



Understanding AIDS-related bereavement and multiple loss among long-term survivors of HIV in Ontario

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Abstract: AIDS-related bereavement has been linked in recent studies with rapid HIV-symptom onset and increased mortality among people living with HIV. Social support and social environments are important elements in grief resiliency and hastened recovery. This study examined the impact of retreats conducted by the AIDS Bereavement Project of Ontario to address these issues. Participants (N = 67, M = 53, F = 13, Trans = 1) were primarily HIV+ (86%), self-identified as gay (64%) or straight (19%), and were between 34-63 years of age. Those who were HIV+ had been living with HIV for an average of 12 years (6-18). Participants had experienced an average of 157 AIDS-related deaths, 76 non-AIDS-related deaths and multiple non-AIDS related losses. Measures of AIDS-related bereavement, social relationships, sexual relationships, psychosocial well-being and resiliency indicated some improvements over baseline in each domain at three week and/or three month follow-up. The policy and community-based partnerships that shaped this program of research are described, as are possible implications for HIV prevention.

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Introduction

Communities across Canada have experienced tremendous loss of life from the human immunodeficiency virus (HIV). As of June 30, 2007 a total of 63,604 positive HIV test results have been reported to the Public Health Agency of Canada (Public Health Agency of Canada, 2007). For the same period, Acquired Immune Deficiency Syndrome (AIDS), the condition ascribed to the effect HIV has upon the human immune system, has been reported for a total of 20,799 people in Canada (PHAC, 2007). As of December, 2006 a total of

13,347 have died from AIDS (PHAC, 2006a). Of the 18,560 adult male AIDS cases reported, 76.1% (14,105) have been gay, bisexual or other men who have sex with men (PHAC, 2006a). In the absence of a cure, AIDS-related loss and bereavement is ongoing; and based on current HIV test reports, losses in Canada will continue to be most centred in the gay and bisexual male community (PHAC, 2006b). For people, primarily gay and bisexual men, who continue to survive the first era of AIDS (1983-1995), we use the term long-term survivors (LTS). These individuals have experienced the cumulative loss of partners, lovers, spouses, friends, brothers, and



acquaintances. For some, the number of deaths experienced has been in the hundreds, equating to an entire decimation of individual social networks and their known communities.

AIDS-related bereavement has been cited as multiple, repetitive and complex, and directly related to the psychological and physical health of people living HIV-positive (Sikkema, Hansen, Meade, Kochman, & Lee, 2005). A growing number of studies report that AIDS-related loss among HIV-positive persons is strongly and significantly associated to early onset and/or frequency of HIV symptomatology, poor cellular immune measures, and faster progression to AIDS (Martin & Dean, 1993; Kemeny & Dean, 1995; Goodkin et al., 1996; Goodkin et al., 1998; Goodkin et al., 1999; Bower, Kemeny, Taylor, & Fahey, 1998; Bower, Kemeny, Taylor, & Fahey, 2003; Reed, Kemeny, Taylor, & Visscher, 1999; Sikkema et al., 2000). In addition, psychosocial factors, such as negative affect, depression, stress, and limited social support have also been significantly associated with HIV disease progression and mortality (Theorell et al., 1995; Leserman et al., 2000; Leserman et al., 2002; Farinpour et al., 2003; Moskowitz, 2003). AIDS-related multiple loss has also been shown to affect the psychological and physical health of HIV-negative gay men, who are also long-term AIDS-related multiple loss survivors (Mallinson, 1999).

Bereavement services assist people in response to past, current and anticipated bereavement, and have the potential to improve individual resiliency and health-related quality of life amidst ongoing AIDS-related loss (Sikkema et al., 2005). Supportive bereavement services were recently noted in an analysis of qualitative interviews from a large Canadian cohort study as an essential service for both HIV-positive and HIV-negative gay and bisexual men (Haubrich et al., 2006). In particular, the contribution of bereavement support to sustaining resiliency in a reality of ongoing loss and community devastation is also being recognized as important from a service provision, occupational health, employment satisfaction and staff retention perspective for both people living HIV-positive and those providing care (Demmer, 2001; PBCHRWG, 2003).

Two comprehensive intervention studies have examined the effectiveness of bereavement support in the address of psychological trauma, distress, psychosocial impact, bereavement symptoms and health outcomes for people who have experienced AIDS-related loss (Sikkema, Kalichman, Kelly, & Koob, 1995; Sikkema, Hansen, Kochman, Tate & Difranceisco, 2004; Sikkema et al., 2005; Goodkin et al., 1999). Longitudinal findings from Sikkema and colleagues' (2004) randomized control trial represent solid scientific evidence for the effectiveness of group-based bereavement support upon health, well-being and quality of life outcomes for people living HIV-positive. Reports from the study found that general and HIV-specific quality of life, personal coping strategies, resiliency across the longitudinal course of grief; and, psychiatric and psychosocial distress all improved for participants assigned the group-based bereavement intervention. Participants assigned to individual psychotherapy remained the same or deteriorated across these domains (Sikkema et al., 2004; 2005; Hansen et al., 2006).

AIDS-related bereavement and HIV prevention

HIV prevention initiatives have traditionally intervened at the point of altering risk behaviours and disseminating knowledge related to HIV transmission. This method is easier for program and policy planners and funding mechanisms to support and follow through upon with respect to funding and staff commitment. However, behaviour change and individual outcomes related to these efforts tend to be short-term and individually unsustainable over time. The inability for risk-behaviour focused prevention to be sustainable over the long-term is likely due to the strong and persistent influence of cognitive-behavioural factors known to mediate sexual risk-behaviours; (Beck, McNally & Petrak, 2003; Strathdee et al., 1998; Kalichman, Kelly, Morgan & Rompa, 1997; Gold & Skinner, 1992; McMahan, Marlow, Jennings & Gomez, 2001). Further, prevention efforts that markedly affect the influences that create a social and cultural environment for the occurrence of risk behaviours to occur have been shown to have a greater impact on sustained cognitive-behaviour change across time than do prevention efforts focused solely on risk-behaviour change (Anderson & Fielding, 2003;



McMichael, 2002; Evans, Barer & Marmor, 1994). In comparison with individual approaches, community-level approaches to health promotion are able to reach large numbers of people quickly and have been used successfully in public health responses to HIV (Hays, Rebchook & Kegeles, 2003; Sikkema et al., 2005) and in a number other areas of health promotion (Bracht, 1990; Taylor et al., 1998; Schensul, 1998). It has been also suggested that community-mobilization efforts may avert the most number of new infections than any other prevention strategy (Cohen, Wu, & Farley, 2005).

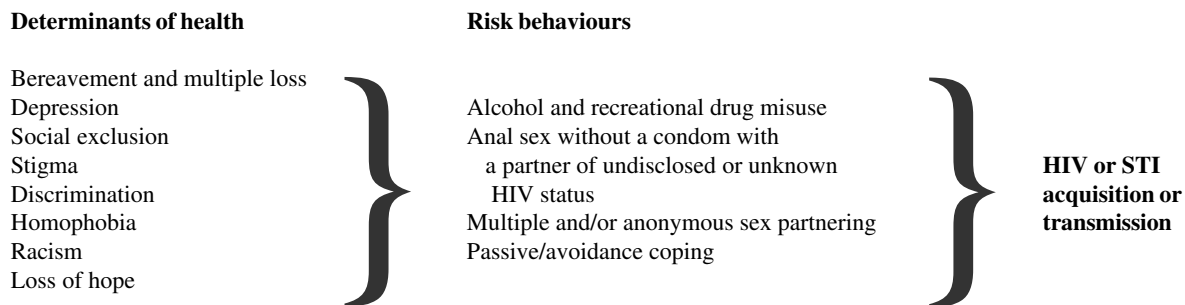
A cognitive behavioural framework offers a model of understanding the disparateness (etiological heterogeneity) of conditions; accounting for emotional, mental, social, spiritual and behavioural influences upon health. Considering the evidence cited above, Figure 1 illustrates how bereavement support may broadly address cognitive-behavioural factors related to HIV risk behaviours from a Determinants of Health perspective, as defined by the Canadian Institute for Advanced Research (Raphael, 2003). Bereavement support intervenes specifically in the areas of personal health practices and coping skills, social status and social support networks, and broadly in the areas of physical and social environments, biology and genetic endowment, and health services. In the context of this model, programming and interventions addressing bereavement, grief and AIDS-related multiple loss may reduce risk behaviours related to the spread of HIV and other STIs. Whereby, social inclusion and resiliency to bereavement, discrimination, homophobia, racism, HIV stigmatism, AIDS phobia and hopelessness is supported by an ontological

framework of self-trust and resilience—potentially enabling contexts of risk behaviour to prevail less in sexual relationships.

Background to the current study

Since 1994, the AIDS Bereavement Project of Ontario (ABPO) has been providing and developing educational workshops, resources, training modules and support services for executive, staff and volunteers of AIDS Service Organizations (ASOs). In 1999, the AIDS Committee of Ottawa asked ABPO to create a workshop to address AIDS-related multiple loss and community devastation. This work generated significant community response and established the need for a province-wide initiative. The resulting intervention framework, “‘Survive & Thrive’: Practical tools for surviving and thriving with ongoing loss”, was designed in consultation and collaboration with ABPO staff, ASO Support Workers who were members of the ‘Survive & Thrive’ Working Group, Long-term Survivors, researchers academically trained in community health and social epidemiology (CL and RT), and ABPO’s Provincial Advisory Committee. The present study assessed the impact of a group bereavement support intervention for people in Ontario who have experienced AIDS-related losses. The analysis reports differences between pre- and post-retreat responses to questions designed to elicit feelings associated with bereavement and related domains including social and sexual relationships, depression and anxiety; and resiliency. Community-based action-outcomes and study implications are interspersed in the discussion.

Figure 1 Cognitive-behavioural determinants of health and factors related to risk and transmission





Methods

The Intervention: ABPO's 'Survive & Thrive'

The intervention was a two-day retreat, hosted in an accessible facility with accommodation and food services on-site. Retreats were conducted in four regional sites in Ontario: Ottawa, London/Windsor, Guelph and Toronto from September 2002 to April 2003. On-site accommodation and/or local travel costs were covered where appropriate and childcare subsidies were made available for parents. Two follow-up sessions at three weeks and three months after the retreat were coordinated for two Ontario sites as a means of ensuring an ongoing support mechanism within the intervention framework.

The intervention itself took the form of a structured bereavement support group informed by the resiliency strategies of long-term HIV-affected community members. The retreat format, a facilitated "sharing circle", was selected to allow participants to explore more deeply emotional aspects of grief, loss and ongoing healing in a safe space with community peers. The agenda combined educational elements of grief, loss, bereavement and trauma theory; a variety of creative arts-based and storytelling exercises; and prior to the beginning of retreat exercises, completion of quantitative and qualitative evaluation instruments. The agenda also included appropriate debrief and closure segments at the end of each day.

Promotion and recruitment for the intervention

Retreat participation was open to any person in Ontario who had experienced AIDS-related losses, regardless of HIV status. Community information forums were hosted at four Ontario regional AIDS Service Organizations, two to four weeks prior to the retreat date. Outreach and promotional materials were provided to ASO staff and support workers prior to the forum as a means to inform existing clients and the broader community, highlighting the opportunity to learn more about attending the 2-day retreat. Forum attendees were encouraged to share this information with others who might be interested in attending including community members not connected with an agency. Promotional posters with

retreat dates and registration information were also distributed to ASOs across Ontario. Potential retreat participants were able to register for the retreat at their local ASO or with ABPO directly.

Evaluation: A community-based research approach

This community-based evaluation of ABPO's bereavement intervention operated under the nine key principles of Community-based Participatory Research (CBPR) (Israel, Schulz, Parker, & Becker, 1998). In the health sciences CBPR is guided by the principles of shared decision-making, power, and resources among the participants. The value of CBPR rests in the collaborative approach of diverse research teams engaged in all aspects of the research process working together to improve health and well-being through taking action and using results to affect social change (Viswanathan et al., 2004).

The AIDS Bereavement Project of Ontario developed and secured funding for the 'Survive & Thrive' community-based bereavement intervention, evaluation protocol and associated instruments in collaboration with community members, ABPO's Provincial Advisory Committee and community-based researchers. At the time this project partnership was formed, the researchers were not affiliated with an academic institution. Hence, formal ethical approval for this evaluation protocol was not sought. To ensure the safety of participants, ABPO's Provincial Advisory Committee served as the review board for the intervention, evaluation procedures and instruments. Volunteer committee members included nurses, social workers, policy makers, bereavement support professionals, researchers, first nation and aboriginal community leaders and service organizations, long-term survivors, and community members.

Evaluation protocol

The objectives of this community-based evaluation project were to understand the experience of multiple AIDS-related losses in Ontario and to measure the initial and sustained impact of the 'Survive & Thrive' intervention on persons attending. The evaluation plan had participants complete a research questionnaire and a qualitative journal tool at three intervals: (1) prior to the retreat; (2) three weeks after the retreat; and (3) three months after the retreat. The



follow-ups were done, when possible, at an in-person evening session facilitated by ABPO staff. At these follow-up sessions, participants took time together to debrief the retreat experience, check-in with current dialogue, and contribute to the facilitated session. Participants completed the follow-up evaluation package at the end of each of these sessions. Those unable to attend the 3-week and/or 3-month, in-person, follow-up sessions and those from regions where in-person sessions were not possible due to funding constraints were sent an evaluation package by mail at the appropriate intervals. The follow-up evaluation package consisted of an information/reminder letter, evaluation instruments, and a prepaid ABPO addressed envelope. Participants were not financially reimbursed for completion of evaluation instruments.

The informed consent process

The research team developed the process to obtain participant informed consent relating to voluntary participation in the evaluation segment of the bereavement intervention. It was the perspective of the research team that oral consent, rather than a printed and signed consent form was the best means to integrate a participatory informed consent process into the 'Survive & Thrive' retreat agenda. Oral consent is generally acceptable for research with minimal risk, or where loss of confidentiality is the primary risk and a signed consent form would be the only piece of identifying information for study participation.

Informed consent was obtained at the beginning of the retreat directly after the official welcome and introductions were completed in the form of a "sharing circle." Facilitators then led an oral informed consent process with retreat participants whereby the facilitator explained in detail: (i) The community-based background, approach, objectives and purpose of the evaluation project; (ii) expectations of participants completing the evaluation materials, including the amount of time likely to be required for this process; (iii) expected risks and benefits; and (iv) the voluntary nature of participation.

With respect to the latter, it was made clear that those who decided to not participate in the evaluation, or who withdrew from the evaluation at any time, would not jeopardize their involvement in the 2-day retreat

(intervention) or their access to ABPO services or other healthcare or social services available to participants. The facilitator also outlined: (v) how confidentiality would be protected and (vi) the name and contact information of the research team where questions could be directed relating to the evaluation. The facilitator then introduced the survey instruments and invited questions from the group to collectively address them and to clarify points of concern. Consenting participants were then provided time to complete the evaluation package. Finally, consenting participants provided their mailing information on a separate form to facilitate the 3-week and 3-month follow-up segments of the evaluation protocol.

Measures

Well-validated and standardized instruments were initially considered for relevant indicators; however, consensus among the research team opted against standardized quantitative measures because of the likelihood that retreat participants would be less receptive to complete all three data collection segments. A key concern guiding the development of the research instrument and associated measures was the understandable possibility of research fatigue among persons living HIV-positive and particularly among men who identify as gay or bisexual, the largest segment of the intervention target population. The research team therefore developed an instrument package that included a detailed quantitative questionnaire with direct community-based measures that would engage participants. For example, instead of using an objective scale to assess depression, we asked respondents: "On a scale of 1 to 10 where 1 is 'never' and 10 is 'all the time', when thinking about your grief and loss, how often do you feel depressed?"

Multiple loss assessment questionnaire

This is the three-section questionnaire newly developed for the purposes of this study.

Section 1: Questions elicited information on sociodemographic, personal background and social identity variables (age, sex, gender, sexuality, ethnocultural and other communities of belonging) and on HIV status; total number of AIDS and non-AIDS-related losses, and counselling and/or therapy background.



Section 2: One qualitative open-ended question allowed participants to identify their experience of physical and emotional effects that they directly ascribed to AIDS-related grief and loss. The other 32 questions spanned the five domains of interest in the study: (i) individual bereavement experience; (ii) social relationships; (iii) sexual relationships; (iv) psychosocial indicators such as depression and anxiety; and (v) resiliency. For all questions in each domain, respondents indicated the frequency of feeling on a scale of 1 to 10, where 1 was “never” and 10 was “all the time.”

Section 3: Sources of social support, volunteer and/or staff involvement with the local AIDS Service Organization (ASO), and overall retreat and facilitator assessments. Follow-up questionnaires included sections two and three only. Participant data were linked using a non-identifying participant code.

Qualitative journal instrument— “Climbing the Tree of Life”

Figure 2 (inset) illustrates the qualitative journal instrument developed for the evaluation: “Climbing the Tree of Life.” The instrument was designed to engage participants in a reflective narrative about their current state of being. Participants were asked to choose a child on the tree that best reflected where they saw themselves in their lives at that moment. Then, using paper provided, explain why the child they circled best illustrated where they saw themselves in their life at that time. In essence, the child chosen on

the tree allows participants to compose their present perception of “self”—or self-perception.

Data analyses

Descriptive statistics and paired pre/post Wilcoxon signed rank test were used to examine the initial and sustained impact of the retreat on quantitative measures. Stage-1 analysis examined baseline (pre-retreat) descriptive results. In Stage 1 responses to the five domains (range: 1-10) were coded as follows: 1 to 3 as “never to rarely,” 4 to 6 as “sometimes” and 7 to 10 as “regularly.” Stage 2 examined changes between paired participant responses from baseline and the first (3-week) follow-up; and stage 3 examined changes between baseline and the second (3-month) follow-up.

Analyses of quantitative data were conducted in SAS V8.12 and SAS V9.1. Qualitative data from the “Climbing the Tree of Life” narrative journal tool were aggregated and analyzed for general themes between baseline and follow-up segments. Results by Ontario retreat site are not presented. Evaluation findings are presented aggregately.

In keeping with CBPR methods all findings were subjected to detailed analytical review and discussion sessions with the research team and ABPO’s Provincial Advisory Committee. Findings were also presented and discussed in sessions facilitated by ABPO staff and researchers to existing, new and emerging project partners; community members—including intervention retreat participants; policy professionals; and healthcare and social support professionals. These discussion sessions greatly informed the final interpretive findings of the data, established implications for stakeholders, and contributed to the development of action-outcomes outlined in the discussion.

Results

Participant characteristics

Among the 70 persons who attended the retreats across Ontario, 67 (96%) completed baseline (i.e. pre-retreat) evaluation materials. The overall provincial response-rate, from pre-retreat to three weeks, was 62% (n = 41). A total of 58% (n = 39) completed 3-month follow-up instruments. This

Figure 2 Climbing the Tree of Life





sample was sufficient to allow for meaningful analyses at all three stages.

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, had been living with HIV for approximately 12 years (range: 6-18). In addition, 56.7% of participants currently volunteered at their local AIDS Service Organization, with a small proportion (8%) currently employed as ASO staff. On average, participants had resided in their city or town of residence for 22 years.

Retreat participants represented a number of cultural and linguistic communities. Self-identified ethnocultural background reported by participants included: African, Arab, British, Caucasian /White, Christian, Canadian, English, French Canadian, Latin, Portuguese, Scottish, Trinidadian and White-Anglo Saxon Protestant. On a scale of 1 to 10, where 1 was “not at all attached” and 10 was “very attached” participants reported the highest degree of attachment with the PHA (People Living with HIV and AIDS) community (mean: 6.9), followed by the gay community (mean: 6.1) and the women’s community (mean: 2.5). Other communities of attachment included: cultural or linguistic communities, personal interest or recreational communities, faith or spiritual communities, and family or strong friendships.

Across Ontario, participants indicated having experienced an average of 157 AIDS-related deaths in their lifetime and 76 non-AIDS-related deaths. Participants also reported experiencing additional “significant” tangible and intangible losses throughout their lifetime, such as: male relationships, partners/lovers, friendships, family, career, income, health, body image, privacy, independence, pets; and losses related to international migration. Travel to the United States was also cited due to the US discriminatory immigration and travel policy that prevents people known or suspected to be living HIV-positive to travel into the United States or cross the Canada-U.S. border.

All retreat participants indicated that they experienced physical and emotional effects from their grief/loss.

While physical effects from grief/loss are difficult to discern due to the potential correlation with side effects from HIV treatments, all participants indicated that they had experienced insomnia and/or fatigue that they specifically associated to their grief and loss. Most often, the emotional impact participants directly related to their grief and loss included: depression, anxiety, stress, anger, frustration and hopelessness. Emotional effects also included “difficulty concentrating,” “lack of interest,” “dealing with non-empathetic family/friends,” “loss of life,” “loss of coping strategies,” “disappointment,” “discouragement,” and “despair.”

Approximately 7% of participants reported using alcohol daily, 32% weekly, 21% monthly; and 39% reported using alcohol less than once a month. Weekly recreational substance use was reported by 22% at baseline, of these, daily use was reported by 21%. We did not ask about what substances were used. This question was omitted from follow-up questionnaires.

The majority of participants (88%) reported having received professional support in the past for such issues as: counselling around HIV status, sexuality, relationships, family and bereavement. Current sources of support at baseline and three months after the retreat are presented in Table 1. At baseline, friends (73%), local AIDS service organizations (61%) and family (45%) were the primary sources of current support for retreat participants. Three months following the retreat participants slightly

Table 1 Current sources of support

Current sources of support	Baseline		3-months post retreat	
	n	%	n	%
Friends	(49)	73%	(30)	79%
AIDS service organization	(41)	61%	(26)	68%
Family	(30)	45%	(20)	53%
Counselor	(18)	27%	(13)	34%
Psychologist	(16)	24%	(10)	26%
Psychiatrist	(12)	18%	(5)	13%
Private therapist	(12)	18%	(9)	24%
Other service organization	(8)	12%	(10)	26%
Partner	(0)	0%	(7)	21%
Spiritual advisor/priest	(8)	12%	(3)	8%



increased the proportion of personal and professional social supports from baseline, except for support from a psychiatrist, spiritual advisor or priest. Of note, three months after the retreat 21% percent cited an intimate partner as a current source of support, where an intimate partner was not mentioned as a source of support at baseline.

The vast majority of participants (86%) reported that they had a personal faith/belief system of some kind (we did not ask religious or spiritual denominations or affiliations). Among those indicating they had a personal faith/belief system, 77% reported that their grief and loss related to HIV and AIDS had changed their belief system in some way—"heightened," "shattered," or "sought new faith/belief system."

Feelings of AIDS-related bereavement and loss: Baseline measures

Table 2 presents baseline results for participant experiences of bereavement, the perceived effect of individual grief and loss on sexual and social relationships, psychosocial well-being and perceptions of individual resiliency. Perceptions of personal bereavement experience varied at baseline, illustrating that retreat participants spanned a broad spectrum of awareness about their losses, their personal grieving process and reality of the losses they have experienced. Results indicate AIDS-related grief and loss considerably affects sexual relationships and individual perceptions on the importance of sex; and adversely impacts capacities for social relationships. Indicators of psychosocial well-being and resiliency also varied, suggesting that perspectives and capacities for well-being and resiliency develop and exist relative to one's own personal capacities and life experience.

Sustained impact of the intervention

Table 3 presents statistically significant mean difference scores across the five domains, and baseline; and follow-up means. The paired Wilcoxon signed rank test was used to determine if scores for the respective measures significantly changed for individual participants after the group intervention, with $p < 0.05$ and $p < 0.001$ indicating statistical significance. The test demonstrated that a number of self-rated scores improved for participants three weeks after the retreat and were sustained

(statistically significant from baseline) three months following the retreat, with additional improvements in each of the measures within the five domains three months following the retreat.

Specifically, three weeks following the intervention participants were less likely than they were at baseline to feel negatively with respect to most measures within the psychosocial well-being domain. (feeling depressed, lonely, sad, anxious), these results were sustained at three months following the intervention. Participants also improved across resiliency measures at three weeks, results suggest participants were more likely to feel happy about the way life is going, not as worried or concerned about their future; and were less likely to feel guilty for still being alive. At three months only less likely to "feel guilty for still being alive" remained statistically significant. Improvements were also notable across sexual relationships: three weeks after the retreat participants were less likely to feel that their grief/loss affected their sex drive, and having less sex. These findings were sustained at three months; and at this time, participants were also less likely to feel that sex was less important to them and reported feeling less frustrated with sexual relationships. Social relationships also improved at follow-up with participants reporting less frustration with others at three weeks and three months after the retreat; and at three months—less like withdrawing from social activities ($p < 0.001$). Bereavement experience also improved at three months; where participants were less likely to feel they didn't understand their feelings and were less likely to feel they had been grieving too long.

We also asked on the final follow-up questionnaire whether participants experienced an AIDS-related death since the intervention, 34% ($n = 13$) of participants who completed this instrument ($n = 39$) reported having experienced one or more AIDS-related loss in their social network within the three months following the retreat.

Longitudinal perceptions of self—Results from "Climbing the Tree of Life"

Three narrative themes emerged from baseline qualitative narrative data.

1. *Contentment with life:* Narratives described life being "full" and "complete," and some



Table 2 Frequency of feeling—prior to the intervention

How often do you feel ...	N	Frequency of feeling - baseline		
		Rarely %	Sometimes %	Regularly %
Experience of AIDS-related bereavement				
that you are grieving too long	63	41.3	15.9	42.9
that you should just 'get on with it'	63	25.4	20.6	54.0
like your losses are somehow not real	64	49.1	18.9	32.1
that your losses are not important	63	65.1	19.0	15.9
that you just don't understand your feelings	63	31.7	36.5	31.7
Sexual relationships				
like having more sex	65	63.1	7.7	29.2
like having less sex	65	55.4	12.3	32.3
that sex is more important to you	65	69.2	10.8	20.0
that sex is less important to you	64	51.6	12.5	35.9
sex drive	54	33.8	15.4	50.8
frustrated with sexual relationships	65	29.2	15.4	55.4
Social relationships				
that you just don't have enough supports in your life	65	38.5	32.3	29.2
like withdrawing from social activities	66	15.2	28.8	56.1
that you somehow don't measure up	65	41.5	20.0	38.5
frustration with others	65	24.6	36.9	38.5
ability to make new friends	66	37.9	21.2	40.9
Psychosocial well-being				
sad	66	25.8	25.8	48.5
lonely	66	21.2	28.8	50.0
depressed	66	25.8	30.3	43.9
like crying	65	46.2	26.2	27.7
anxious	66	28.8	33.3	37.9
helpless	66	43.9	25.8	30.3
Resiliency				
that there is no point to life anymore	63	50.8	27.0	22.2
ability to conduct my day to day responsibilities	66	40.0	27.3	31.8
ability to take care of myself	66	47.0	22.7	30.3
unhappy about the way life is going	66	34.8	19.7	45.5
worried about your future	66	22.7	30.3	47.0
that there is nothing worth planning or saving for	66	37.9	36.4	25.8
that you just can't cope	66	53.0	28.8	18.2
guilty for still being alive	66	53.0	16.7	30.3
like taking your own life	66	75.8	7.6	16.7
afraid of dying	66	60.0	21.2	18.2

Frequency of feeling on a scale of 1 to 10, where 1 was "never" and 10 was "all the time". Responses from 1 to 3 coded as "never to rarely", 4 to 6 as "sometimes" and 7 to 10 as "regularly."

2. *Illness fatigue:* Narratives described feeling "worn down" and "fatigued" living with a long-term, episodic and debilitating disease.
3. *Coping with multiple loss:* Narratives described respondents seeing themselves as being "beaten" by HIV, "isolating themselves," "withdrawing as a means of coping with effects of multiple loss," and feeling "lonely," "despondent" and "hopeless."



Table 3 Impact of the intervention

Since the retreat, how often have you felt...	N	3-weeks and 3-months from baseline‡		Mean for study period†			
		3-week mean difference score (±SD)	N	3-month mean difference score (±SD)	Baseline (n=66)	3w (n=41)	3m (n=38)
Experience of AIDS-related bereavement							
that you are grieving too long	41	0.76 (2.5)	38	1.31* (3.1)	5.2	4.7	4.4
that you should just “get on with it”	41	1.27* (3.2)	38	0.95 (3.1)	6.2	5.1	5.2
that you just don’t understand your feelings	41	0.61 (2.7)	38	1.03* (3.2)	5.1	4.5	4.1
Sexual relationships							
like having less sex	41	1.29* (4.2)	39	1.49* (3.4)	4.2	3.5	2.8
that sex is less important to you	41	1.12 (3.4)	38	1.42* (3.5)	4.5	3.9	3.4
sex drive	41	1.05* (3.7)	39	1.36* (3.7)	5.7	4.5	1.7
frustrated with sexual relationships	41	0.39 (4.1)	37	1.08* (2.8)	6.1	5.6	5.5
Social relationships							
like withdrawing from social activities	41	0.71 (3.8)	39	1.67** (2.8)	6.4	5.8	4.9
frustration with others	41	1.05* (2.8)	39	1.31* (3.1)	5.7	4.9	4.6
Psychosocial well-being							
sad	41	0.88* (2.3)	39	0.95* (2.1)	6.0	5.5	5.0
lonely	41	0.78* (2.5)	39	1.20* (2.8)	6.3	5.8	5.3
depressed	41	0.90* (2.1)	39	1.20* (2.5)	5.9	5.4	4.9
anxious	41	0.93* (2.8)	39	0.95* (2.8)	5.7	5.0	4.9
Resiliency							
unhappy about the way life is going	41	1.46** (2.9)	39	0.82 (2.2)	5.7	5.2	4.9
worried about your future	41	1.54** (2.7)	39	1.00 (3.0)	6.3	5.2	5.5
guilty for still being alive	41	1.07* (3.0)	39	1.33* (3.0)	4.1	3.3	2.4

‡ Change values based on paired respondents across study period. Responses ranged from 1 (never) to 10 (all the time); thus difference scores may range from -10 to 10. Change values represent mean differences among paired responses at 3 weeks and 3 months and do not illustrate the direction of the change, but instead the average difference of scores. +/- Values are ignored in the computation of ranking the differences on which p-values of the test statistic are based. The broad standard deviations that cross 0 in all items are indicative of the breadth of reduced “negative affect” in paired responses from baseline to follow-up periods among paired respondents. The direction of the change is illustrated by the change in mean score across the study period.

† Approximate n values identified for baseline, 3m and 3w period (unpaired responses).

* 95% : $p < 0.05$

** 99% : $p < 0.001$

Three weeks after the retreat many narratives described participants seeing themselves as having “fallen from the tree,” now “struggling to get back on,” or on an “emotional roller coaster,” “feeling exhausted, less able to cope and fragile.” Three months following the retreat respondent narratives describe 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.”

Discussion

This project sought to understand the experience of AIDS-related loss among long-term survivors in Ontario; and examine outcomes related to ABPO’s peer-based bereavement support group intervention. Our community-based approach to the intervention and evaluation made every effort to honour the gay, bisexual, lesbian and trans communities that continue a legacy of community, organizational and individual development, understanding, and recognition of



multiple loss in the context of HIV. This article represents the first report of AIDS-related losses for Ontario at the community level and the effectiveness of a community-based resiliency intervention. The fact that an average of 157 AIDS-related losses has, at the time of this research, been experienced by this community sample of long-term survivors is astounding and devastatingly realistic. At the beginning of the epidemic in Ontario, the gay, bisexual, lesbian, transgendered and transsexual communities galvanized with supportive networks of compassionate and palliative care in response. In a climate of fear that pervaded the delayed professional response to HIV and AIDS at this time, the community mobilized—and it was from here that local AIDS service organizations evolved; and in 1994 that the effort to address grief and loss for survivors working in Ontario communities commenced with the AIDS Bereavement Project of Ontario.

ABPO's intervention framework, *'Survive & Thrive'* significantly improved outcomes of reinvestment in sexual and social relationships, individual psychosocial well-being and resiliency. Scientifically robust bereavement intervention studies support these findings (Sikkema et al., 1995; Sikkema et al., 2004; Sikkema et al., 2005; Hansen et al., 2006; Goodkin et al., 1999); and lend further support for the potential impact that peer-based bereavement support may have on health, well-being and resiliency in the context of HIV and AIDS (Goodkin et al., 1998; Swindells et al., 1999; Sikkema et al., 2000; Ruiz et al., 2005).

While our study does not examine sexual events or their relationship to HIV transmission risk behaviours, our results do suggest that grief and loss support successfully intervenes in this regard to positively address the determinants of health implicated in the cognitive-behavioural risk model (Figure 1) by potentially reducing cognitive behavioural contexts of HIV risk behaviour. In short, people who are better connected socially: feel better about themselves and others, will protect themselves and others from harm, and may be more likely to practice and sustain healthy sexual relationships, thus preventing the spread of HIV and STIs. High-quality research examining bereavement support and sexual relationships is warranted to discern whether and to what degree bereavement support may in fact prevent

the frequency of risk behaviours; and also to determine the potential underlying mechanisms of sustainability and change for both people living HIV-positive and vulnerable populations in global communities that may well be served by bereavement support/resiliency interventions.

Results from the qualitative journal tool deserve some attention. Grounded by grief theory (Warden, 1982), themes suggest that following the retreat some participants were struggling and experiencing emotional distress. This may seem incongruent with the demonstrated improvements in our quantitative results across domains of interest. However, grief theory acknowledges a process of: loss/death, protest, searching, deep questioning—*"the pit,"* reorganization and reinvestment (Kübler-Ross, 1969; Bowlby, 1980, Attig, 2001, Neimeyer, 2001) along a continuum. Our data suggest that participants are situated across this continuum, where the memory of things past and the metamorphosis of letting go of who you were, in order to become who you will be is a difficult process. When sense is made from experience the measurement of loss and recovery may never be wholly justified in research summations of data and may instead be found in the stories of survivors. One participant's journal entry is worth quoting at length:

Before the retreat I had seen myself as pretty "on-course" with my life. I'm [HIV] 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.

Limitations

This community-based evaluation has notable limitations. The loss to follow-up between baseline



and longitudinal data collection phases, though adequate for analysis, may nevertheless subject our results to a degree of bias. The fact that our analysis could not include an examination of characteristics of participants lost to follow-up is also a concern and we suggest some degree of caution in the interpretation of our results. It is possible that respondents who completed all three segments of the evaluation did so because they attended the in-person, follow-up sessions facilitated by ABPO, thus potentially contributing to the effect of social desirability in our results. It is also possible that those in a positive mood, i.e., generally feeling and doing well in addressing their grief and loss and capacities to cope, were more likely to attend follow-up sessions, which served as an ongoing supportive and therapeutic framework of the intervention. If so, this would have affected our quantitative results. However, our qualitative results would suggest the experience of recovery is more complex than this. Recall that 34% of those who responded at the 3-month follow-up had experienced at least one AIDS-related death since the retreat, which suggests that despite ongoing losses, improvements were observed. In addition, the paired-analysis approach addresses this issue by examining individual change from baseline to post-retreat follow-up periods for each individual participant rather than pooling participant scores. Alternative strategies that could potentially minimize volunteer bias were beyond the resources of this project. It was neither possible to offer additional formats to complete the evaluation instruments (online), nor was it possible to include secondary reminders via phone or mail to non-responders. Limitations also arise with the absence of clinical indicators to determine health status (CD4 and Viral load) and the use of self-report psychosocial measures in lieu of objective estimates of mental health. A “waiting group” control sample was beyond the scope of this study but would have added another comparative dimension. Further research is needed to explore the long-term impact of bereavement interventions across clinical, social, mental and spiritual well-being and the potential variations in the effect of the single versus multiple intervention exposure; and the influence of potential mediating factors on sustained resiliency.

Core implications of findings and community-based action outcomes

During the course of this CBPR project new partnerships developed with the Ontario HIV Treatment Network (OHTN); the Public Health Agency of Canada; and HIV and AIDS-serving organizations across Ontario focused on serving women and specific cultural and linguistic communities. Since 2003, evaluation findings have resulted in four concrete action-outcomes directly related to enhancing long-term survivor bereavement support in the province of Ontario. First, numerous core implications were identified by the research team and our partners. These included:

1. Establish better services for community members through strengthening of loss awareness and coping strategies.
2. Address the experience of isolation among long-term survivors through increased opportunity for community involvement.
3. Create opportunities for people’s re-investment in themselves and each other.
4. Improve understandings of depression and strategies towards improved quality of life.
5. Build bridges to members of marginalized communities and to the broader community.

Second, the ‘*Survive & Thrive*’ *Intervention Framework Manual* was designed and made available for agencies to organize and facilitate their own locally defined intervention retreat. The manual is in the public domain and can be accessed via ABPO’s website (www.abpo.org). Third, in partnership with the Ontario HIV Treatment Network and the Ontario AIDS Network, ABPO developed a provincial peer-facilitator training program for long-term survivors. Trainees represented all geographic regions of the province and new partnerships with women’s organizations and ASOs serving ethno-cultural communities and youth.

The fourth action outcome was developed in partnership with the Public Health Agency of Canada. The research team developed a conceptual model for bereavement support to potentially serve as an effective HIV prevention strategy in addressing risk behaviours related to the spread of HIV and other sexually transmitted infections (STIs).

A new era of HIV prevention

Whether prevention programming takes the form of one-to-one voluntary counselling or testing, increased condom availability, partner notification or mass media campaigns, it is impossible to know exactly how many infections are being prevented by such efforts. The fact that surveillance estimates and reports of new infections have not greatly declined in more than five years suggests that the impact of current HIV prevention efforts has reached a plateau (Cohen et al., 2005), particularly with Canada’s most affected population, gay and bisexual men, who continue to represent the greatest proportion of new infections annually (Public Health Agency of Canada, 2006). Our results suggest that improving aspects of the self and one’s relationship and resiliency with the broader community and social-political context through the mechanism of bereavement support has the likely potential to increase the desire for sex (Table 3). A healthy sexual desire, after all, is a marker of well-being. The influence of improved resiliency on increased sexual desire has direct implications for the transmission of HIV and other STIs.

Figure 3 illustrates a cyclical process in which unaddressed AIDS-related bereavement, grief, and loss may result in increased sexual risk behaviours. The model maps the impact of AIDS-related multiple loss within the broader community and social context. It tracks the experience through which individual grief and loss remains largely unaddressed by community health and social service models. It then

links this with evidence from community psychology, behaviour and prevention science to propose that grief and loss support may contribute to a new era of HIV prevention programming.

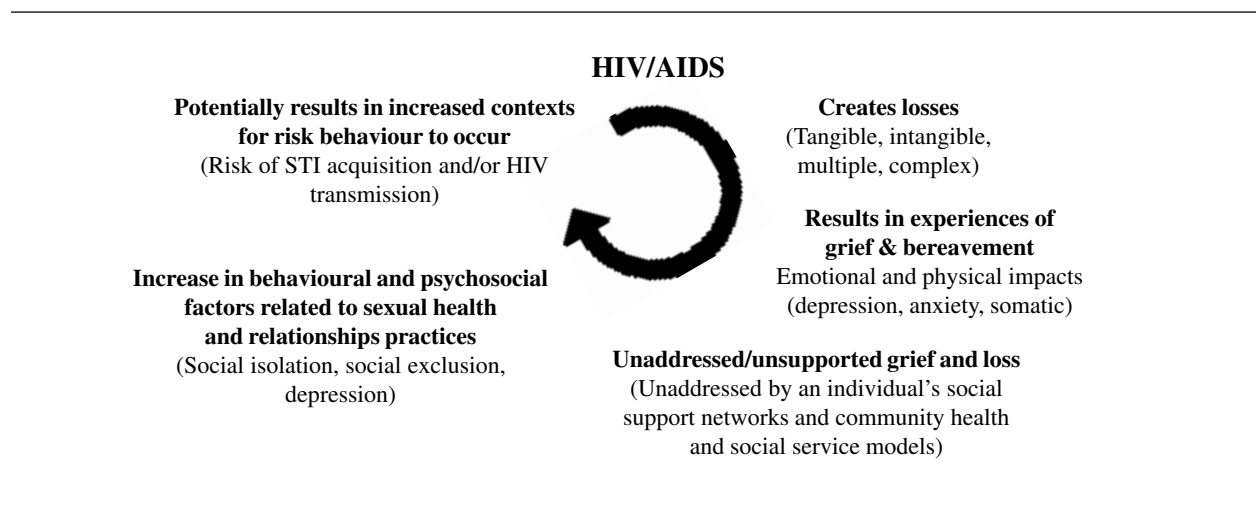
AIDS service organizations (ASOs) and community health centres are well positioned to develop group-based resiliency programming as these agencies are equipped with skilled staff and structural resources to facilitate such initiatives. Further, ASOs in Ontario have been shown to have an impact on sexual risk contexts between men (Leaver, Allman, Meyers, & Veugelers, 2004). Given the demonstrated importance of their presence, ASOs should be encouraged to offer bereavement and resiliency initiatives and support for long-term survivors and the broader communities they serve.

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Figure 3 Conceptual model of bereavement, grief and loss support and HIV risk behaviours





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