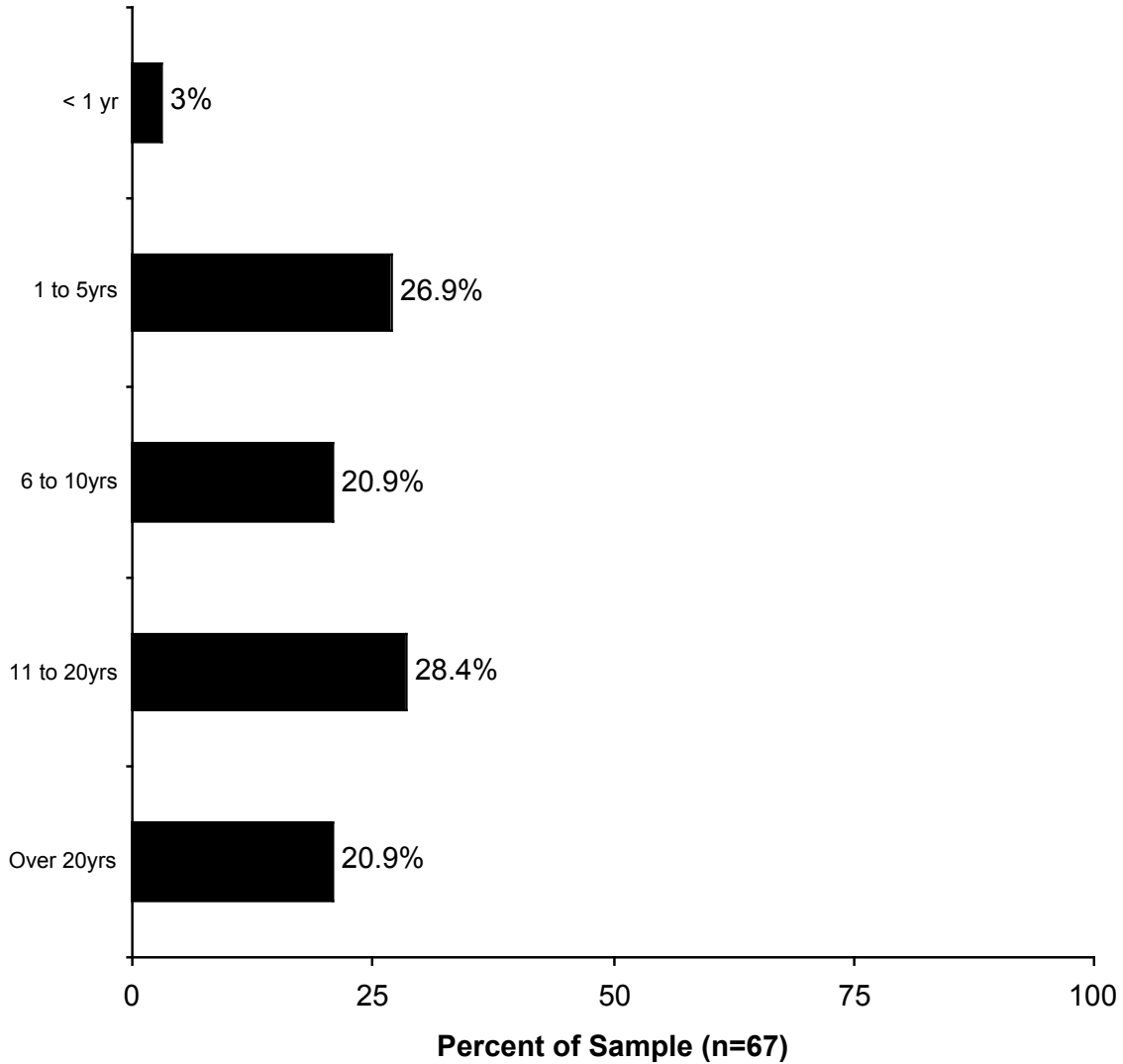
Average # of years in city of residence - All Ontario: **21.8 years**

DQ7. What city do you live in? For how long? (#years)



Years in City of Residence - Phase II

of Years in City of Residence



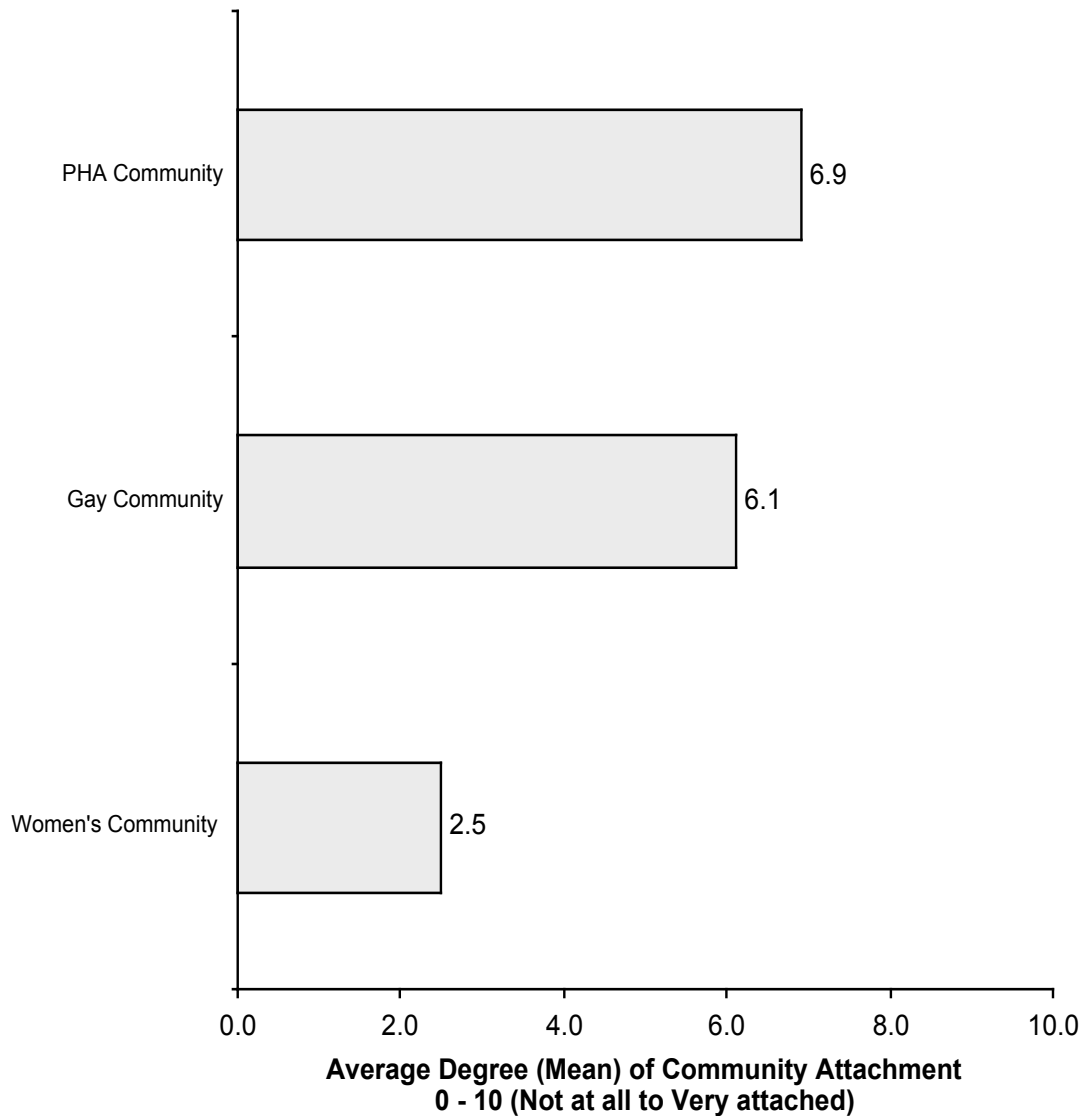
Average # of years in city of residence - All Ontario: **15.0 years**

Q7b. What city do you live in? For how long? (#years)



Communities of Attachment - Phase I

Degree of Community Attachment

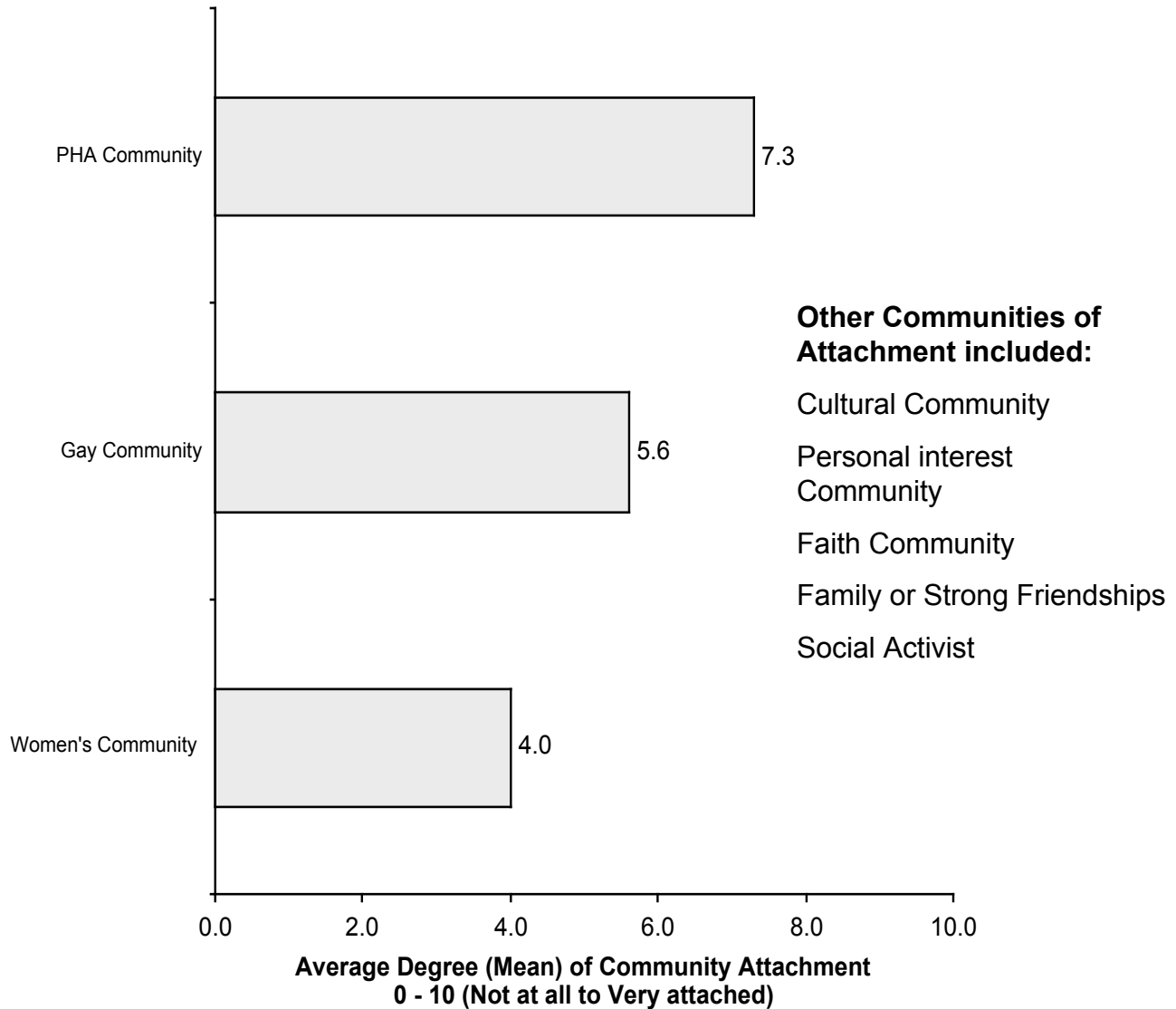


DQ10. On a scale of 1 to 10, where 1 is 'not at all attached' and 10 is 'very attached', how attached to, or a part of the following communities do you feel?



Communities of Attachment - Phase II

Degree of Community Attachment

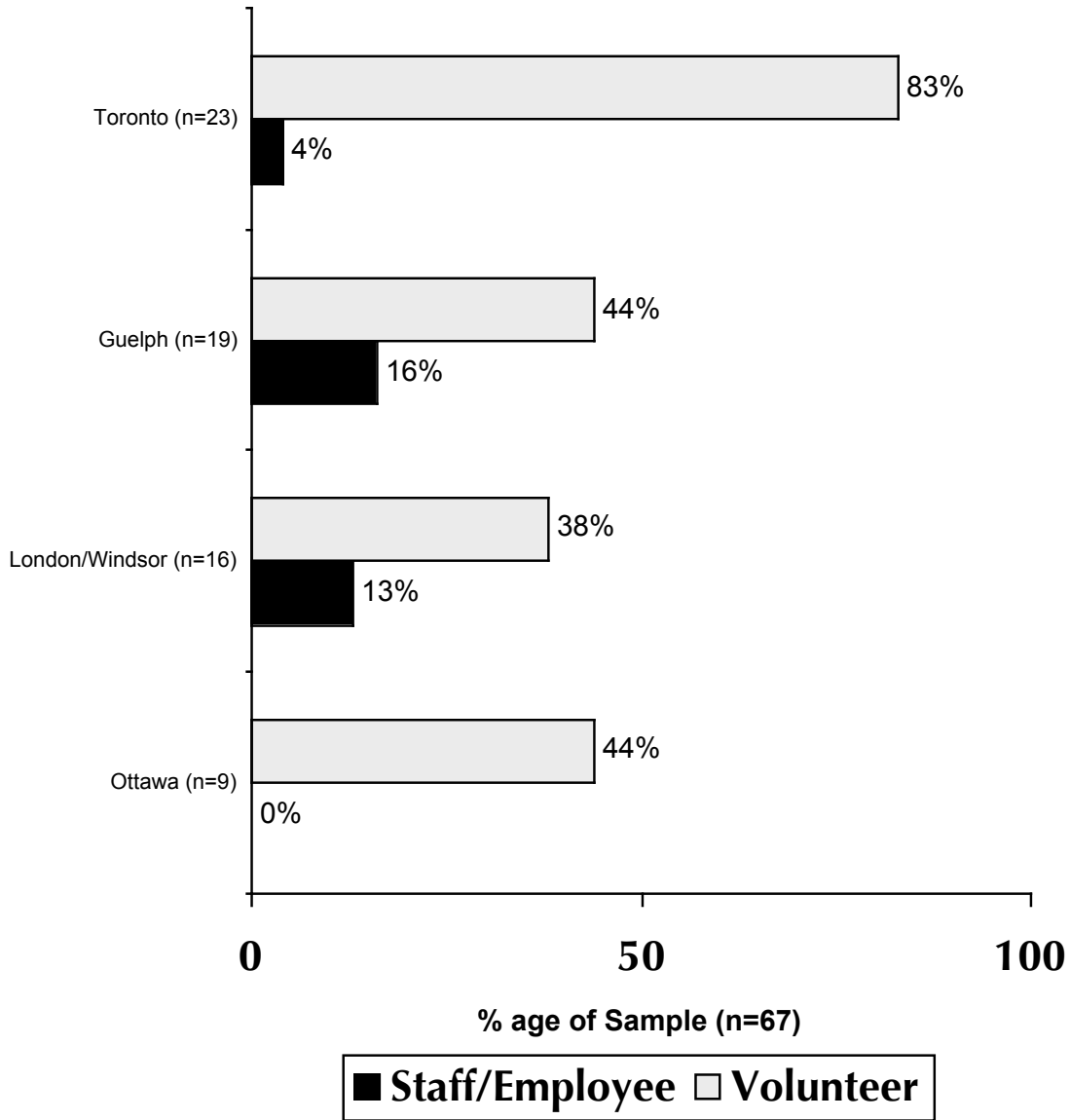


DQ10. On a scale of 1 to 10, where 1 is 'not at all attached' and 10 is 'very attached', how attached to, or a part of the following communities do you feel?



Involved with local ASO - Phase I

Current Volunteer or Staff with Local ASO



Involved with local ASO - Overall Ontario: 56.7% Volunteer
8% Staff/Employee

DQ15a/Post2Q11d. Do you currently do volunteer work at an AIDS Service Organization?

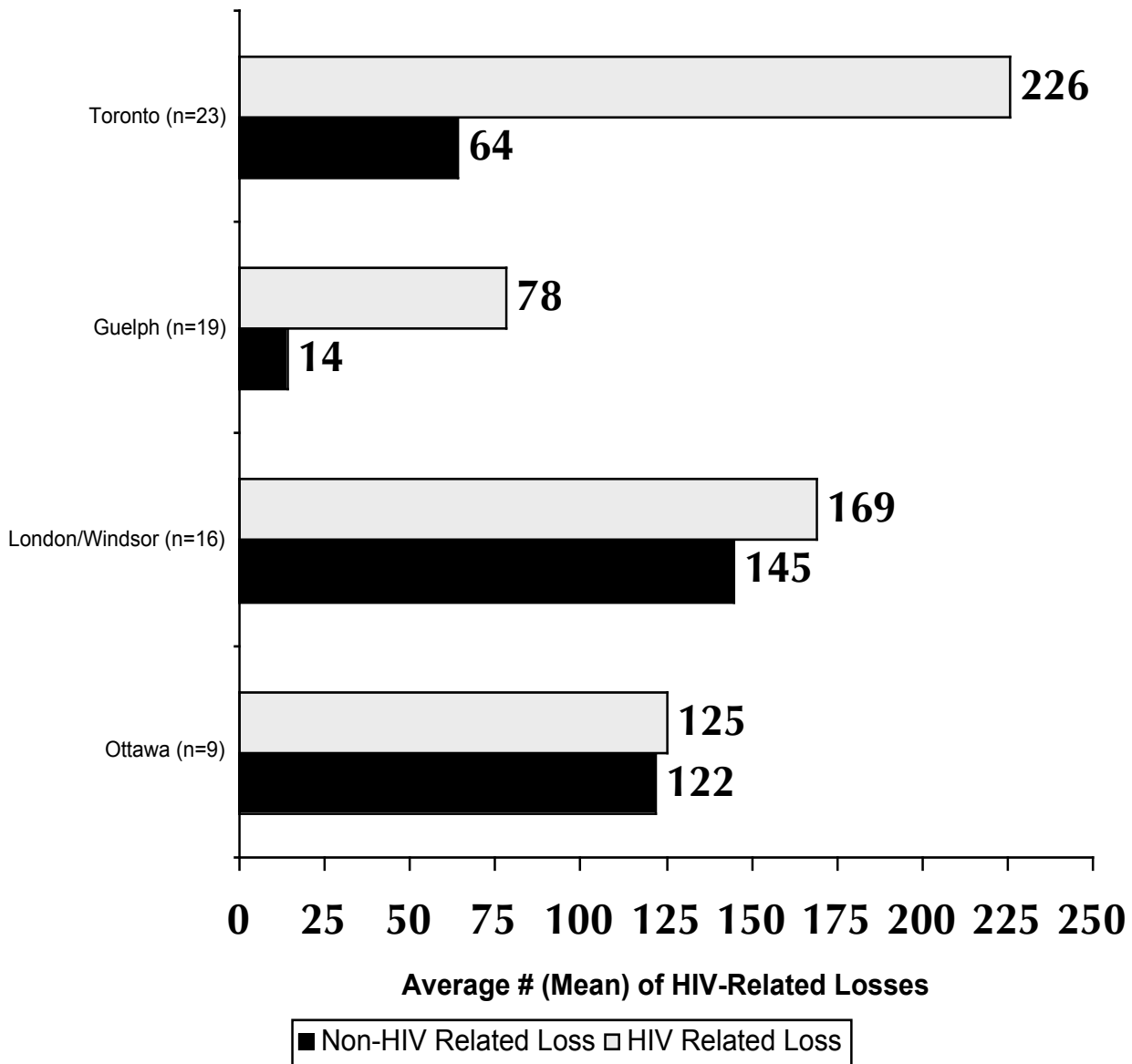
DQ15b/Post2Q11e. Are you currently employed by an AIDS Service Organization?



HIV & Non-HIV-Related Loss - Phase I

PHASE I - Losses

Average # of HIV and Non-HIV Related Losses by Retreat Site



DQ9. Can you estimate how many friends, acquaintances, or partners/lovers in your life that have died from HIV/AIDS?

DQ10. Can you estimate how many people in your life have died from other non-HIV/AIDS causes?



HIV & Non-HIV Related Loss - *Phase II*

PHASE II - Losses

Participants have lost an average of 19 friends acquaintances, partners/lovers in their lifetime due to HIV/AIDS.

Average HIV Related Losses

All Ontario: MEAN: 19 (Range: 0 - 207)

Long-Term Survivor participants: *Mean:* - 12

Provincial Workers: *Mean* - 51

Average Non-HIV Related Losses

All Ontario: 17 (range 0-200)

Long-Term Survivor participants: 12

Provincial Workers: 40

Other Significant Losses Mentioned:

Pets

Partner, Boyfriend, relationships, friends, family members

Job Profession

Faith

Trust

Autonomy

Health

Vision

Home

Q9. Can you estimate how many friends, acquaintances, or partners/lovers in your life that have died from HIV/AIDS?

Q10. Can you estimate how many people in your life have died from other non-HIV/AIDS causes?

Q11. Are there other losses that you have experienced that you think are important?



Effects of Loss - Phase I

Other Significant Losses

- Male relationships
- Pets
- Employment, Income Security, Career
- Independence, Privacy
- Community, Culture, Social Life
- Health, physical strength, body image, eyesight
- Sex, Sexual function
- Confidence
- Choices
- Not dying
- Dignity
- Travel / Socializing in the United States

The top 5 emotional effects from loss include:

Depression, Anxiety, Stress, Anger/Frustration, Hopelessness

Additional emotional effects include:

- Difficulty concentrating / Lack of Interest
- Dealing with unempathetic family/friends
- Loss of life / coping strategies
- Disappointment, Discouragement, Despair

Physical Effects from Loss

The myriad of physical effects due to grief/loss identified by participants may have more of a 'causal association' related to side-effects from HIV treatment medications. Nevertheless most participants indicate they have experienced both 'insomnia and fatigue or inability to sleep' as a physical effect due to their grief.

DQ11. Are there other losses that you have experienced that you think are important?

*DQ12-13. Thinking about these losses, did you experience any **emotional** / **physical** effects what may have been due to your grief?*



Effects of Loss - *Phase II*

The top 5 emotional effects from loss include:

Depression, Anxiety, Stress, Anger/Frustration, Hopelessness

Additional emotional effects include:

Difficulty concentrating / Lack of Interest

Physical Effects from Loss

The myriad of physical effects due to grief/loss identified by participants may have more of a 'causal association' related to side-effects from HIV treatment medications. Nevertheless most participants indicate they have experienced both 'insomnia and fatigue or inability to sleep' as a physical effect due to their grief.

Other Effects from Loss

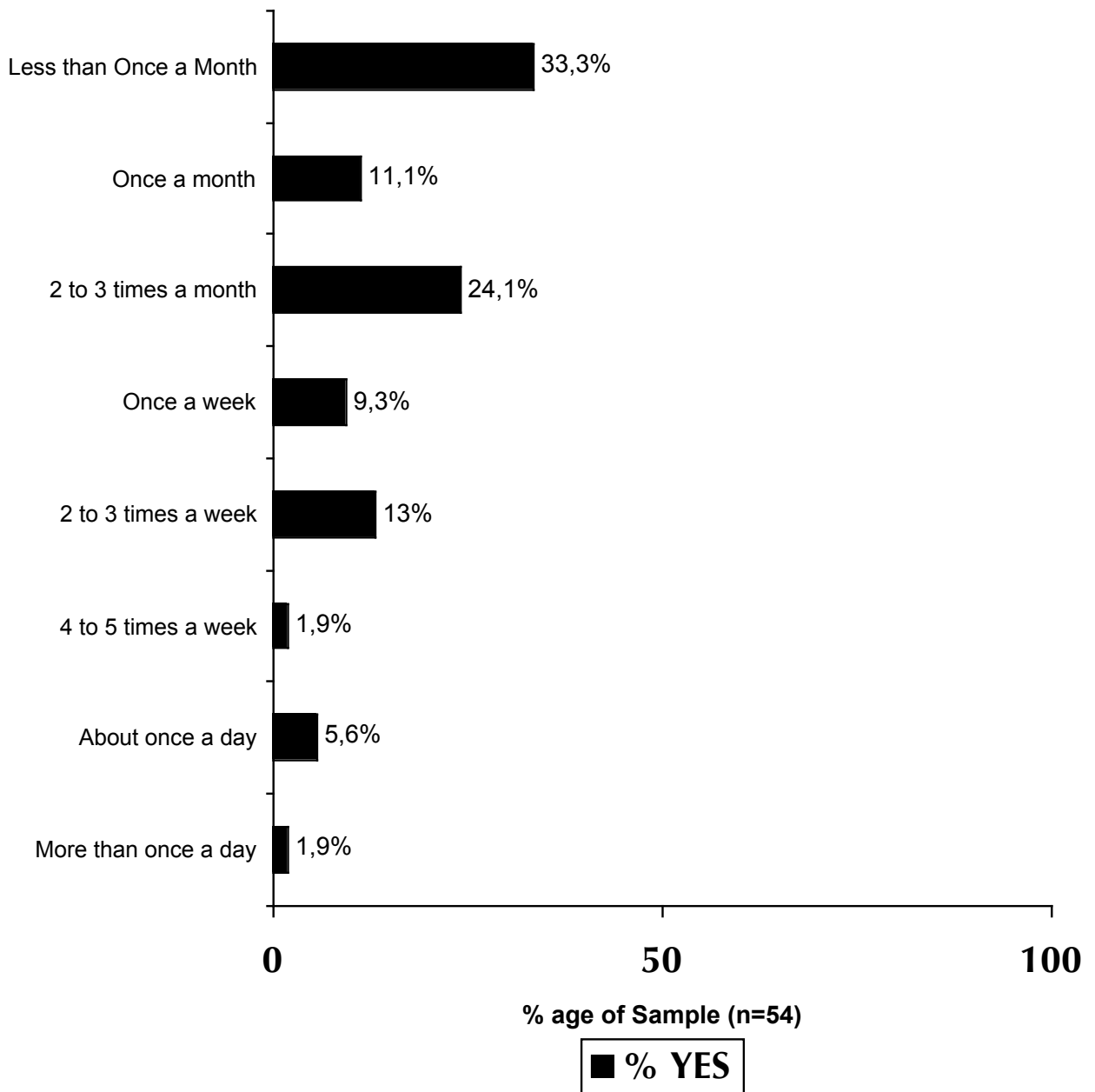
Overwhelmingly most participants acknowledged that other effects from their loss include social and sexual withdrawal (isolation); difficulties maintaining and creating friendships.

*Q17-19. Thinking about these losses, did you experience any **emotional / physical** effects what may have been due to your grief?*



Alcohol Use - Phase I

Current Use of Alcohol

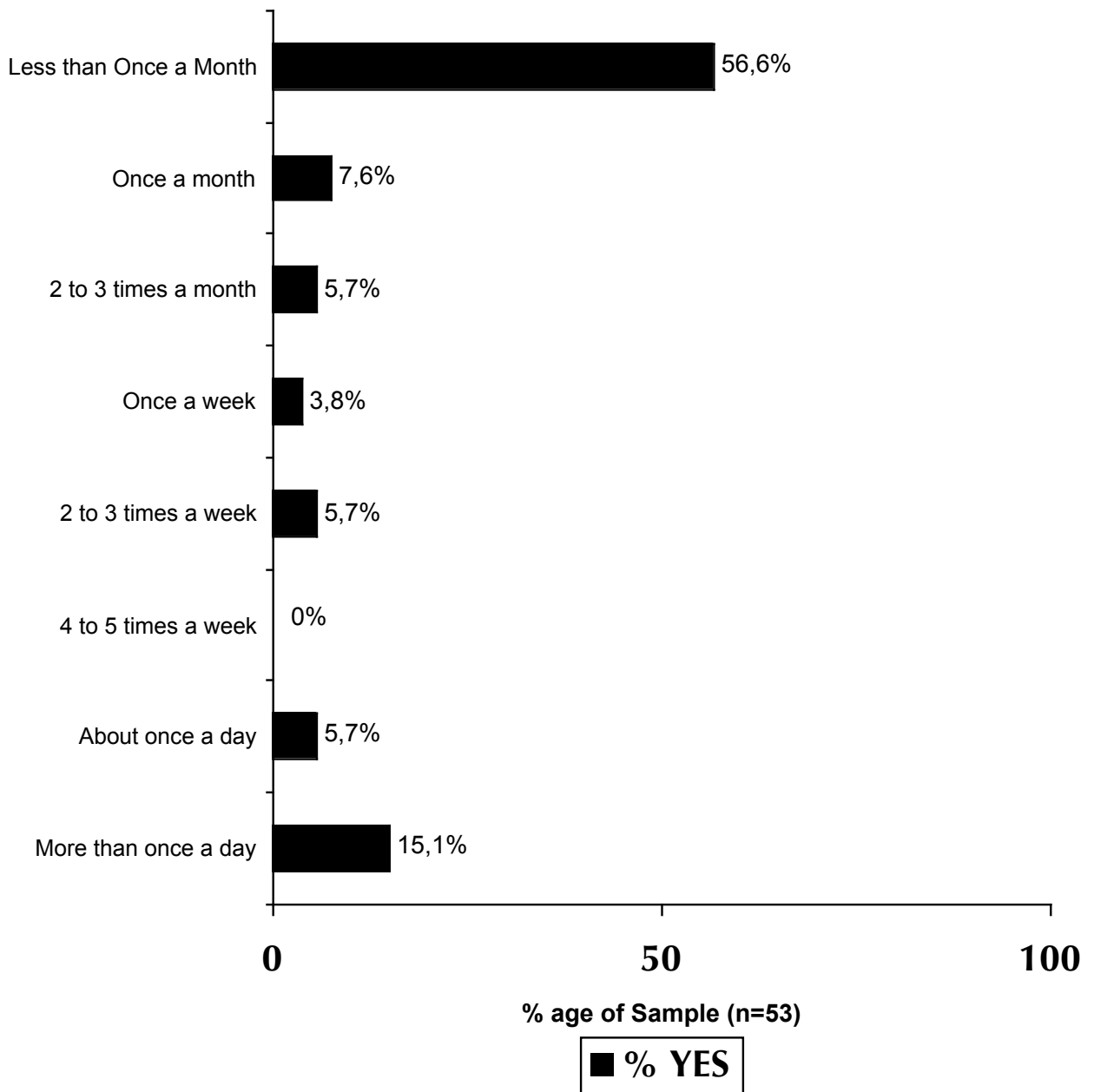


PreQ6/Post2Q7. How often would you say you use alcohol?



Recreational Substance Use - Phase I

Current Recreational Substance Use

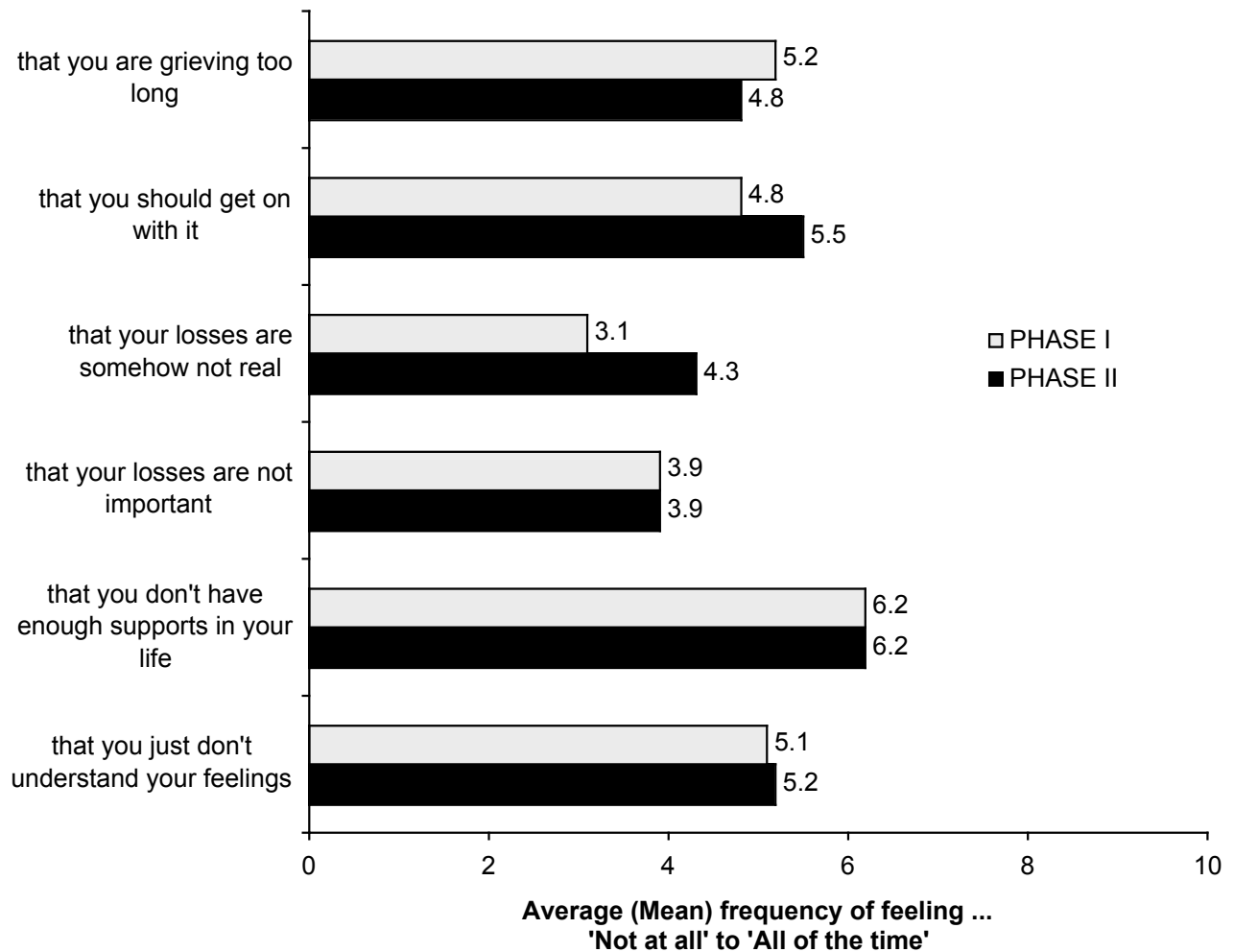


PreQ7/Post2Q8. How often do you use drugs for recreational purposes?



Attitudes - Grief/Loss - Phase I & II

**When thinking about your grief/loss/sorrow,
how often do you feel ...**

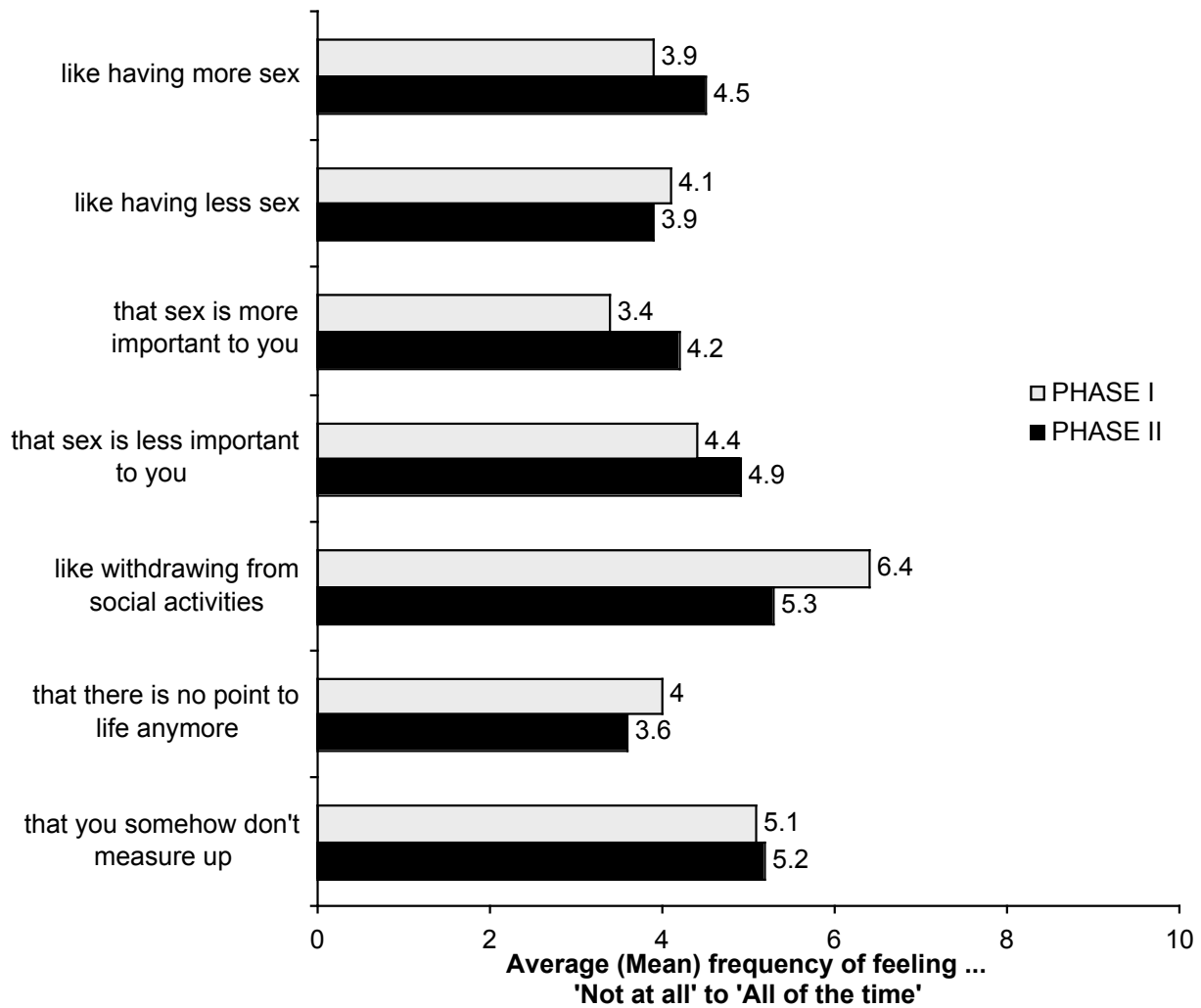


Q12. On a scale of 1 to 10, where 1 is 'Not at all' and 10 is 'All the time', when thinking about your grief/loss/sorrow, how often do you feel?



Attitudes - Grief - Phase I & II

When thinking about how your grief/loss/sorrow, affects you, how often do you feel ...

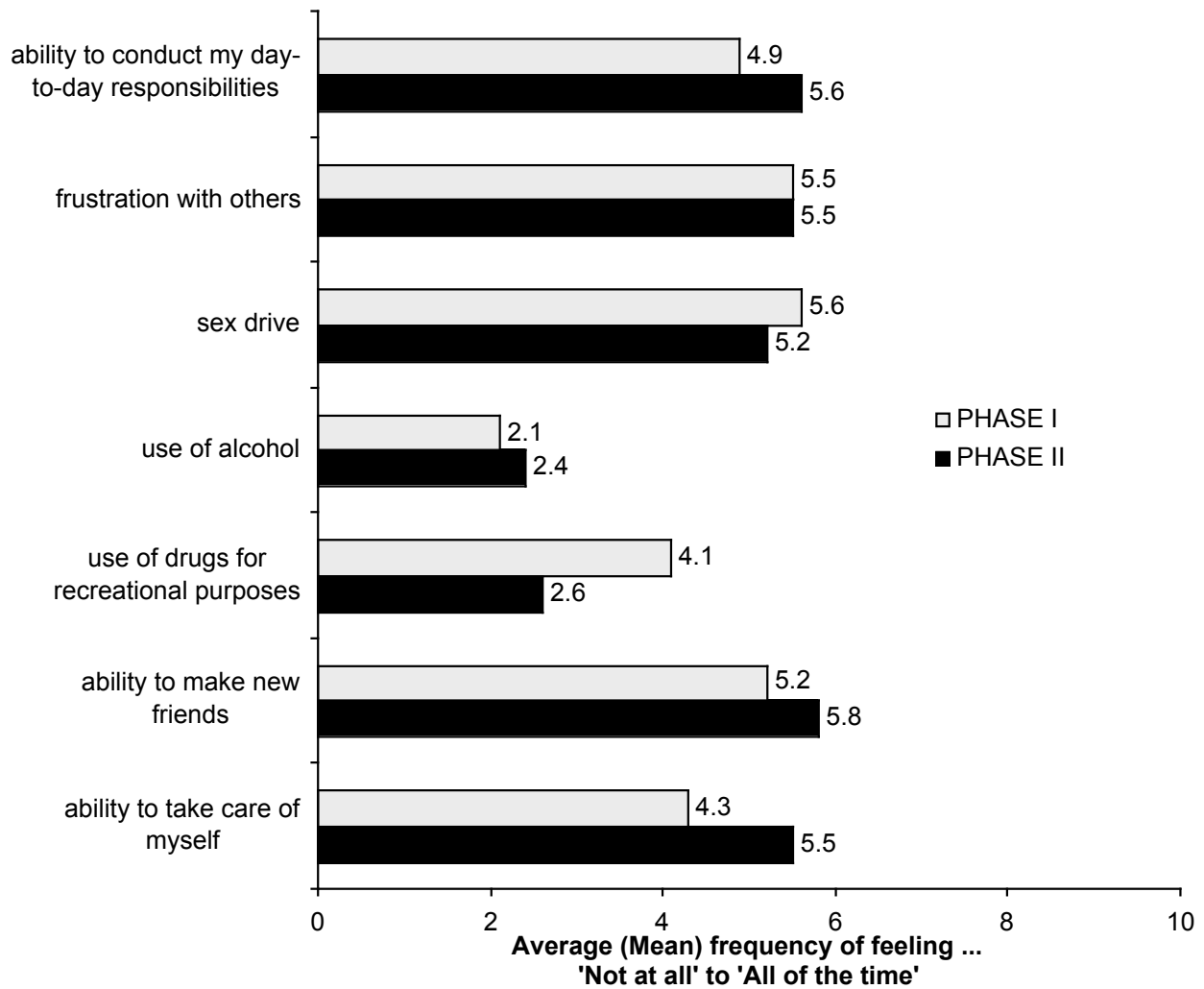


DQ13. On a scale of 1 to 10, where 1 is 'Not at all' and 10 is 'All the time', when thinking about how your grief/loss/sorrow affects you, how often do you feel?



Attitudes - Grief/Loss - Phase I & II

I believe my grief/loss/sorrow affects my ...

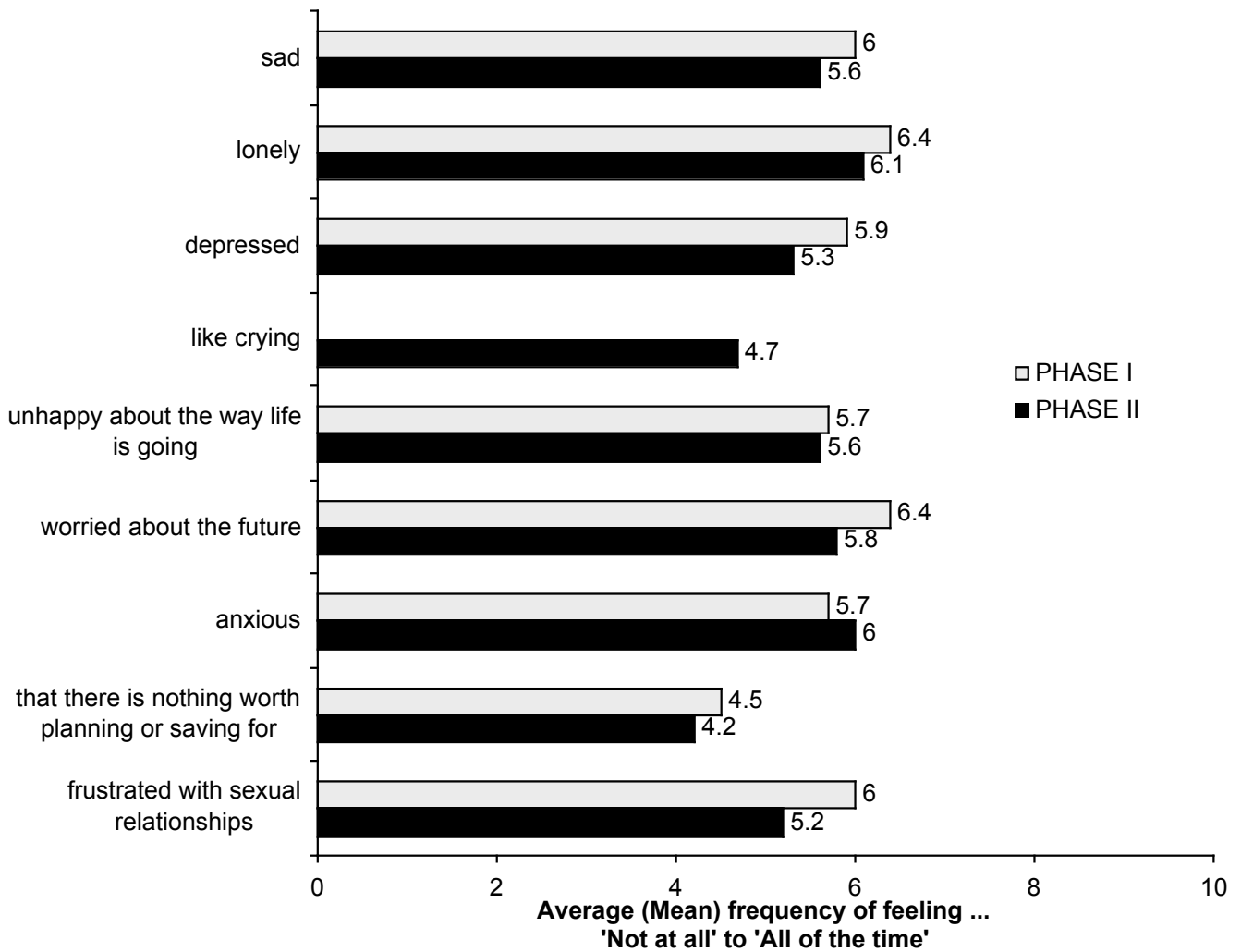


DQ14. I believe my grief/loss/sorry affects my ...



General Frequency of Feeling - Phase I & II

General Frequency of Feeling ...

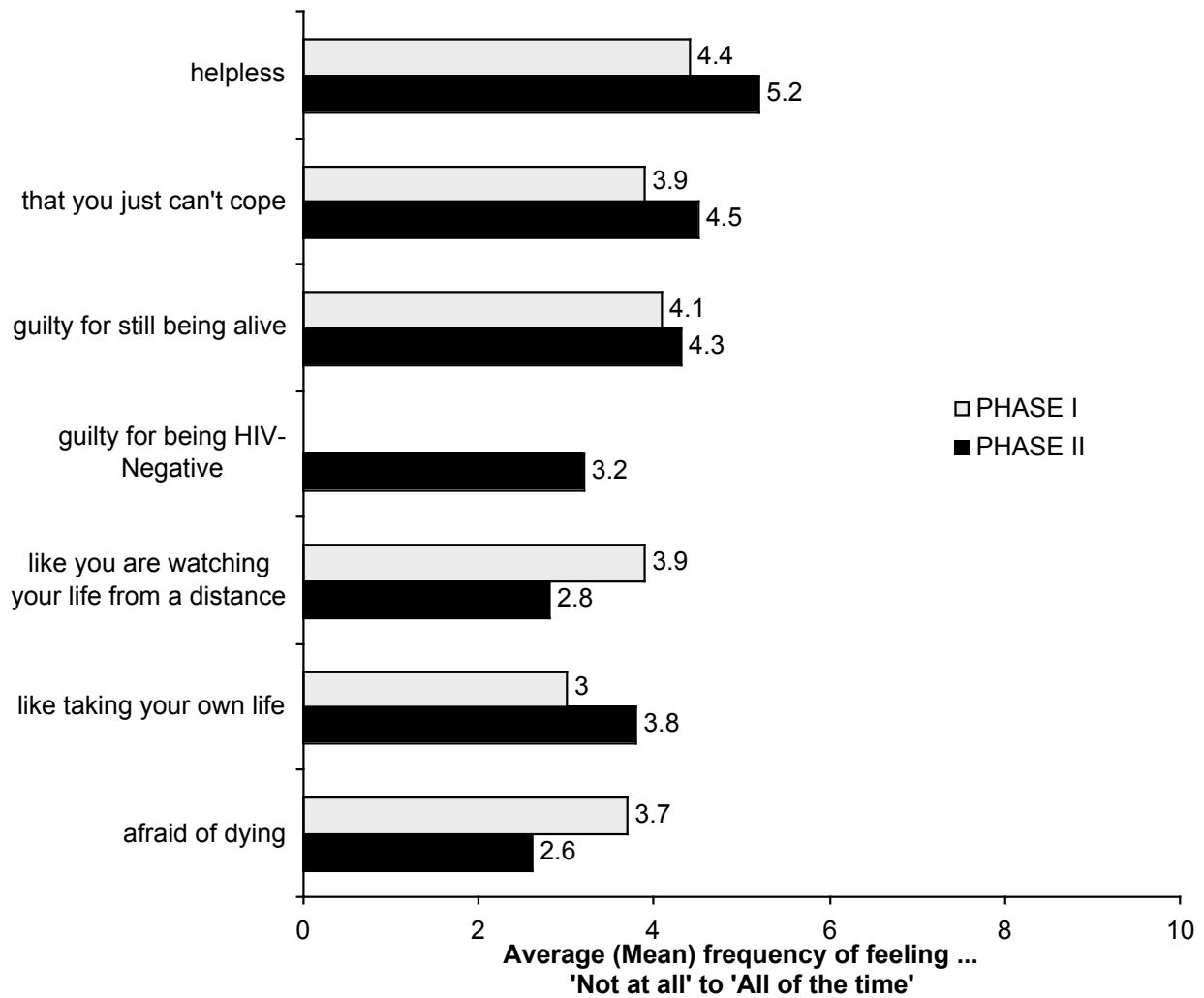


DQ15. How often do you feel...



General Frequency of Feeling - Phase I & II

General Frequency of Feeling ...

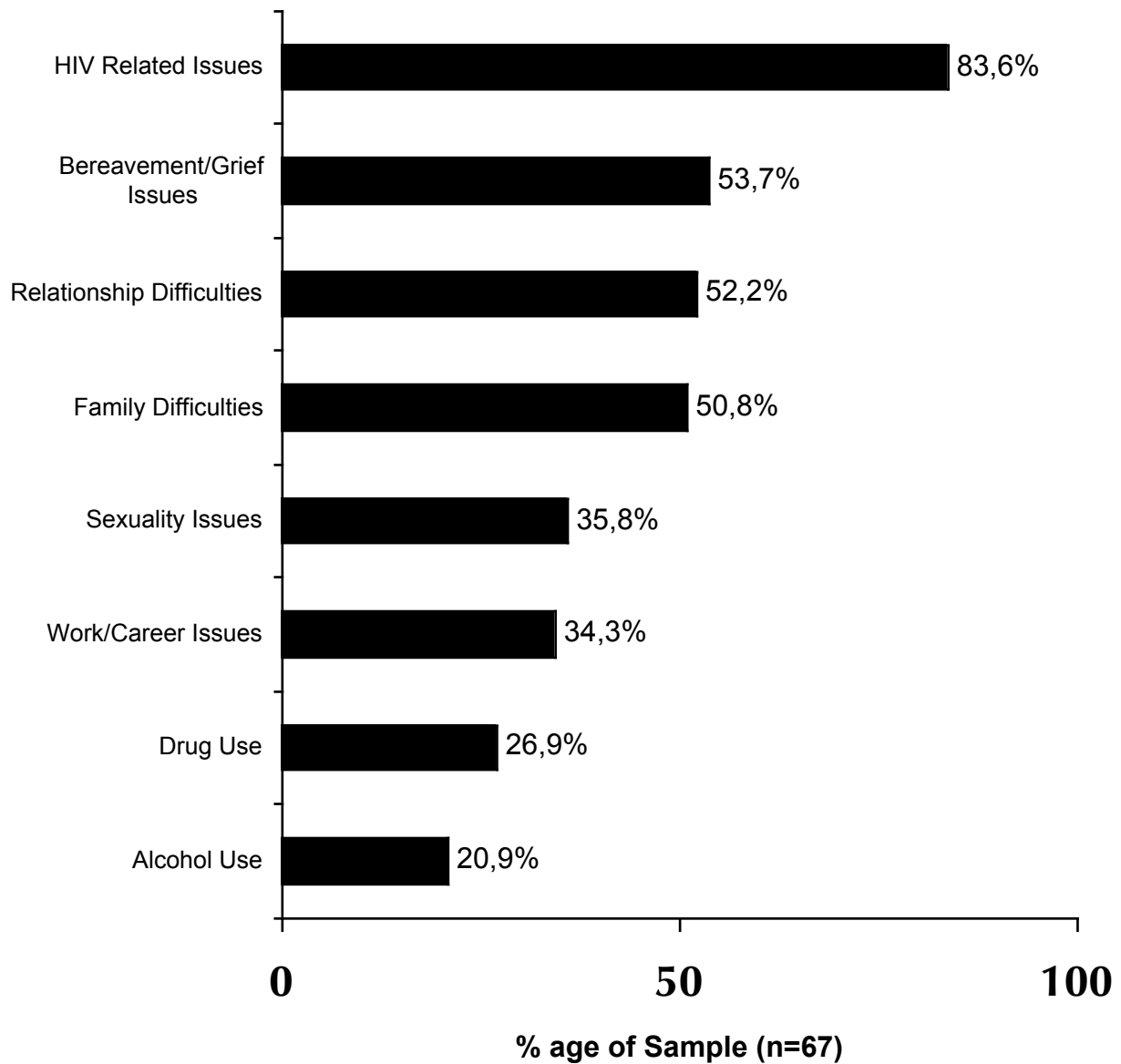


DQ15. How often do you feel ...



Support History - Ontario - Phase I

Issue Specific Support History - Ontario



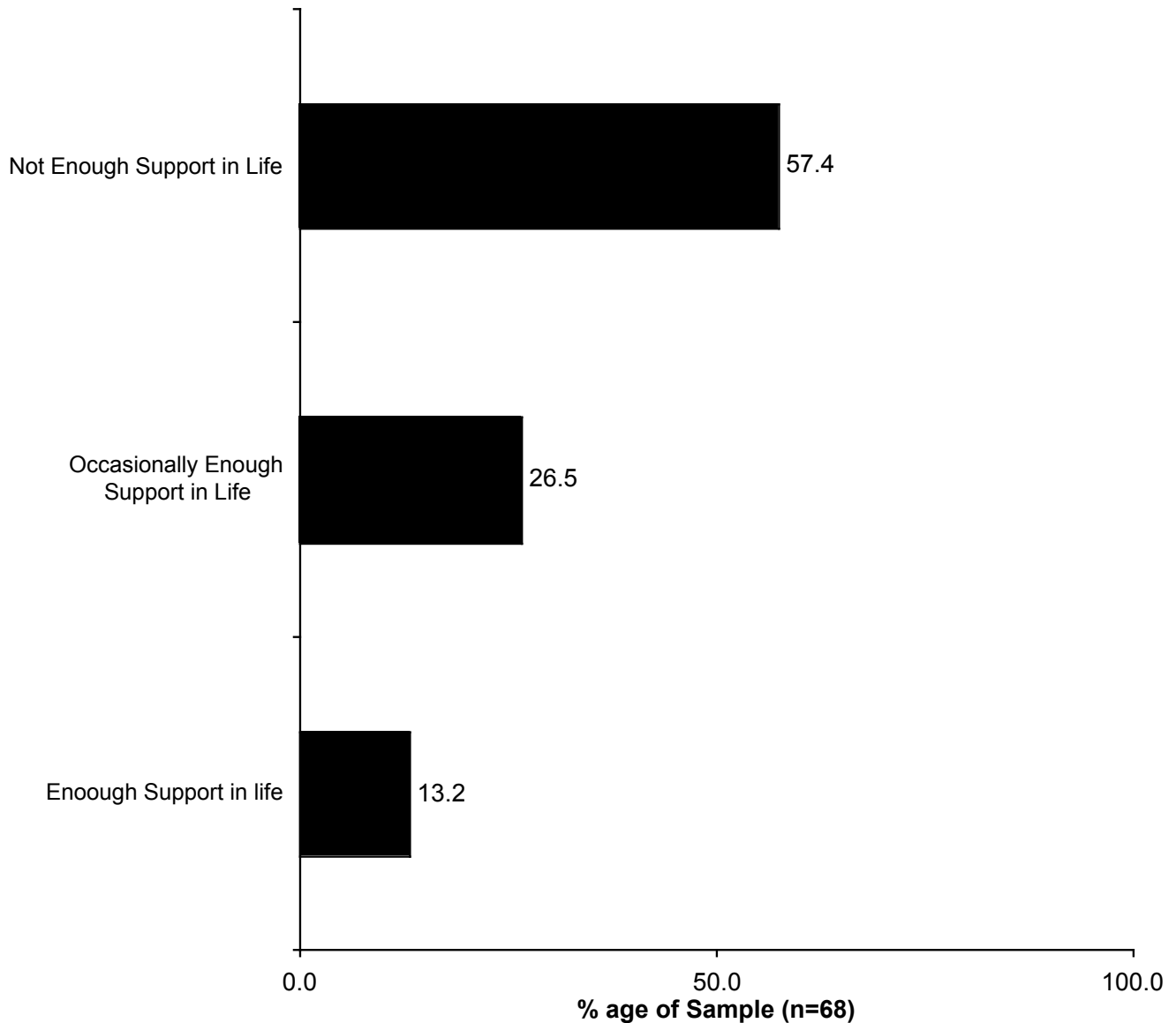
88% of total retreat participants indicate having ever received support in the past.

DQ14. Have you ever sought the advice or support to a helping professional (counselor, therapist, psychiatrist, priest, etc.) specifically for ...



Self Assessed Adequacy of Support - Phase II

Self Assessed Adequacy of Current Supports in Life

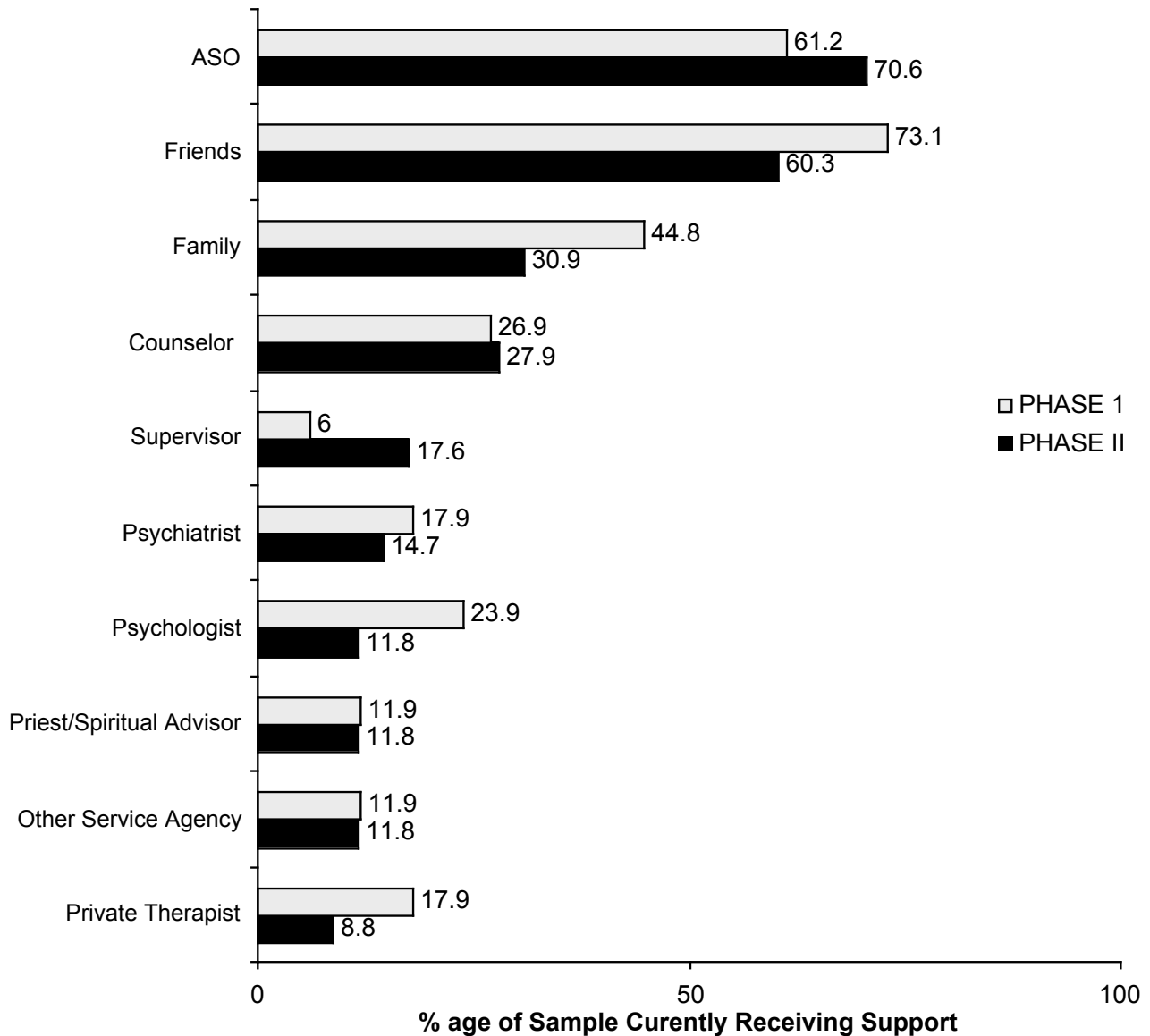


Q12. On a scale of 1 to 10, where 1 is 'Not at all' and 10 is 'All the time', when thinking about your grief/loss/sorrow, how often do you feel: That you do not have enough supports in your life:



Current Sources of Support - Phase I & II

Current Sources of Professional Support - Ontario



91% of participants currently receiving support indicate they currently receive support from: ASOs, friends, family, counselor or supervisor.

DQ16. Where do you currently get support for feelings associated with grief, loss, sorrow, or other issues in your life?



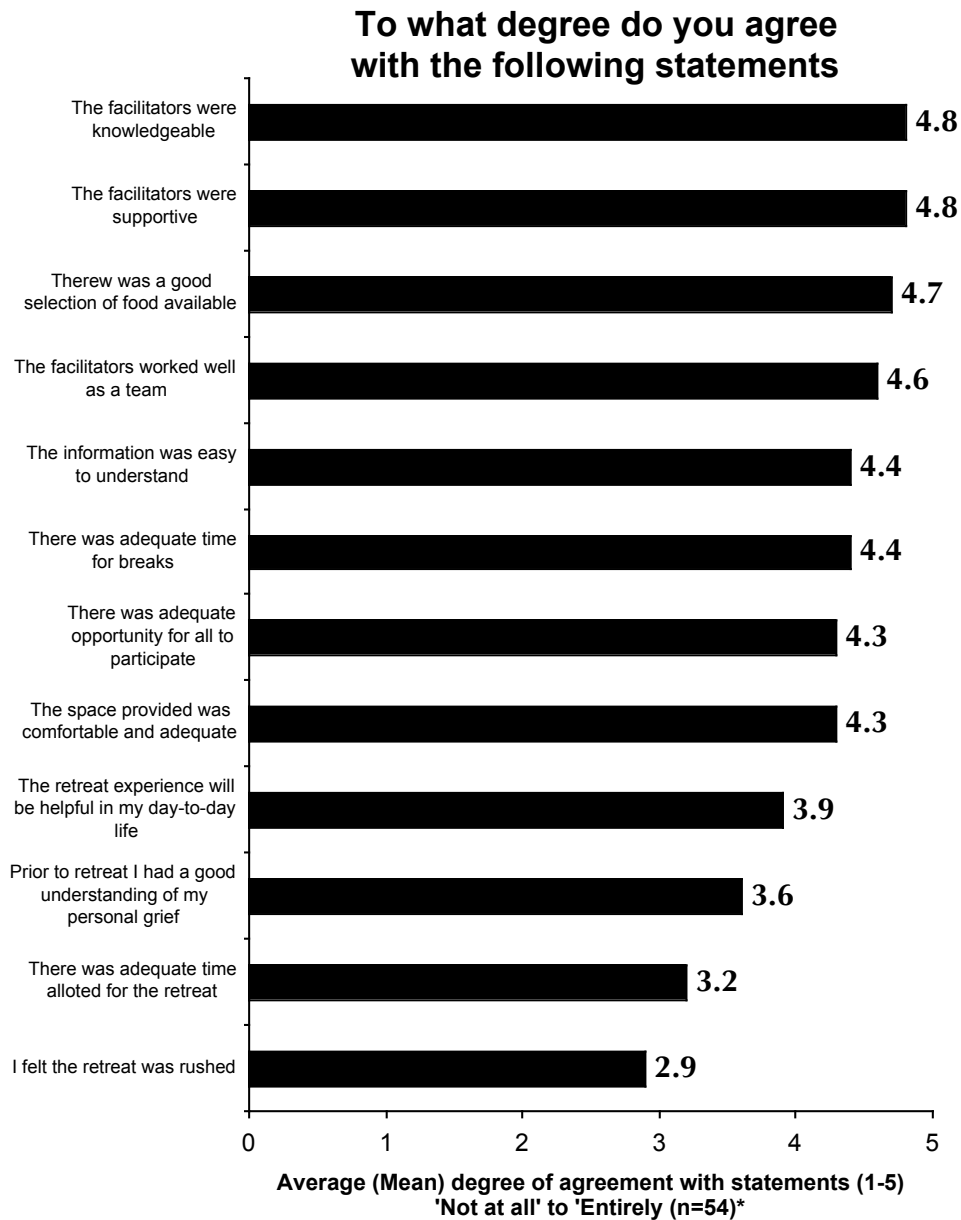
Facilitation & Venue Rankings

Facilitation and Venue Rankings
& Constructive Comments

- PHASE I & II



Facilitation & Venue Rankings - Phase I



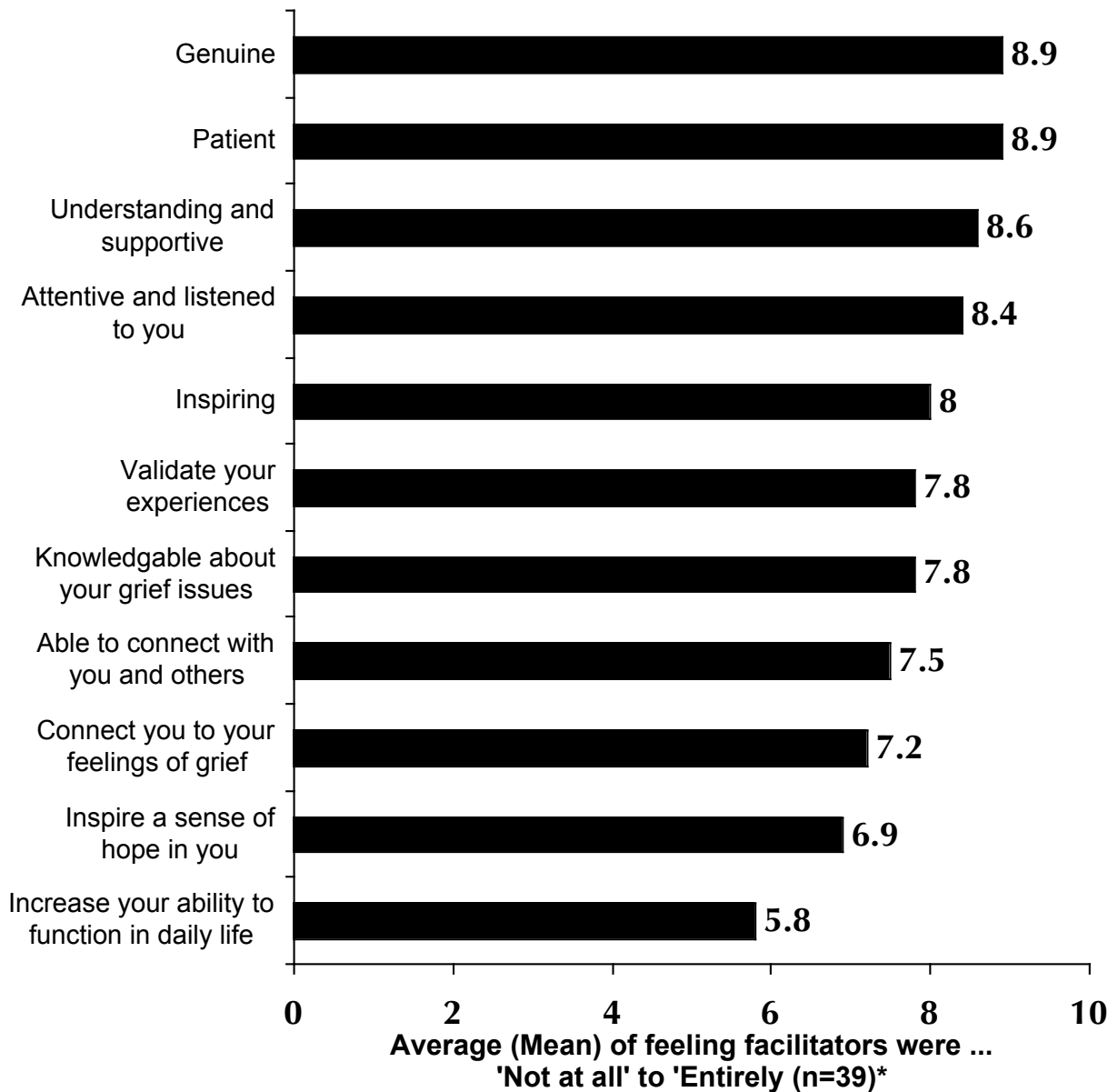
Post1Q9. On a scale of 1 to 5, where 1 is 'Not at all' and 10 is 'Entirely', please indicate the degree to which facilitators of your retreat were ...

Note: 13 missing



Facilitation Rankings - Phase I

To what degree were facilitators of your retreat ...

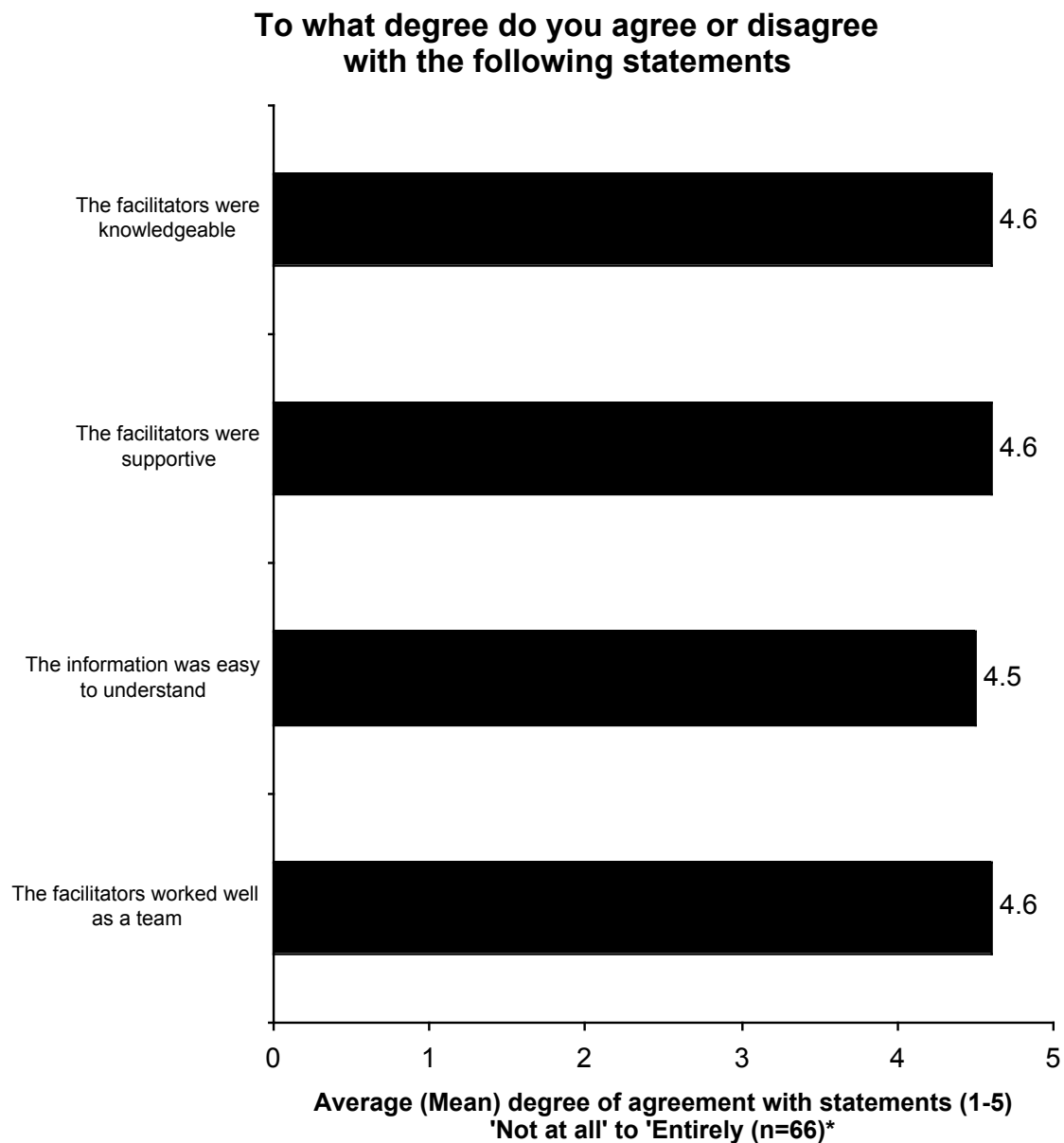


Post2Q14. On a scale of 1 to 10, where 1 is 'Not at all' and 10 is 'Entirely', please indicate the degree to which facilitators of your retreat were ...

Note: Total Ontario Post2 respondents n=39



Facilitator Rankings - Phase II

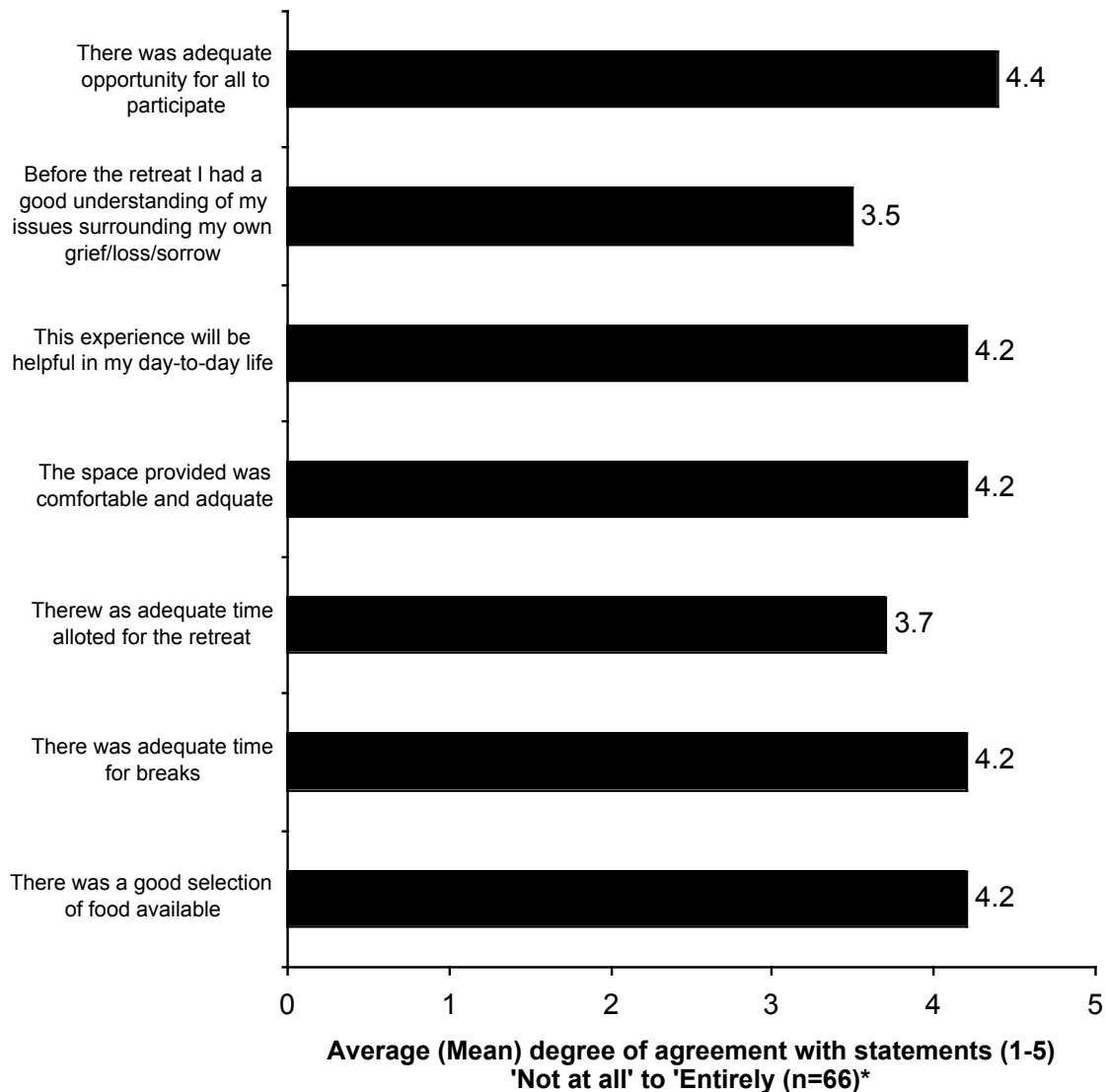


Weekend Evaluation. On a scale of 1 to 5, where 1 is 'Not at all' and 10 is 'Entirely', please indicate the degree to which agree or disagree with the following statements ...



Retreat Rankings - Phase II

To what degree do you agree or disagree with the following statements



Weekend Evaluation: On a scale of 1 to 5, where 1 is 'Not at all' and 5 is 'Entirely', please indicate the degree to which you agree or disagree with the following statements ...



Facilitation & Venue Rankings - Phase II

Qualitative Evaluation Exercise
Long-Term Survivor Weekend Retreats 2004/2005

*There is a light that I am trying to express”
- Long-Term Survivor*

Method

Evaluation exercises included participant completion of a visual qualitative feedback instrument of the two and a half day weekend retreat. Participants were asked: ‘what they liked most about the retreat experience; what didn’t work for them; comments about the facilitators; suggestions for future retreats; and what ‘gifts’ they see themselves taking away from their experience.

FINDINGS

Overall Retreat Experience

Overwhelmingly participant commentary on the retreat experience, venue, attributes of each session segment (multiple-loss theory, collage, grief-journey and resiliency map) and retreat facilitation was positive and complimentary.

Survivor comments on positive aspects of the retreat focus on the ability of the facilitators to create a safe and comfortable atmosphere throughout the retreat – an environment of compassion safety and connection. Survivor and Provincial AIDS Service Organization Worker statements express that there was a genuine ‘feeling of being supported’ and a strong connection to the ‘sharing of life stories’ and the fellowship’ created through the ‘compassion and solidarity among the participants and facilitators.’ Survivors and Provincial Workers liked that facilitators were able to sustain a non-pressure, non-judgmental environment allowing everyone to share and ‘fully participate honestly and openly’.



Overall Experience - Phase II

The environmental setting of the retreat, for some participants also contributed to their positive experience, being in a comfortable space, with comfortable seating (couches and not conference chairs) and an outdoor environment to enjoy contributed to the comfort and quality of their experience. In addition, there was a general receptiveness of learning multiple-loss theory and having adequate time and 'facilitator patience' to complete the creative/artistic segments of the retreat.

- *The facilitators were very wonderful, they did a great job. The sharing circle was my favorite part, it gave everybody a chance to speak, knowing that we all shared some sort of burden that we carry. Thank you for your support and thank you for being so understanding.*
 - – Long-Term Survivor.

- *Interaction with others, kindness of others, amount of support from others, knowledge, education, techniques I.e. breathing techniques, aromatherapy.*
 - – Long-Term Survivor.

- *That everyone got along and no one was judgmental, and that there was a strong understanding of what everyone was going through.*
 - – Provincial AIDS Service Organization Worker.

- *Met new people and made me feel less alone in my sorrow that I wish I could've met under different circumstances*
 - – Provincial AIDS Service Organization Worker.



Constructive Comments - *Phase II*

Constructive Comments

There were very few comments by survivors on negative aspects of their retreat experience. Indeed, most comments to this question were that ‘everything was positive’ or ‘Every part of the experience worked for me’. A couple of Survivors did not like the amount of time spent on ‘Board member roles’ - stating that this segment was ‘too long and irrelevant for the objective of the retreat.’

As there were multiple retreats across Ontario, not every retreat was conducted in the same venue or geographic location. While the overwhelming majority of comments were positive with respect to retreat venue, setting and catering, there was one region where an alternative setting should be sought for future retreats, as multiple comments were noted on the food and sleeping quarter quality.

There was a substantial and significant qualitative difference between Provincial Worker and Survivors comments on aspects they did not like about their retreat experience. Survivor comments were highly introspective and acknowledged the challenge or discomfort with ‘[their] own personal barriers to [full] participation’. Conversely, some Provincial Workers felt that there was too much time allotted to check-in segments, one worker expressed discomfort with acknowledging current or present grief, and that they were ‘just trying to put it behind them’; and dislike of having to be ‘in a supportive role’. For one Provincial Worker having the retreat commence on Friday, after a week of work was ‘tough’.



Constructive Enhancements - Phase II

Constructive Enhancements to the Retreat Experience

Most retreat participants, both Survivors and Provincial Workers expressed the need to add at least one more day to their experience or begin offering the retreat at least twice a year. While the opening segments, on multiple loss theory and information, the creative expressions; and story-sharing were all received positively, the impact of the Resiliency Map left many retreat participants prepared and open for 'more processing'. Small group sizes in some retreat settings were seen very positively and likely contributed to the positive statements above on the provision of a safe, comfortable and compassionate setting. Some participants expressed that they would like to have future sessions include partners or focused workshops for couples.

There was a resounding expression from Survivors that there be time and/or space either within or outside of the retreat schedule for physical activity and movement, beyond the yogic breathing and focus segments. While our quantitative data did not inquire about physical fitness and activity levels, many Survivors lead a regularly active physical lifestyle to some degree (as much as their wellness and ability allows); and allowance for - or even incorporation of coordinated activities (group hikes) or ensured access at the retreat venue to universal (gym/fitness) facilities should be considered in future retreat planning and venue selection. In addition, there were a few comments on the retreat schedule to follow a 'work-a-day' format with structured morning and afternoon sessions. Survivors suggest a general receptiveness to evening sessions, or allowing time for afternoon breaks for naps or fitness, that are part of their general wellness routine; and individual treatment management and coping strategies. Alternatively, participants suggest commencing sessions in the afternoon running through into early evening, which allows for the morning-time and late-evening time free for personal activities and rest. Lastly, final commentary suggests that aromatherapy be available in a separate space from the facilitated sessions to accommodate those with environmental (scent) sensitivities.



A Message to Facilitators - Phase II

A Message to Facilitators

Survivor and Provincial Worker statements to retreat facilitators steep with gratitude and encouragement to continue and extend the impact of the Project. Their heartfelt statements from Long-Term Survivors, inclusive of Provincial Workers speak for themselves:

Wow! Awesome as usual Yvette and we need to do this at least 2 times a year, seriously!

Yvette and Wayne you're our angel of hope - keep up the work.

You do great necessary work and we still need more.

Thank you, I appreciate the tools you have given me to further understand "The Journey for Multiple Losses" This helps me cope with the reality of loss.

Keep on going! Specially Anna, her radiant soul and her great generosity glued the group together.

They [Facilitators] were all great! With all do respect to others, especially mentioning Anna for being there for me when I was so sick.

I love all the facilitators and a fantastic job they do. Keep the work and sharing.

You're doing one hell of a job. It's quite evident the level of experience you possess.

Excellent team work. We need this type of workshop to keep going, to build team support and to take care of our selves.

Do more and get that funding and get our voices heard.



Participant Acknowledgements - Phase II

Acknowledgment of Gifts from Retreat Experience

Participants acknowledge a number of gifts they found in their experience at the Survivor Retreats. Only one participant from the 2004/2005 retreats said they were taking 'nothing' away from their experience at the retreat. The remainder of retreat participant mentions on gifts they acknowledge from their participation, were as follows:

–“ Love, Hope, I am not alone any more, Resiliency to live, gift of learning to appreciate so much hope and strength, Feeling of belonging at last, Love myself and others, Many new friends, Other people’s voices, other people’s faces, Perseverance, Compassion, –Community, A warmed heart, a warm and wonderful experience, serenity, permission, a new understanding of where I am now with my losses, being able to tell my life story and [having] friends that understand, that I am not alone and there is hope, ability to deal appropriately with loss, grief and depression, my life back, peace and heart of soul, motivation to help and give back to the HIV Community, less isolation, more willingness to share openly and honestly without fear of rejection.”

Cumulative survivor statements express – overwhelmingly - the recognition and acknowledgement of their own life-expression and the safety to do so, within their community and personal relationships. As one Survivor states ‘I have a light I am trying to express’; when asked – what gift they are taking away from the retreat experience, this Survivor responds: ‘A brighter light’.