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## Sampling, Recruitment, and Retention in a Bereavement Intervention Study: Experiences from the *Living After Loss* Project

Michael Caserta, Ph.D.<sup>1,2</sup>, Rebecca Utz, Ph.D.<sup>2,3</sup>, Dale Lund, Ph.D.<sup>4</sup>, and Brian de Vries, Ph.D.<sup>5</sup>

<sup>1</sup>Gerontology Interdisciplinary Program, University of Utah, Salt Lake City, UT

<sup>2</sup>Center on Aging, University of Utah, Salt Lake City, UT

<sup>3</sup>Department of Sociology, University of Utah, Salt Lake City, UT

<sup>4</sup>Department of Sociology, California State University – San Bernardino, CA

<sup>5</sup>Gerontology Program, San Francisco State University, San Francisco, CA

### Abstract

This paper reports on the sampling and recruitment challenges, as well as the strategies used to address them in the *Living After Loss* (LAL) project, a bereavement intervention study conducted in Salt Lake City and San Francisco comparing two 14-week group conditions with follow-up. We encountered three major challenges: 1) difficulty determining eligibility for some potential participants who were contacted, 2) locating and recruiting nonwhites, and 3) unavailable phone numbers for approximately one-third of those we attempted to contact. Despite these challenges, we achieved a 42% response rate with a sample size of 328 participants comprising 15% nonwhite. Eighty-five percent of the participants completed all of the follow-up data points. Leading factors in participants' decisions to join and remain in the study were 1) opportunities to obtain help and support, 2) to potentially help other bereaved individuals, 3) to contribute to research, and 4) their on-going interactions with a professional, empathetic, and culturally sensitive project staff. Effectively focusing recruitment efforts and carefully and systematically training research staff were among the most effective strategies we employed and therefore suggest for those planning similar investigations.

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Widowhood and spousal bereavement research presents unique challenges in sampling and recruitment of participants (Cook, 2001; Lund & Caserta, 1998; Neal, Carder, & Morgan, 1996). Early assessments are often essential, meaning that research participants must be contacted at a particularly sensitive time soon after the death has occurred. Furthermore, the longitudinal nature of many bereavement studies could contribute to greater reluctance on the part of potential participants to make an initial long-term commitment. Researchers face further challenges in retaining those who have been recruited for the duration of the study (Carr, 2006; Lund & Caserta, 1998; Stroebe, Stroebe, & Schut, 2003).

Recruitment into a bereavement group-based intervention study has additional challenges because potential participants are asked to take part in meetings outside their homes with persons they have never met and also complete highly personal and sensitive questionnaires or interviews. Unlike community based programs into which participants self-select,

intervention research often requires attention to representative sampling and blind study designs with random assignment. Most bereaved individuals will join an intervention study (or any study for that matter) if they believe participating will fulfill their specific needs for support, to help them cope, to share their experiences with others, or to learn new valuable information (Beck & Konnert, 2007; Carr, 2006; Lund & Caserta, 1998; Stroebe et al., 2003). Others are motivated to participate because of altruistic reasons – to help other participants directly or to benefit society by contributing to the development of science (Beck & Konnert, 2007; Lund & Caserta, 1998; Stroebe et al., 2003).

Finally, in bereavement studies as in other research projects, it is also important to enhance participation of persons from diverse ethnic and racial backgrounds. Not only is the inclusion of minorities critical to the generalizability of findings but proposals submitted to federal agencies like the National Institutes of Health require enrollment targets for all racial and ethnic categories. Minorities are among difficult-to-reach segments of the population because they often have less reliance on formal services and some are reluctant to participate due to their distrust of researchers given past historical experiences like the Tuskegee syphilis experiments in the mid 20<sup>th</sup> Century and the associated mistreatment of African American male participants. Consequently, independent of study focus, minority recruitment often requires multiple strategies, including focused outreach efforts, initiating contacts with key members of the community, and use of print and broadcast media (Austin-Wells, McDougall, & Becker, 2006; Gallagher-Thompson et al., 2006; McCallum & Arlien, 2006; Stahl & Vasquez, 2004).

The purpose of this paper is to share with others the effectiveness of the diverse methodological strategies we employed in the *Living After Loss* (LAL) project, a 5-year federally funded widowhood study conducted in Salt Lake City and San Francisco. We will discuss the challenges, strategies, outcomes and lessons learned from our experiences in conducting a longitudinal design that compared two 14-week theoretically-based group interventions. The sampling, recruitment, and data collection phases of the project are now complete, which allows us to report on our experiences so other researchers can use this information as they plan investigations with similar features.

## PROJECT OVERVIEW

The overall purpose of the LAL study was to compare the effectiveness of an intervention guided by Stroebe and Schut's (1999) dual process model (DPM) of coping with bereavement to that of a comparison group that consisted of traditional bereavement support. Briefly, the DPM emphasizes the need for bereaved individuals to oscillate between two coping processes in order to adapt effectively. *Loss-orientation* involves the coping processes directly focused on the stress attributed to the loss itself (such as emotional or affective adjustments) while *restoration-orientation* focuses on coping strategies directed toward ongoing secondary stressors consequential to one's new status as a widow or widower – for example, the need for the bereaved to assume new responsibilities, learn new skills and to adapt to new role expectations, as well as to periodically take time away from grieving itself. The DPM treatment group incorporated elements of both bereavement affective support (loss orientation) and bereavement-related skill-building and education (restoration-orientation), whereas the content of the comparison group meetings was primarily a loss-oriented focus – similar to what is done in most community-based bereavement support groups. We decided to create a meaningful title and logo for the study that would facilitate our communications with participants and community groups. The *Living After Loss* title emphasized the practical nature of our effort and was intended to improve the recruitment of participants.

The initial target sample for this study was 330 individuals, age 50 and older, whose spouse or partner had died within the previous 2-6 months. Equal numbers (n = 165) were intended

to be drawn from Salt Lake City and San Francisco. Participants at both sites were randomly assigned to one of the two study conditions. Both group conditions consisted of 14 weekly 90-minute sessions plus a one-time booster session that occurred approximately 6 months following the conclusion of the weekly meetings.

Once the participants were recruited and then randomly assigned to one of the two study groups, they completed self-administered questionnaires largely consisting of background information and a variety of process and outcome measures commonly used in bereavement research according to the following schedule: Baseline (O1) data were collected prior to the intervention at 2-6 months of bereavement. Post-test (O2) occurred at the conclusion of the 14-week intervention period (at 5 to 9 months of bereavement) with the O3 assessment following 3 months later. The final data point (O4) was 6 months following O3, equivalent to 14-18 months after the loss. The booster session took place midway between O3 and O4, which also was at or near the one-year anniversary of the loss. The focus of the booster session was on addressing and sharing ways to cope with the one-year anniversary as well as to share both the successes and challenges that were experienced since the weekly meetings ended. Besides the four primary data collection points, the study design also included two brief phone interviews (each about 10 to 15 minutes) following the 4<sup>th</sup> and 10<sup>th</sup> weekly sessions to monitor coping processes initiated by each study condition. This was assessed by administering the Inventory of Daily Widowed Life (Caserta & Lund, 2007), a 22-item scale designed specifically to assess the extent to which the participants were engaging in loss- versus restoration-oriented coping.

### Initial Sampling and Recruitment Plan

In order to be eligible to participate in the study, potential respondents must have met the following criteria: (1) their spouse or co-residing partner must have died within the past 2-6 months, (2) they were 50 years of age or older at baseline, (3) intended to reside in the local area for the duration of their participation in the study, (4) were English-speaking, and (5) cognitively and physically able to complete questionnaires and participate in the group meetings. Potential participants at both sites were identified from information gathered through death certificate data filed with the Utah Department of Health and the San Francisco Center for Health Statistics. Death certificates in Utah and California are filed in these offices within 5 days after the death of the individual. The name and address of the surviving spouse or partner as well as information on the decedent are included on the death records. The age of the surviving spouse or partner was inferred by the age of the decedent and was then confirmed by telephone. Men were oversampled in order to insure having adequate numbers of them in the group meetings. Far more women than men become widowed with nearly four widows for every widower after age 55 (U. S. Bureau of the Census, 2006).

Once potential participants were identified, they were sent an invitation letter (described in greater detail below) at 2 – 6 months of bereavement informing them they could be eligible to participate in the study if they met the study criteria. Approximately 5 - 7 days after the letters were mailed, a trained research assistant contacted potential participants by telephone. The purpose of the call was to verify that they received the letter, that they met the study criteria, to address any questions about the study, and solicit their preliminary agreement to participate. If all the criteria were met and the potential participant agreed, the RA made an appointment to visit his or her home to obtain informed consent, explain the self-administered baseline (O1) questionnaire (returned to the project office in a self-addressed stamped envelope), and confirm the time and place of the first group meeting.

Those who met the criteria and agreed to participate were paid \$25 per questionnaire (4 total, \$100) as each one was completed and returned. If the person who was contacted did not meet the study criteria or refused to participate, he or she was thanked for their interest and provided with a list of bereavement-related resources in the community should they decide to use them

in the future. Reasons for refusal were solicited from eligible individuals who declined participation.

### Features of Interest Regarding the Invitation Letters

Letters of invitation provided an overview of the study, described how the recipient was identified and what they would be requested to do (i.e., complete questionnaires and attend group meetings). The letter also explained the voluntary nature of participation, remuneration, and assurances of confidentiality. Much of this same information was provided at greater length as part of the informed consent procedure. We encouraged recipients to discuss their potential participation with others, whether it be family, friends, health care providers, clergy or with anyone with whom they would feel comfortable. This helped to foster an atmosphere of openness and alleviated any perceived sense of coercion or pressure. As we mentioned earlier, individuals are most likely to participate in a study if they perceive they will benefit somehow by doing so. Conversely, however, individuals are reluctant to participate in an intervention study if they feel they do not need to receive any form of “treatment.” A typical response might be, “I don’t need to be in your study because I am handling things just fine.” In anticipation that this could happen for some individuals we contacted, the invitation letters contained a statement emphasizing that their participation was still valued even if they were not experiencing exceptional difficulty because what we learn from them will be used to help others in the future and that by participating they might also be able to help others in their group. In this way, we were attempting to recognize and appeal to their sense of altruism rather than personal benefit (Lund & Caserta, 1998; Stroebe et al, 2003).

Along with the invitation letter we included a variety of materials intended to enhance the importance and professionalism of the study and more importantly, to help them make an informed decision. We included a professionally produced multi-colored tri-fold brochure emphasizing potential benefits of participating (while making no guarantees) – including quotes from participants of the investigators’ past studies like the *Pathfinders* demonstration project (Caserta, Lund, & O Bray, 2004), the history of the investigators’ experience in the field, as well as highlighting that LAL was funded by a federal agency (in this case, the National Institute on Aging). The brochure, which included racially diverse images, stated that participants from all racial, ethnic, and religious backgrounds were encouraged to participate, and that all group sessions were conducted with cultural sensitivity, respect for individual differences, and confidentiality.

We also included answers to a series of frequently asked questions (FAQs) that we anticipated could be raised based on our experience with earlier projects. Typical items in the FAQs addressed the purpose of such things as informed consent, consent documents, and questionnaires; they also reiterated that participation was voluntary and confidential. A key purpose of including FAQs with the invitation letter was to preempt potential concerns about perceived barriers to participation as well as to encourage participation among those who would have been more likely to do so if they had enough information. A copy of the FAQs is located in the Appendix.

Finally, beginning with the third wave of participants, the invitation letter was accompanied by a copy of a published magazine story about one previous study participant, which provided a “human face” to the project. Each potential participant was directed to a project website (<http://aging.utah.edu/gerontology/livingafterloss>) containing all the above materials as well as suggested reading lists, project updates, and links to the academic programs associated with the two study sites. The purpose of these materials was to foster an assurance of credibility, professionalism and community connectedness in an effort to dispel the notion that University-based research is strictly an “Ivory Tower” affair without practical application. (Complete

copies of all LAL recruitment materials, including the brochure mentioned earlier, are available upon request.)

### Challenges and Attempted Solutions

Although not necessarily unique to the LAL project, we encountered three major challenges to our sampling and recruitment efforts, which we addressed with varying degrees of effectiveness. In this section we identify the major issues we faced and discuss the strategies we employed for each one.

**Identifying and Reaching Potential Participants**—While death records are available electronically for the entire state in Utah (of which we only required those from the Salt Lake metropolitan area), similar information is not centralized in California but rather resides on a county to county basis. For the first two years of the project, death records were not available electronically in San Francisco, which became more cost prohibitive because each death record had to be purchased individually (at a cost of \$12 per record) and subjected to a time-consuming manual screening search by project staff.

Given this added expense and required personnel-hours to first identify the records to extract and then transfer the information into a data base, the San Francisco team found it necessary to use newspaper obituaries as a supplemental strategy to identify potential participants. Using obituaries to identify widows and widowers for bereavement research has been a proven effective way to construct a sampling frame and was quite commonly employed before death record information became electronically available in a timely fashion (Lund & Caserta, 1998; Neal et al., 1996). Obituaries are typically available within days after the death and they often contain enough information to determine if someone has a surviving spouse or partner. Furthermore, like death record data, the age of the decedent is often mentioned, from which the age of the surviving spouse or partner can be inferred pending verification with additional screening. While still somewhat time consuming many obituaries are now available online. Therefore, although not initially planned, obituaries became an integral part of the way the San Francisco sample was identified, accounting for approximately 35% of the potential contacts at that site until the death certificate data were available electronically during the third year of the project. A limitation associated with using obituaries is that some deaths are not listed, whereas death record data provide a more comprehensive sampling frame (Lund & Caserta, 1998). Given the obstacles we initially encountered, however, we believed that turning to obituaries represented a reasonable alternative until death records later became electronically available in San Francisco.

In addition to using death records and obituaries, both sites engaged in a variety of community outreach strategies that served multiple purposes. First, it was important to inform those in the larger community who had regular contact with bereaved individuals (e.g., hospices, funeral directors, religious leaders, health care providers) about the purposes of the project. We regularly sent letters to these individuals shortly before each wave of recruitment took place. We anticipated that any one of these organizations and individuals could have had clients who were contacted by the project inviting them to participate. It was, therefore, important that these community contacts supported the project and did not dissuade their clients from participating. We wanted to assure each of those in the community serving the bereaved whom we contacted that the LAL project was not intended to compete with their own efforts, as any one of their current clientele could still have participated in the project as long as they met the study criteria. (Consequently, we were careful to include in our study questionnaires items that inquired into other services or programs the participants had used in order to control for these factors later.)

We also used print (local newspapers and magazines) and broadcast media to reinforce and supplement our recruitment efforts in both local areas. During some of the earlier recruitment

periods we purchased radio spots on stations that catered to mature markets. These spots consisted of 30-second advertisements promoting the project, briefly mentioning that those age 50 and older and widowed 2-6 months would be eligible to participate. These were supplemented by 8-10 on-air weekly interviews with members of the LAL staff who discussed how aspects of bereavement and widowhood pertained to the project. Anytime the project was discussed in the media, however, we were especially careful to speak only generally about the study in order to preserve the blind nature of the random assignment and avoid revealing that we had two different types of interventions being compared. We also did not want to disclose any preliminary or interim findings; project updates on the website were similarly presented in more general terms. Interested individuals identified through these strategies were merely encouraged to call the project office for more information.

Early in the second year of funding, a magazine article featured a past participant who spoke about her involvement in the study. The magazine, which targets the Utah 55+ market, offered to print an article about LAL when we purchased advertising space in the publication. In order to preserve confidentiality, we did not give the magazine contact information for any participants. Alternatively, however, we announced to those in selected groups what the magazine was planning to do, suggesting that if anyone was interested in being interviewed to contact the magazine directly. We also were careful to only approach group members who were in the comparison condition to avoid any mention of RO activities that were provided only to those in the DPM groups. Loss-orientation sessions were included in both study conditions so any reference to these activities still preserved the blind nature of the study.

We primarily used the media to enhance the project's legitimacy and visibility as well as the credibility of LAL staff within the larger community. Media exposure was intended to further convince the listeners and readers about the importance of the project, so that they might be less reluctant and more interested in participating if/when invited. We also hoped that this might prompt those without listed phone numbers who received the invitation letter to proactively contact the project office. Finally, we realized that media attention might attract eligible participants who were not strictly within the targeted catchment area but close enough geographically to still participate. Anyone who called the project office as a result of media coverage underwent the same screening and randomization procedures as those who were sent letters. With careful monitoring and tracking, media outlets can provide supplements to the primary sampling and recruitment protocol without sacrificing the methodological rigor needed to protect against selection factors that can compromise internal validity (Anderson, Fogler, & Dedrick, 1995; Patrick, Pruchno, & Rose, 1998).

**Locating and Recruiting Nonwhite Participants**—A second challenge was related to our difficulty recruiting nonwhite participants, which we initially projected would comprise about 30% of the overall sample based on available census data (U. S. Bureau of the Census, 2003). San Francisco was chosen as a study site to enhance participation of a more diverse nonwhite population compared to Utah, which is a much more homogeneous state with only about 6% of the older population being nonwhite (Wright, 1998). Even with a greater proportion of nonwhites potentially available for this study in San Francisco, recruitment was more challenging than we initially anticipated. In several instances, particularly among the Latino and Asian communities, the language barrier rendered individuals ineligible to participate. Some simply did not speak English while others for whom English was a second language were more reluctant to participate out of a lack of confidence in their English-speaking ability.

Community outreach efforts are especially important to foster the recruitment and participation of those from racially and ethnically diverse communities (Austin-Wells et al., 2006; Gallagher-Thompson et al., 2006; McNeilly et al., 2000). Consequently, we made a

considerable effort to increase the project's visibility among nonwhite community groups. Although this was important at both sites, it represented a large part of the recruitment effort in San Francisco, where an African American staff person focused much of her efforts contacting churches, civic organizations and other focal points in the minority community in order to generate support for the project. This, however, was not without its challenges. Notwithstanding the strong and positive association that exists between the University and the residents of the city, there remained skepticism about the research program and its efforts to include African-Americans (with not infrequent reference to Tuskegee, given the age group targeted). Several leaders and prospective participants commented on the fact that this was a time-limited effort, implying that the program was reaping the benefits of African American participation but was not going to be there "for the long haul" with continued contributions to the community, a criticism rooted in references to previous and unsatisfying experiences with research and programs. There also were some organizations already offering bereavement support groups, not restricted to bereaved spouses and partners, which initially saw the study as competition. All of these factors necessitated many and frequent contacts with African American groups and organizations to allay fears of mistreatment and to demonstrate our commitment and authenticity.

Socio-demographic factors further complicated these recruitment efforts. Given the vast area considered the San Francisco Bay Area (nine counties and over 100 cities) and the county-specific ways in which death records were managed, the focus of our recruitment efforts were on the city and county of San Francisco with subsequent efforts extending to those cities nearest in distance (primarily using obituaries). The housing crisis of recent years directly affected these efforts. The costs of living in San Francisco has led large numbers of persons, particularly those in lower socio-economic groups among which Bay Area African Americans are over-represented, to leave the city for less expensive accommodation in other counties. According to the *San Francisco Chronicle* (Fulbright, 2007), the African American population fell to 6.5% in 2005, from more than double that in the 1970's. The height of the housing crisis, the period of time during which our study was being conducted, saw the greatest period of decline in the proportion of African Americans in the city. The beneficiaries of this exodus were primarily outer communities of the region and even other states—locales outside of the recruitment area.

**The Challenge Presented by Unlisted Phone Numbers**—A persistent recruitment barrier at both sites was the large number of potential participants without listed phone numbers, making it difficult to have a convenient cost effective way to contact them as a follow-up to the invitation letter. We envision this will become even more problematic for many future research studies as younger cohorts in larger numbers will rely exclusively on cell phones (which at the current time are not listed in a publically available organized way) as opposed to land lines. Recent data from the National Health Interview Survey (Blumberg & Luke, 2009) suggest that as much as 35% of American households use cell phones as their primary or sole source of telephone communication. Low income, unmarried cohabiting couples, and nonwhites are more likely to live in households that rely solely on cell phones. This however, is more typical for younger versus older age groups, according to the report.

When the invitation letters were mailed we began the process of looking up potential participants' phone numbers in order to make the follow-up phone calls (death records do not contain phone numbers). Those with listed land lines were identified through printed and online telephone directories like whitepages.com. Consistent to what the Blumberg and Luke (2009) reported, the LAL project was not immune from the challenges posed by unavailable phone numbers in that approximately one-third (n = 1030) of those to whom we sent invitation letters did not have a phone listing.

The remedies available to the project were somewhat limited. A possible course of action was to limit the invitation mailing to those who had published phone numbers. Excluding these persons, however, would seriously limit the desired diversity in the sampling frame and introduce a source of bias associated with unlisted numbers, which would adversely impact the study's external validity. Therefore, our only other alternative was to include an additional note in the invitation letter to everyone who did not have a listed phone number asking them to contact us. These notes were printed on brightly colored paper that stated the following:

Because we do not have a phone number to reach you we hope that you will give serious consideration to **calling us**. Even if you may not be interested in participating right now, we would like to be able to chat with you over the phone so that we can explain in more detail how the project can help you and how we can benefit from learning about your experiences. The 14 weekly sessions can be a great way to spend some time meeting new interesting people, learning more about grief, sharing experiences with others and helping us with an important research project.

Please give us a call at our project office even if you might be reluctant to participate. Your call would not necessarily mean that you want to participate but that you simply willing to talk with us about the project. We look forward to talking with you.

Only 10 individuals, all of whom were interested in joining the project, contacted one of the project offices to obtain additional information. For these few we did gain, however, this was an inexpensive way to obtain participants who otherwise might not have joined the project.

The demographic information within the death certificates allowed us to explore whether the availability of a phone number was correlated with the race of the decedent. Similar to what was reported in the National Health Interview Survey (Blumberg & Luke, 2009), we were less likely to have a published land line listing for potential participants from racial and ethnic minority groups. Of those invitation letters with a known phone number approximately 50% were from Caucasian deaths. However, of those without known phone numbers, the majority (62%) were from nonwhite decedents. Therefore, it is apparent that the challenges we faced recruiting nonwhites were exacerbated by a disproportionate number of nonwhites without listed numbers.

## THE RESULTS OF OUR EFFORTS

Now that we have provided the project overview and described several specific challenges we faced and strategies we pursued, we now present the outcomes of our efforts regarding sampling, recruitment, and participant retention.

### Potential Participants Contacted

Altogether, we sent 3,104 letters of invitation to potential participants. The majority of potential participants were identified through death records (n=2412, 77.7%); very few came from personal referrals (n=78, 2.6%); and some (in San Francisco only) were identified by obituaries (n=614; 19.8%). The project staff successfully matched the name and address to a probable phone number for approximately two-thirds of the potential participants who received an initial invitation letter (n = 2,074 total). About a week after the invitation letters were sent, research assistants called each individual to confirm receipt of the letter and solicit interest in the study. After repeated call attempts, the research assistants were able to contact 1,474 persons: this represents 47% of all invitations sent and 71% of the invitations that had a known phone number. We defined "contact" as having actually spoken to the potential participant, rather than leaving a message on an answering machine or with another member of the household. The number of call attempts per individual ranged from 1 to 14, with 4 or 5 being the norm for

each potential participant. Despite repeated call attempts, we were unable to contact 1,630 of the persons who received an initial invitation letter.

### Eligibility, Refusal, and Participation Rates

During the follow-up telephone call, research assistants tried to confirm eligibility as well as the interest of each potential participant. Unfortunately, some participants refused or declined participation before eligibility was ascertained, so it is hard to estimate with accuracy the number of eligible and non-eligible persons. We successfully screened eligibility for 976 persons (66% of those contacted): 143 persons were ineligible for participation because they were under the age of 50, had a serious physical, psychological, or cognitive impairment preventing participation, had moved from the area, had died, or were unable to speak English. Another 44 persons were categorized as ineligible because although they may have been interested in and/or eligible to participate, they were unable to attend the group-based intervention because of transportation reasons, work conflicts, or being out-of-town for the majority of the 14-week session. Among those who were otherwise eligible to participate in the study, 454 declined participation. The most common reasons for refusal were “too busy” or “not interested.”

As depicted below, somewhere between 789 and 1,287 persons were *potentially eligible* to participate in the study. The lower bound of this range represents the confirmed eligible persons, whereas the upper bound is estimated as the total number of persons contacted minus the persons with confirmed ineligibility. The discrepancy, again, comes from the fact that many potential participants (n=311) declined prior to the RAs being able to confirm their eligibility status.

Contacted	1474	
Eligibility Screened	976	
Ineligible	143	
Unable to attend/participate	44	
Known Eligible	789	
Eligibility Unknown	311	
Eligible to participate	789	<i>estimated as 976 - (143 + 44)</i>
	1287	<i>estimated as 1474 - (143 + 44)</i>

Three hundred and thirty-five individuals consented to participate in the LAL study. However, the final sample of participants resulted in 328 persons because seven of those who originally consented failed to complete the first questionnaire or attend any of the weekly intervention sessions. Considering this final accrued sample size and the strictest definition of known eligibility, we calculated a participation rate as 42% (328/789). However, given the difficulty in determining eligibility prior to refusal for some individuals, a more conservative participation rate would be 25% (328/1287). We believe that 42% is a more valid participation rate for this study because it represents those who are truly eligible (Wiseman & Billington, 1984).

### Sample Characteristics

Of the 328 total participants, 197 (60%) came from the Salt Lake City subsample and 131 (40%) from the San Francisco site. The proportions of the sample associated with each study site deviated by 10% from the initially targeted 50/50 distribution because the accrual was slowed in San Francisco by the fact that death records were not initially electronically available. Another factor contributing to the uneven distribution of participants between the two sites

was that proportionately, more of those identified in San Francisco (compared to Salt Lake) did not have listed phone numbers.

Sixty-one percent ( $n = 200$ ) of those enrolled in the study were women and 39% ( $n = 128$ ) were men. The average age of the sample at the beginning of the study was 69.6 years ( $SD = 10.6$ ), with a range of 50 to 93 years. Participants had been married or partnered for an average of 39.8 years ( $SD = 16.9$ ) at the time of the death. The sample was quite educated: only 15% of the sample had a high school education or less; 41% had some college; and 44% had graduated from a college. The majority were Caucasian (85%), with 7% Asian, 5% African American, 2%, Latino and 1% other. Also, 10 participants or 3% of the sample had been in a same-sex relationship. A little more than half (57%) said they expected their spouse's or partner's death. Fifty-six percent ( $n = 185$ ) were randomly assigned to the DPM study condition and 44% ( $n = 143$ ) to the comparison condition. During the final wave of recruitment we only conducted DPM groups, thus explaining why there is a higher percentage of participants in that study condition.

### Retention and Attrition

Retention was quite high throughout the study. More than nine out of ten (91%;  $n = 298/328$ ) participants remained in the study at the posttest (O2) assessment (the first data point following the conclusion of the intervention), where the greatest amount of attrition for the entire project took place. The most common reasons for drop-out at this stage included: "I decided that the group was not for me," "My grief is too strong and I am unable to participate in a group," or the participant decided that he/she "no longer wanted to participate." One widower died after he completed the baseline questionnaire, but before the groups started. Two participants experienced significant health declines prior to the start of the group, and 4 withdrew in order to take care of unexpected family emergencies. Finally, the group leaders discovered that 3 enrolled participants were not suitable for the group intervention, due to cognitive impairment or significant hearing loss; they were withdrawn from the study and directed to community-based resources more capable of meeting their needs.

Attrition during the later follow-up periods was much less than that between baseline and the first posttest. Five individuals were lost from O2 to O3 and 13 more from O3 to O4. Attrition at these later waves was more commonly due to a known death or significant health decline ( $n=5$ ) or they were lost to follow-up for unknown reasons. The overall attrition rate for the entire study, therefore, was approximately 15% (48 out of 328).

At the final data collection, we asked the participants to indicate how important several factors were in their decision to both join as well as remain in the study. Ten factors were listed in which they were asked to rate how important each was on a scale of 1 (not at all important) to 5 (very important). The ten items and mean level of importance for each one are presented in Table 1.

Clearly the most important factor for at least 80% of the participants was the potential opportunity to personally benefit by obtaining useful help and support. Almost equally important, however, were those factors (endorsed by 68% - 78% of the participants) reflecting a sense of altruism – whether it be the opportunity to help other bereaved or to contribute to research. Other factors that were at least moderately influential in decisions to join and continue participating were ongoing contact with the study, including (assumably positive) interactions with the project staff. More than two-thirds of the participants rated this as important factor in their remaining in the project. Ongoing contact during recruitment largely involved follow-up with those still not sure about joining the project in order to answer questions and address concerns potential participants may have had prior to making a firm commitment to become involved. Through the course of participants' involvement in the study, we kept in regular

contact through a 2-page annual project newsletter, mailings reminding them of upcoming data collections and booster sessions as well as requests to advise us of changes in contact information. We believe these efforts helped the participants feel personally connected to the project, fostering an overall sense of commitment from the beginning through the completion of the study.

Least important in recruitment and continued participation were the project website and media coverage with mean scores approximating 1.5 on a scale of 1-5. Although these promoted a professional presence in the community, these were not necessarily “tipping factors” except for a select few who said that they were instrumental in their decision to join and remain in the project. Somewhat surprisingly, however, was that the \$25 remuneration associated with questionnaire completion was only important to no more than about 1 in 8 respondents as they considered joining (11%) and continuing (12%) in the study. While it is difficult to determine to what extent recruitment and retention would have been hampered without the financial incentive, we do not believe it deterred participation and for a few it may have at least played a partial role in their decision to join and remain involved in the study.

Because of the outreach efforts we made to recruit nonwhites into the study, we were interested in whether they differed from whites in the sample in terms of how important each of these factors were in their decisions to join and remain in the study. A series of bonferroni-corrected (at  $p \leq .003$ ) t-tests revealed statistically significant differences among three factors in the decision to join the project. Nonwhites placed greater importance than whites on the potential to receive useful help and support (Ms [SDs] = 4.5 [0.6] vs. 4.1 [1.1]), ongoing contact with project staff (Ms [SDs] = 3.7 [1.2] vs. 3.0 [1.5]), and the project brochure (Ms [SDs] = 3.5 [1.2] vs. 2.7 [1.5]). Nonwhites also placed significantly more importance than whites on the brochure as a factor in remaining in the project (Ms [SDs] = 3.4 [1.4] vs. 2.2 [1.4]).

## CONCLUSIONS AND RECOMMENDATIONS

The LAL project’s sampling and recruitment efforts were successful on several fronts. The target sample size was virtually met (N = 328 compared to a projected N = 330), although the logistical issues associated with how the death records were organized in the two sites in the earlier phases of the project resulted in 10% deviation in the targeted proportions from both locations. We believe, however, that this was not problematic because comparisons between the two subsamples were not among the primary aims of the study. We also were quite successful in our attempt to oversample men in order to ensure adequate numbers. Nineteen percent of the 55+ widowed population in the U.S. is male (U. S. Bureau of the Census, 2006); however, men accounted for 39% of the LAL sample. It is apparent as well that our emphasizing both potential personal benefits and altruism in the recruitment materials had a positive impact on recruitment. Receiving useful help and support, as well as contributing to research and potentially helping others accounted for the three most important factors in the participants’ decisions to join and remain in the study. It is likely that most potential participants have more than one reason for being in a study of this type so future efforts should recognize these multiple benefits.

One of the first decisions made by intervention researchers is to decide where it is best to focus limited resources for sampling and recruitment efforts in community-based studies. The experience of the LAL project suggested that relying on referrals, advertisements, and print and broadcast media did not result in a substantial yield in terms of participant enrollment. We believe there was some value in creating a visible community presence to support our project but there was no compelling evidence that it was necessary. However, it may be noteworthy that we did not receive a single complaint from any community agency or person that we had ignored them or were competing against them – although this sometimes required regular

contact (at least initially) with some representatives of the nonwhite community. In short, we recommend appropriately directed efforts to inform relevant agencies and persons in the community but utilizing radio spots and advertisements may not be necessary.

Alternatively, it is still clear that resources are better devoted to obtaining and using available health statistics data bases (provided they are cost effective) supplemented by obituaries when necessary. Invitation letters are most effective when they contain ample information that allays anticipated concerns, that appeals to both potential personal benefits and a sense of altruism, as well as enable the participants make an informed decision about participating. We suggest that careful thought and feedback from a variety of professionals and previously bereaved persons be used in the development of the invitation letters. It is very likely that the invitation letter is the single most important element to successful recruitment of participants.

Not always having the opportunity to determine eligibility for many potential participants hampered our ability to determine a precise participation rate. The 42% participation rate for the LAL project, which is indeed higher than most bereavement intervention studies (Lund & Caserta, 1998; Neal et al., 1996; Stroebe et al., 2003), was based on the strictest definition of eligibility. However, the difficulty we encountered in determining eligibility for 311 individuals suggests that this might be a liberal estimate of the true rate. This is potentially a common problem associated with recruitment methods involving the telephone to screen for eligibility. Reluctance on the part of some individuals to participate in research leads to immediate refusals prior to allowing for an opportunity for eligibility to be determined. Our experience reminds us that the definition and calculation of response or participation rates strives for a concrete number but an accurate standard for how they are defined and calculated is difficult to achieve.

The project was quite effective in retaining those who enrolled in that 85% of the initial sample completed the study. Some of the 15% attrition was due to participants' declining health or death prior to finishing the study or being withdrawn by the project because it eventually became clear that some could not continue because of cognitive or sensory deficits that interfered with participating.

We think that the following factors could have contributed to the high completion rate for this study. First, there was a great deal of consistency between those factors that were influential in one's decision to join and those that were important reasons to remain in the study. In other words, those who joined the study for personal and/or altruistic reasons continued to participate because they found they were accomplishing these goals. More importantly, however, was the time and resources we devoted to keeping in contact with the participants throughout the entire study. Regularly following up on mailed questionnaires, providing booster sessions, mailing newsletters and requesting ongoing contact updates demonstrated a professional and personal commitment to the participants.

Also critical to our success was the careful selection and training of a highly competent research and intervention staff at both sites. Although many of the recruitment and retention issues discussed in this article are common to most health-related studies, the role of an engaged, empathetic staff is particularly salient to bereavement intervention research. The staff needed to be knowledgeable about all facets of the study protocol, to communicate with potential participants in a sensitive manner, to take the necessary time to answer questions, and be willing to listen to their concerns during the difficult time in which they were contacted about the study and throughout the course of the project. We developed and used a standardized training and treatment manual (available on request) to guide nearly every aspect of the study. An important section in the manual focused on cultural sensitivity issues and recommendations. The staff regularly used the manual to answer questions that arose during the project. This type of training

in empathy and sensitivity is important not only for bereavement research but also for studies involving individuals in other potentially vulnerable situations (i.e., serious chronic illness, stressful family caregiving circumstances, or being diagnosed with terminal illness).

The two primary areas in sampling and recruitment that remained particularly challenging throughout the project were the unavailability of published phone numbers and locating, accessing and recruiting nonwhite potential participants. As mentioned earlier, unpublished phone numbers likely will be a growing obstacle to recruitment efforts in those studies where phone follow-up is a necessary part of the research protocol. This also was a contributing factor in why we were unable to obtain precise participation rates. Households' increasing reliance on using exclusively unlisted cell phones will be a growing challenge not unique to bereavement intervention research (Blumberg & Luke, 2009). With the significant decline in having telephone listings future studies might need to budget for staff resources to make personal visits to the homes of potential participants following initial contact by letter in order to obtain representative samples. Even when published numbers are available, it is necessary to plan for significant staff time to make repeated phone calls in order to reach those who have received invitation letters at varying times of day and days of the week, including weekends.

Despite persistent outreach efforts we fell short of our overall goal of having about 30% of the sample be nonwhite. In retrospect, we might have had unrealistic target goals, especially given the lack of racial and ethnic diversity in the Salt Lake metropolitan area as well as the unanticipated exodus of large numbers of the San Francisco nonwhite community due to the recent housing crisis (Fulbright, 2007). Future recruitment of nonwhites (not only limited to primarily Caucasian areas) will continue to be a challenge for a variety of reasons, largely related to accessibility (Stahl & Vasquez, 2004). The inability of those from certain nonwhite segments of the population to speak English seriously curtails their representation in projects like LAL unless accommodations are made to deliver interventions and design data collection instruments in their native language. Oftentimes, however, these strategies are not realistic either from a practical and/or budgetary perspective whereby the first goal of an overall research program is to determine the efficacy of treatment modalities before they are adapted for those who are not English speaking.

Alternatively, despite these challenges, having a location like San Francisco as a study site where there is notable racial/ethnic diversity resulted in an overall sample in which 15% were nonwhite. Those in ethnic/racial minority groups comprised 32% of the San Francisco sample compared to 4% of the Salt Lake sample (which is reflective of the Utah nonwhite population). Consequently, even though we fell short of our initial projections, the entire LAL study sample was more racially diverse than it would have been had it been entirely drawn from Salt Lake City. We believe the successes we had in recruiting nonwhite participants might have been due, at least in part, to ongoing consistent contact between project and those from racial minority groups as well as the racially diverse images in the project brochure. Furthermore, the fact that some of the material in the brochure referred to the benefits reported by participants in previous studies could have allayed some initial fear and mistrust held by some nonwhites toward research participation (Austin-Wells et al., 2006; Stahl & Vasquez, 2004).

### Concluding note

Bereavement intervention research, while a rewarding endeavor important to our field, is a challenging enterprise to design and implement. The *Living After Loss* study exemplified the challenges to sampling, recruitment and retention that are commonly confronted but demonstrated that many of these could be successfully addressed if resources are wisely focused and staff are adequately trained so that study participants are more effectively accessed, recruited, and retained. While several of the issues we faced are commonly described in methodological literature and research texts, we were in a position to document these

challenges and possible solutions based on our actual experiences and data we collected. We learned that it was worthwhile to pursue a variety of approaches tailored to each unique component of our target population and that achieving a personalized rapport with research participants was critical. In order to enhance participant sampling, recruitment and retention in future bereavement intervention studies we need to pay careful attention to what works and what does not work well and share strategies and outcomes with others. Obvious improvements need to be made with respect to achieving higher participation rates and greater inclusion of those from diverse racial and ethnic groups. Our most current research experiences remind us again, that scientific research requires not only having high and rigorous standards but finding creative ways to achieve them.

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## Appendix: Questions Frequently Asked by Participants

### 1. Is this is a research project?

Yes, it is funded by the National Institute on Aging, one of the National Institutes of Health, which is part of the federal government. Because you were scientifically selected to be invited to participate in the study and because you are being asked to complete questionnaires throughout the project (as indicated on the consent form), this is considered research, in addition to being an educational or support program.

### 2. Why did you contact me? I'm not having any problems

It is important that we have people participate who are not experiencing unusual difficulty and get information from them as we need to learn from everyone's experiences. We need to learn from those who are doing well and from those who are having much greater difficulty. Everyone who participates in this study and program are likely to obtain some information that will be useful to them and also have a chance to be helpful to others who attend the group meetings.

### 3. Why do I have to sign the consent form?

Because it is required by the University and by law. It is for your protection. Its purpose is to make sure you understand all that the project entails and that you know what your rights are as a participant in a research project. A research assistant will explain this in detail when they deliver your first questionnaire.

### 4. Why do I have to complete a questionnaire? Isn't the program mainly a series of group meetings?

The reason why we are asking you to complete the questionnaire is so we can have information that will tell us how well the group sessions meet the needs of the participants as well as find ways to improve and develop future programs. We need to gather this information several times throughout the project, including before you begin attending the groups so that we can make the necessary comparisons that will tell us what aspects of the groups are most beneficial for

the participants. As stated in the consent form, the information you provide will be held strictly confidential and the responses from all the participants in the study will be examined as a group and not in a way that links your identity with your answers. We will also pay you **\$25 for each** of the four questionnaires that you complete to show our appreciation for your time.

### **5. What if I skip a question or two?**

It is your right to refuse to answer any of the questions that are in the questionnaire, but we hope you will do your best to complete the entire questionnaire because we need to know how well the group really works. Remember, your answers will be held in the strictest confidence so we cannot reveal to anyone how you personally answered any particular question.

### **6. How soon do you need the questionnaire back?**

It is important to complete the questionnaire within 2-4 days after you receive it and mail it back to us in the self-addressed stamped envelope that we provide to you. The reason we prefer the questionnaire being returned to us sooner rather than later is that we need to know your feelings and experiences as they are for you at the present time so we can compare them with how you will be doing later after the group meetings are over.

### **7. The questionnaire might look a bit long**

Although it is about 19 pages long, it should only take you about 45 minutes to complete. As you begin to go through the questions you will see that it gives you a chance to think about many important things and be able to express your thoughts and feelings. Feel free to make comments, if you wish, on the questionnaire at any time as you answer the questions. If you should happen to tire or otherwise get interrupted as you are completing the questionnaire, that is okay. Take a break and come back to it later, but do try to get it back to us within the next few days.

### **8. I cannot use a pen or pencil so I cannot fill out the questionnaire**

We will have a member of our project staff come to your home (or another location you prefer) and ask you the questions and write your answers for you. All your answers will be held in the strictest confidence.

### **9. What happens in the group meetings?**

Each group will be led by an individual trained by our professional staff. The group meetings will give you the opportunity to talk with others who are experiencing similar situations and to learn from each other. You also could potentially obtain some new information to help you take better care of yourself and adapt more effectively. You will receive a workbook containing information that goes along with what is covered in the group meetings.

### **10. Do I have to attend all the group meetings?**

We hope you will try to attend all the meetings or at least as many as you possibly can. We realize that there may be times when it is difficult for you to attend a meeting but it will be helpful for everyone to attend regularly. You can also share your knowledge with others in the group.

## 11. I'm afraid that I may have problems with transportation to the meetings

Is there public transportation nearby that you can use? Is there a friend or relative that can take you and pick you up when you are up afterwards? There is a possibility that you may meet someone in the group with whom you can travel to and from the meetings. Our group leaders may be able to help arrange this for you. If none of these are viable options, our project staff will help find a solution (University of Utah site: 801-581-7954, or San Francisco State University site: 415-405-7582).

## 12. I am still not sure if I want to participate. Can I think about it and get back to you?

Please get advice from friends, relatives and other professionals in the community. We also welcome you and others to contact us if you have any questions. Please know that your participation will be very helpful to us and other participants as well.

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Table 1

Relative Importance<sup>a</sup> of Various Factors in Participants' Decision to Join and Remain in the LAL Study.

	Join			Remain		
	M	SD	Important <sup>b</sup>	M	SD	Important <sup>b</sup>
Receive useful help and support	4.2	1.0	81 %	4.2	1.1	80 %
Contribution to research	4.1	1.0	76 %	4.2	1.0	78 %
Potentially help others	3.9	1.2	68 %	4.1	1.0	75 %
Project staff	3.7	1.4	64 %	3.9	1.3	71 %
Ongoing contact with project	3.1	1.5	50 %	3.7	1.4	66 %
Encouragement from others	2.9	1.5	39 %	3.0	1.5	40 %
Project brochure	2.8	1.4	37 %	2.3	1.5	24 %
\$25 remunerations	1.9	1.2	11 %	1.9	1.2	12 %
Media coverage	1.5	1.1	7 %	1.6	1.1	9 %
Project website	1.5	0.9	6 %	1.4	0.9	5 %

<sup>a</sup>Based on a 5-point scale (1=not at all important, 5=very important)

<sup>b</sup>Defined as % of respondents reporting a score  $\geq 4$  on the item