

# A CONTEMPLATIVE CARE APPROACH TO TRAINING AND SUPPORTING HOSPICE VOLUNTEERS: A PROSPECTIVE STUDY OF SPIRITUAL PRACTICE, WELL-BEING, AND FEAR OF DEATH

Larry Scherwitz, PhD,<sup>1#</sup> Marcie Pullman,<sup>1</sup> Pamela McHenry, MA,<sup>1</sup> Billy Gao,<sup>1</sup> and Frank Ostaseski<sup>2,3</sup>

**Background:** Inspired by a 2,500-year-old Buddhist tradition, the Zen Hospice Project (ZHP) provides residential hospice care, volunteer programs, and educational efforts that cultivate wisdom and compassion in service.

**Objective:** The present study was designed to understand how being with dying hospice residents affects hospice volunteers well-being and the role of spiritual practice in ameliorating the fear of death.

**Design:** A one-year longitudinal study of two volunteer cohorts ( $N = 24$  and  $N = 22$ ) with repeated measures of spiritual practice, well-being, and hospice performance during one-year service as volunteers.

**Setting:** The Zen Hospice Guest House and Laguna Honda Residential Hospital of San Francisco, CA.

**Participants:** All 46 individuals who became ZHP volunteers during two years.

**Interventions:** A 40-hour training program for beginning hospice volunteers stressing compassion, equanimity, mindfulness,

and practical bedside care; a one-year caregiver assignment five hours per week; and monthly group meeting.

**Main Outcome Measures:** Self-report FACIT spiritual well-being, general well-being, self-transcendence scale, and a volunteer coordinator-rated ZHP performance scale.

**Results:** The volunteers had a high level of self-care and well-being at baseline and maintained both throughout the year; they increased compassion and decreased fear of death. Those ( $n = 20$ ) practicing yoga were found to have consistently lower fear of death than the group average ( $P = .04$ ,  $P = .008$ , respectively). All rated the training and program highly, and 63% continued to volunteer after the first year's commitment. The results suggest that this approach to training and supporting hospice volunteers fosters emotional well-being and spiritual growth.

**Key words:** Zen, hospice, meditation, lifestyle, death, dying, fear of dying, depression, spiritual well-being

(*Explore* 2006; 2:304-313. © Elsevier Inc. 2006)

*If you can find a friend to go with you who is steady, careful, and mature, you can overcome all hardships with mindfulness and joy.—The Buddha<sup>1</sup>*

## INTRODUCTION

When residents enter hospice they take an important step in accepting their own impending death. This step opens the possibility for other steps toward a meaningful dying experience, such as remaining alert and conscious, putting aside medical concerns in favor of reflections on life and death, connecting with loved ones, and addressing the deep spiritual issues of their lives. Terminal illness may in fact challenge the

hospice patient to reevaluate the meaning of life, traditional values, and their spiritual belief systems. As Smith et al<sup>2</sup> indicate, this is a time when the patient may turn to others for help in exploring issues of meaning and purpose in life. In their study, Smith et al found that the majority of cancer patients felt that religion and spiritual values were important. Thus, hospice patients may be particularly receptive to evaluating and exploring spiritual well-being.

There then is the issue of who will supply this spiritual care. Some argue that spiritual care be modeled and delivered by trained theologians, but there is the danger of splitting the hospice care audience into sectarian groups.<sup>3</sup> Walters<sup>4</sup> suggests that the growing recognition of the universality of spirituality suggests that all staff, including hospice volunteers, can and should participate in this process with the hospice patient. Bollwinkel<sup>5</sup> agrees, while noting that spiritual support is best provided by someone with self-knowledge of his/her own spiritual needs, authenticity, honesty, and respect for the beliefs and practices of the patient and family. Hospice patient care volunteers, particularly those who undergo specialized contemplative training, may be in a unique position to supply spiritual support for the hospice resident and to advance their own spiritual development.

<sup>1</sup> Institute for Health and Healing, California Pacific Medical Center, San Francisco, CA

<sup>2</sup> Zen Hospice Project, San Francisco, CA

<sup>3</sup> Alaya Institute, Sausalito, CA

Supported by a grant from the Cummings Foundation and Funding from the Institute for Health and Healing at California Pacific Medical Center.

# Corresponding Author. Address:

80 Lincoln Dr. 2C, Sausalito, CA 04065

## **Contemplative Care Approach**

Within the hospice movement, the philosophy and social action of Buddhism has taken root, and the values of focusing on death to enhance life are particularly relevant.<sup>6-8</sup> The focus on mindfulness, compassion, and service provide a good fit for the spiritual needs of hospice residents. Inspired by a 2500-year-old spiritual tradition, The Zen Hospice Project (ZHP)<sup>9,10</sup> offers a unique opportunity for volunteers to cultivate mindfulness and compassion through service. The project is a fusion of spiritual insight and practical social action. As a nationally innovative model of contemplative care, the program brings together caregivers with a meditation or spiritual practice and individuals facing the final weeks of life. The project creates a mutually beneficial relationship between people who are cultivating an empathetic presence and individuals who need to be heard. Volunteers provide practical, emotional, and spiritual support to men and women with cancer, AIDS, and other life-threatening diseases.

If the contemplative care approach is a good fit for the patient, it may also be a good fit for the hospice volunteer as well as the hospice organization. Given that volunteer recruitment, retention, and burnout are a continuing challenge for hospice agencies, an approach is needed that will address the volunteer's needs as well as the residents. The Buddhist contemplative care approach places an equal emphasis on supporting the caregiver as well as the patient. Compassion as an actual practice has grown out of Buddhist philosophy that emphasizes the interconnectedness and interdependence of all things. From the Buddhist perspective, the condition of one being, sentient or insentient, is inextricably tied to all beings. Therefore, the well-being of others is intimately related to our own lives; it is not abstract. Thus volunteer service is designed to support the volunteers' well-being and spiritual development.

## **Setting**

The ZHP is an institution dedicated to providing compassionate care for the dying. Begun in 1987, ZHP is now nationally recognized as an innovative model in the movement to improve end-of-life care. ZHP has a well-developed training curriculum for volunteers and creates a safe environment for volunteers to explore deeply their own relationship to the dying process and facilitate their own personal growth. Each year, over 100 volunteers provide an estimated 25,000 hours of practical, emotional, and spiritual support to 200 individuals and their families as they face death.

The present study was designed to evaluate whether lifestyle and spiritual practice helps foster well-being and performance as volunteers, during a year's commitment to being with dying hospice residents. Measures of lifestyle and spiritual practice and emotional and spiritual well-being were collected at baseline and throughout the year. Hospice performance measures were developed and rated by volunteer coordinators at intervals throughout the year. In addition, qualitative measures are designed to assess the volunteers' motivation for joining the program, what the experience was like, and how they coped with suffering and grief. The present paper presents the quantitative results.

## **METHODS**

### **Design**

The study design is a one-year prospective study of two Zen hospice volunteer cohorts (spring, N = 24 and fall, N = 22; 2001) with measures taken at baseline, after training, and every four months for a year.

### **Procedure**

The ZHP recruited volunteers from their Web site, targeted mailings to spiritual organizations including the San Francisco Zen Center database, advertisements in specific journals, personal outreach by ZHP staff and volunteers, and word of mouth. Candidates were asked to complete an application asking for background information and for the time they had available to serve as volunteers. They were asked their motivations for volunteering and experience being with those who are dying. Candidates who show maturity and had not lost a loved one in the last six months were invited for an interview with the volunteer coordinator. The volunteer coordinators selected candidates who demonstrated social skills, a readiness to volunteer, and psychological stability. Also important is that the applicants be mature with a genuine heart and mind for compassionate and mindful acts of service to the dying. Candidates needed to be available for a one-year commitment of five hours per week. Other criteria included the willingness to attend monthly community meetings, have a spiritual practice, not necessarily Buddhist, but amenable to the fact that the community of volunteers is largely composed of Buddhist practitioners. Excluded were applicants who have mental or physical aversion to the realities of death and dying, inappropriate agendas of conversion of the patient/resident to a specific point of view or behavior, poor listening skills, a recent loss with unresolved grieving issues (this includes personal illness), and any recent major life changes, eg, divorce, marriage, childbirth, employment, and education, which could impact the applicant's life in unforeseen ways. All volunteers agreed to pay \$150 for the 40-hour intensive training, and all new volunteers accepted into the ZHP were invited into the study and agreed and signed a consent form approved by the California Pacific Medical Center Institutional Review Board.

### **Data Collection**

All volunteers completed questionnaires before and after the training began and at four, eight, and 12 months (see *Figure 1*). At baseline, volunteers completed questions on demographics and responded to open-ended questions on why they were volunteering and their prior experience with death and dying. At each time, period questions focused on the volunteers' type, frequency, and duration of spiritual practices and exercise. Three validated measures of well-being were administered throughout the year, including the General Health scale with subscales for depression and anxiety, social facilitation, anhedonia, and insomnia<sup>11</sup>; the Functional Assessment of Chronic Illness Therapy-Breast (FACIT-B) spiritual subscale; and Self-Transcendence Survey. The Self-Transcendence Scale is a 15-item self-report measure of intrapersonal, interpersonal, and temporal experiences that extend bound-

| <b>Measures</b>                              | <b>Baseline</b> | <b>Post-Training</b> | <b>4 months</b> | <b>8 months</b> | <b>12 months</b> |
|--|-----------------|----------------------|-----------------|-----------------|------------------|
| Demographic                                  | X               |                      |                 |                 |                  |
| General Health                               | X               | X                    | X               | X               | X                |
| FACIT Spiritual Survey                       |                 | X                    | X               | X               | X                |
| Self Transcendence                           | X               |                      | X               | X               | X                |
| Lifestyle Factors                            | X               |                      | X               | X               | X                |
| Hospice Performance                          | X               |                      | X               | X               | X                |
| Qualitative Questions                        | X               | X                    |                 |                 | X                |
| Rating of Hospice Training<br>And Experience |                 |                      | X               |                 | X                |
| Hospice Performance                          |                 |                      | X               | X               | X                |

**Figure 1.** Measures and Testing Schedule.

aries of the self.<sup>12</sup> It has an internal consistency range of .80 to .93. Test-retest reliability was .95, and the scale has been used with older adults.<sup>12</sup> The FACIT-B is a self-report measure to assess quality of life designed for breast cancer patients chosen for its popularity and therefore ability to generalize results.<sup>13</sup> We employed the 10-item Spiritual Well-Being subscale, which has good concurrent validity and internal consistency for the individual domains.

To assess the volunteer's performance, we worked closely with the ZHP staff to define and assess what characteristics they regarded as ideal for volunteers. This resulted in 15 items (see Table 1) that covers skills, attitudes, and behaviors. Both volunteers and their coordinators rated the volunteer's performance on 15 characteristics (see Table 1 for volunteer coordinator ratings). The volunteer coordinators used a seven-point scale with "four" average and "seven" excellent. These are further defined in Appendix A. Criteria were developed to be specific about what features to observe for each item. The volunteer coordinators rated each volunteer on these characteristics at four, eight, and 12 months, and the volunteers rated themselves with the scale.

The transcribed text answers to the open-ended questions were grouped into baseline and 12-month batches and analyzed by a Linguistic Inquiry and Word Count Analysis (LIWC) developed by Dr. James Pennebaker.<sup>14</sup> LIWC uses a word count strategy, whereby it searches for over 2,300 words or word stems within any given text file. The search words have previously been categorized by independent judges into over 70 linguistic dimensions. These dimensions include standard language categories,

psychological processes, relatively related words, and traditional content dimensions.

### Volunteer Training

The training program "Caring for the Dying" spans two weeks, covering four evenings and one full weekend, and includes content that stimulates the individual volunteer to begin a personal inquiry into death, while bringing the group of 25 together as a cohesive whole to share and learn how to communicate openly about their experiences and feel compassion for each other. The program prepares volunteers by allowing them to focus on death—the resident's experience touches on physical suffering and loss of ability, the psychological challenge of saying goodbye, and the spiritual challenge of coming to terms with one's own life. The course focuses on practical ways for volunteers to keep their heart open and ready to serve the resident, with an introduction to the Buddhist technique of mindfulness meditation, and sensitizes them for talking to residents in the hospice and physically taking care of them. There are 22 individual teachings, exercises, lectures, and discussions led by an assortment of ZHP community members, including a Buddhist monk, palliative care nurse and doctor, experienced volunteers, residents and their family, volunteer coordinators, and the founding director, Frank Ostaseski. The exercises that have evolved to be the main teachings of the training are: loss exercise, in which volunteers think on their own favorite things including objects, activities, people, and roles in the world, and then psychologically enact the loss of all of them;

**Table 1.** Volunteer Coordinators Progress Evaluation

| Rating Dimension   | 4 Months |     | 8 Months         |     |
|--|----------|-----|------------------|-----|
|  | Mean     | SD  | Mean             | SD  |
| Behaves appropriately in volunteer role                            | 5.5      | 1.1 | 5.6              | 1.0 |
| Develops a relationship between mindfulness and caregiving         | 5.1      | 1.3 | 5.4              | 1.0 |
| Shows awareness to death and dying                                 | 5.3      | 1.0 | 5.5              | 1.0 |
| Shows community value  | 5.2      | 1.3 | 5.2              | 1.2 |
| Understands hospice and palliative care approach                   | 5.0      | 1.0 | 5.1              | 1.0 |
| Manages pain and symptoms  | 4.8      | 1.0 | 5.4 <sup>a</sup> | 1.0 |
| Demonstrates knowledge of bedside care skills                      | 4.9      | 1.3 | 5.2 <sup>b</sup> | 1.1 |
| Brings and sustains calm presence                                  | 4.8      | 1.4 | 5.4 <sup>a</sup> | 1.2 |
| Bears witness to suffering and demonstrates an empathetic response | 4.9      | 1.3 | 5.6 <sup>a</sup> | 1.3 |
| Listens empathetically   | 4.8      | 1.4 | 5.5 <sup>a</sup> | 1.2 |
| Maintains clear boundaries with self and others                    | 4.5      | 1.5 | 4.8              | 1.3 |
| Demonstrates awareness of family dynamics                          | 4.8      | 1.2 | 5.3 <sup>a</sup> | 1.1 |
| Shows spiritual concerns for dying patient and family              | 4.5      | 1.3 | 5.0 <sup>a</sup> | 1.2 |
| Touches skillfully   | 4.6      | 1.6 | 5.4 <sup>a</sup> | 1.3 |
| Please assess your overall skills as a volunteer                   | 5.0      | 1.2 | 5.6 <sup>a</sup> | 1.1 |

NOTE: A "four" represents average, "five" is above average, and "six" is good.

<sup>a</sup> $P < .01$ .

<sup>b</sup> $P < .05$ .

skillful touch, which addresses how to initiate contact with a resident by eye contact, asking permission to touch, and basic massage techniques to relieve tired, inactive muscles; photo exercise in which a series of photographs of residents who have died at the hospice are shown to the volunteers, and a circle is formed to share reactions; and Buddhist memorial ritual, a candle ritual in which the volunteers said goodbye to their own loved ones who were gone and reflected on what was missed most about them and what they still need to say. At the end of the training program, each volunteer is assigned a five-hour weekly shift, with one or two other volunteers. Each change of shift occurs with a meeting to acknowledge volunteers leaving and arriving and to bring the newcomers up to date on residents. Time is given for each volunteer to check in with the group and share what they are feeling in that moment. Volunteers assemble as a group once a month for a

lecture on a Buddhist or dying theme by different speakers and to reconnect as a community.

### Data Analysis

Statistical Package for the Social Sciences version 11.5 (SPSS Inc, Chicago, IL) was used to compute means and standard deviations to describe the population, eg, lifestyle well-being. Bivariate correlations were used to determine associations between classes of variables such as lifestyle, fear of death, and well-being. Changes over time were analyzed by a general linear model using repeated measures as the within factor.

## RESULTS

### Demographic Characteristics

The 46 Zen hospice volunteers varied in age from 22 to 65 years (average 41 years) and are mostly female (76%); all reported having some college schooling, 18% completed college, and another 22% completed graduate school. Of the sample, 43% were single, 22% were married, and 20% lived with a partner; 15% were divorced or separated. The great majority (87%) are white, with 9% Pacific Islander, and 3% Hispanic; household income ranged from <\$15,000 (n = 4) to >\$125,000 (n = 6). Over the course of one year, two people were asked to leave the ZHP program because of personal conflicts within the group.

### Religious and Spiritual Orientation

The great majority had a Christian heritage (37% Protestant, 35% Catholic); 17% did not report a religious heritage; 7% reported a Hindu heritage, 2% Jewish heritage, and 2% Buddhist. When asked to list their current religious affiliation, it was clear that a majority (67%) had converted to a Buddhist perspective, with a variety of other religious perspectives. Only 10 participants reported attending a regular religious service. All but three reported a current spiritual practice, and 43 of them reported meditating at baseline, 21 report practiced yoga, 15 indicated they prayed, nine did breath work, five read scriptures, four did mantras, and one reported doing Tai Chi and one Chi Gong. Based on retrospective self-report, they increased their combined spiritual practice at 4.7 hours/wk six months before volunteering to 5.6 hours/wk at baseline.

### Lifestyle at Baseline

Most volunteers (n = 32) reported doing regular aerobic exercise, at an average of 44 minutes 2.3 times per week. Some (n = 11) did resistance training for strengthening, with an average of 2.5 times a week for 28 minutes per session. The 22 who report stretching do so an average of 4.8 times per week for 19 minutes per session.

### Emotional and Spiritual Well-Being

The General Health Scale shows that the sample had a fairly high state of well-being at baseline and improves slightly throughout the year (see Table 2). A score of 51.2 is in the lower range of the scale (30-120) in which lower scores indicate a higher state of well-being. However, the General Health subscale of anxiety and depression improved significantly as assessed by a repeated mea-

**Table 2.** Health Measures Over Time

| Variable           | Baseline |     | Posttraining |      | 4 Months |     | 8 Months |      | 12 Months |     |
|--------------------|----------|-----|--------------|------|----------|-----|----------|------|-----------|-----|
|                    | M        | SD  | M            | SD   | M        | SD  | M        | SD   | M         | SD  |
| General health     | 51.20    | 9.6 | 50.4         | 12.1 | 51.1     | 9.8 | 51.5     | 13.7 | 47.1      | 8.6 |
| FACT               | 48.9     | 6.4 |              |      | 48.0     | 7.5 | 43.4     | 6.4  | 50.8      | 7.0 |
| Self-transcendence | 51.3     | 4.7 |              |      | 55.1     | 4.4 | 51.4     | 4.3  | 52.2      | 4.6 |

NOTE: Lower general health scores indicate a sense of higher well-being; higher FACT and self-transcendence scores indicate a sense of higher well-being. Changes are nonsignificant over time.

sures general linear model ( $F(1,35) = 21.9, P < .001$ ). There were no significant differences over time for the General Health subscales of insomnia or anhedonia, although social facilitation (working well with others) rose at the post-training phase and returned to its baseline levels for the remaining follow-up periods. The range of the FACT-B spiritual scale is from 10 to 50 with higher scores indicating a higher level of well-being. The mean at baseline is 40.4, indicating a moderately high average of "quite a bit" to such questions, as "I feel peaceful." There are small fluctuations around this mean during the year and an insignificant rise above baseline at 12 months. The self-transcendence baseline mean score of 51.3 is above the average, indicating a moderately high level of self-transcendence based on statements such as "having an interest in continuing to learn about things," and this did not change substantially throughout the year.

A repeated measures analysis shows that both the fear of the process of dying (Figure 2) and the fear of death transition (Figure 3) markedly decreased in a step-wise fashion from six months before baseline to 12-month follow-up ( $F = 4.2, P = .008$  and  $F = 16.2, P < .001$ , respectively). The fear of the process of dying was the greater fear and the one that was reduced less, perhaps because of their observing the suffering that preceded death.

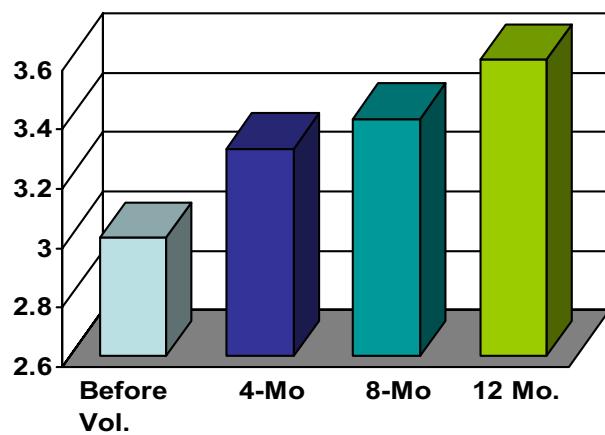
### Compassion and Knowledge

As expected, the self-ratings of knowledge increased significantly after the Zen hospice training, and it maintained an average rating of "knowledgeable" on the scale. The self-ratings to the question, "Are you able to feel and express compassion to others?" increased over time ( $F = 32.4, P < .001$ ). This increase in compassion was evident in the way volunteers answered the question, "What did you do to honor your feelings when a patient you had bonded with died?" Although the responses varied widely, they consistently showed their connection and respect to those who died. Eighteen volunteers reported that they had honored the patient by sitting in their room after a patient had departed. Eighteen reported that they meditated on their feelings and reflections. Ten volunteers went into an emotional state, and they found that it helped them with honoring the patient. There were also nine volunteers who performed rituals after a patient passed away. The following passage illustrates the multitiered responses to the question:

"I would ideally come to see their body and grieve. That was not always possible. My second choice was to go and sit in their room at the first shift after they passed and grieve, feeling the empty room, remembering their presence."

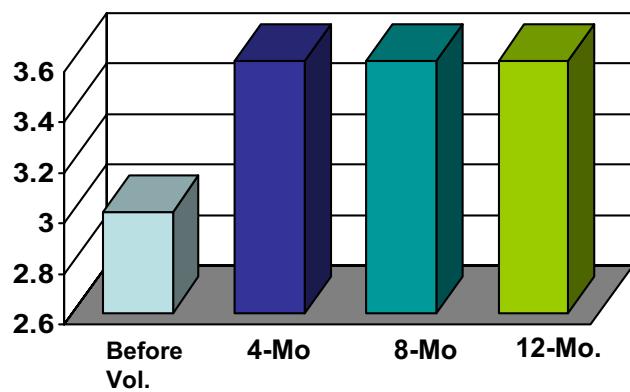
### Volunteer Performance

Both the volunteer and the volunteer coordinator ratings of performance as a hospice volunteer increased over time (see Table 1). The volunteers' self-ratings were above "average" at four months, and they increased at eight months ( $t = 4.3, P <$



Note: Higher numbers are moving to less fear and more acceptance of death

**Figure 2.** Fear of the Process of Dying.



**Figure 3.** Fear of Death's Transition.

**Table 3.** Fear of Death and Well-Being Correlations at four, eight, and 12 Months

| Measures<br>Fear of Death (rows)<br>Well-Being (columns) | Process at<br>4 Months | Experience at<br>4 Months | Process at<br>8 Months | Experience at<br>8 Months | Process at<br>12 Months | Experience at<br>12 Months |
|--|------------------------|---------------------------|------------------------|---------------------------|-------------------------|----------------------------|
| GWB at 4 months  | -.307                  | -.341 <sup>a</sup>        | -.395 <sup>a</sup>     | -.117                     | -.321 <sup>a</sup>      | -.220                      |
| GWB at 8 months  | -.169                  | -.335 <sup>a</sup>        | -.329                  | -.383 <sup>a</sup>        | -.304                   | -.365 <sup>a</sup>         |
| GWB at 12 months   | -.380 <sup>a</sup>     | -.294                     | -.509 <sup>b</sup>     | -.174                     | -.672 <sup>b</sup>      | -.241                      |
| Self-trans at 4 months                                   | .330 <sup>a</sup>      | .593 <sup>b</sup>         | .257                   | .324 <sup>a</sup>         | .228                    | .389 <sup>a</sup>          |
| Self-trans at 8 months                                   | .138                   | .416 <sup>b</sup>         | .345 <sup>a</sup>      | .393 <sup>a</sup>         | .212                    | .340 <sup>a</sup>          |
| Self-trans at 12 months                                  | .119                   | .506 <sup>b</sup>         | .298                   | .351 <sup>a</sup>         | .354 <sup>a</sup>       | .436 <sup>b</sup>          |
| Fact-B at 4 months                                       | .344 <sup>a</sup>      | .342 <sup>a</sup>         | .436 <sup>b</sup>      | .137                      | .304                    | .161                       |
| Fact-B at 8 months                                       | .245                   | .475 <sup>b</sup>         | .397 <sup>b</sup>      | .305 <sup>a</sup>         | .268                    | .280                       |
| Fact-B at 12 months                                      | .096                   | .414 <sup>b</sup>         | .366 <sup>a</sup>      | .121                      | .294                    | .153                       |

NOTE: Boldfaced correlations are for measures taken at the time period. Negative correlations for GWB (General Well-Being Scale) indicate more well-being with less fear of dying. Positive correlations for the other measures show more well-being with less fear of death.

Self-trans, Self-transcendence.

<sup>a</sup>Correlation is significant at the .05 level (2-tailed).

<sup>b</sup>Correlation is significant at the .01 level (2-tailed).

.001). A look at the volunteer coordinator's component ratings show statistically significant improvements in skillful touching, bringing and sustaining a calm presence, listening empathetically, bearing witness to suffering, demonstrating an empathetic response, and demonstrating knowledge of bedside care skills.

### One-Year Ratings of the Hospice Experience

At one-year, volunteers were asked to rate the portions of the hospice experience they found fulfilling and nurturing using a four-point scale: a four was labeled as "Very Important" and one "Not a Factor." Overall, the individual components were rated as highly fulfilling. The most important components in order of their scores were the experience of being with residents (3.9), followed by the relationship with their shift volunteer (3.6), change of shift meeting being next (3.4), and continued support on my spiritual path (3.2), and, next, was the relationship with the Zen hospice community (2.8) and the volunteer coordinators at (2.6). Volunteer burnout was very low. At the end of the first year, 29 volunteers agreed to continue volunteering past their commitment. At the end of the year, the 10 who did not volunteer had reasons such as family obligations; they were moving away, traveling, or taking long retreats. Here is an example of the attitude toward their service: "The fellow volunteers and staff are some of the most grounded, open, loving, compassionate, wise people I have ever known. I feel connected, known, valued. Each shift is an opportunity to meet other beings at an extraordinary time in their lives."

### Spiritual Practices During the Year

Volunteers participated in a considerable number of outside, spiritually oriented gatherings during the year. At one year, 31 volunteers reported having participated in at least one spiritual retreat with a group average of 1.9; 37 reported participating in a spiritual teaching, averaging 19 teachings; and 38 participated in a group meditation, averaging 46.5 times in the year.

### Correlations of Fear of Death and Well-Being

Of the 18 correlations between fear of death and well-being, 16 are significant, showing an association of higher well-being with less fear of death (See Table 3). To be more specific about what qualities of the General Well-Being Scale were associated with fear of death, we use the subscales of General Health. The Anxiety/Depression subscale was significantly correlated with both measures of fear of death for each time period. The Social Facilitation subscale was not significantly correlated with fear of death, but more fear of death correlated significantly positively with more insomnia and anhedonia at the final follow-up measure.

Given that the fear of the process of dying decreased over time, we checked whether those who decreased their fear of dying over time increased their well-being scores. The changes in the general well-being scores from baseline to one year are correlated with the changes in the fear of dying ( $r = .44, P = .007$ ). A scatter plot of this correlation shows that the five who increased their fear of the process of dying during the year all had a poorer well-being scores after one year than at baseline, whereas 11 of the 16 who decreased their fear of the process of dying had an improved well-being score, and five of the six who had the most sizable (two-point) decreased fear (on a five-point scale) had an improvement in well-being score.

### Fear of Death and Spiritual Practice

Further correlations revealed that the fear of death measures were not associated with total time spent in spiritual practice or number of spiritual practices or time doing physical exercise. However, the 20 volunteers who reported practicing hatha yoga had a consistently lower fear rating for the process of dying than those who reported not doing hatha yoga. The independent  $t$  tests were almost significant at four months ( $P = .08$ ), and they are significant for both the eight and 12-month follow-up ( $P = .04, P = .008$ , respectively). There were no differences in the fear of the death transition measure between those who practiced

and did not practice yoga. A similar analysis for prayer did not show differences for either measure of fear of death. There are too few volunteers who were not meditating (3) to do a valid comparison.

### High Versus Lower Well-Being Volunteers

In an effort to distinguish volunteers with high versus low well-being scores, the qualitative responses for key questions were compared (blind to well-being status) between the four with the highest and four with the lowest well-being scores at 12 months. The volunteers with the highest well-being scores had the singular goal of helping others, while the volunteers with the lowest well-being scores had more self-motivated goals; they volunteered to fulfill a psychological or practical need of their own. Two of these low-well-being-score volunteers expressed a fear of death and the belief that joining the ZHP would help them to come to grips with their insecurities and fear of dying. The other two reported that ZHP fell in line with their careers and thought that ZHP would be a positive and educational experience that offered the support they needed. In addition, the high-well-being-score volunteers indicated that they felt more compassion for those who are suffering and dying and reported higher knowledge of the process of dying than the low-well-being-score volunteers.

## DISCUSSION

The ZHP attracted a remarkable group of volunteers. They were mostly white, well-educated women with a diverse income, who lived an almost abstemious lifestyle and were unusually dedicated to a spiritual practice, most typically to several hours of meditation each week. Most exercised regularly, prepared their own food, drank little alcohol, and drank tea or coffee moderately. Consistent with findings from other hospices, they volunteered to serve for altruistic and personal growth reasons,<sup>15</sup> and they rated the intensive training they received very highly. During the year, they consistently showed up for their five-hour shifts and attended the great majority of the training and support group meetings. As a result of the extraordinary group process, the support given, and the heart-opening experience of being with dying individuals, two thirds chose to continue beyond their first year commitment. Given their moderate to high levels of fear of dying, they especially appreciated the training emphasis on personally facing their own mortality, and this training appeared to reduce both the fear of the process of dying and the fear of the transition of dying.

Also appealing to the volunteers was ZHP's emphasis on self-care, developing a focused presence, feeling and expressing compassion for others, and service to a good cause. The ZHP also offers other benefits that a state-wide survey indicates as important to volunteers: a support group, ongoing training, and opportunities to get to know other volunteers.<sup>16</sup> Based on ratings by volunteers and volunteer coordinators, the program was successful in increasing the ability to feel and express compassion and the increased knowledge about hospice care. The volunteer coordinators ratings also show that volunteers increased their bedside skills in touching, bringing and sustaining a calm presence, listening empathetically, and bearing witness to suffering.

Despite being in the presence of deep suffering and facing death on a regular basis, their well-being levels remained high throughout the year by all three well-being measures. Their anxiety and depression significantly decreased. Although the self-reported measure of well-being can be questioned, the results are corroborated by the objective word count, indicating that after one year the group referred to themselves less, used fewer sad words and more positive-emotion words, and more optimism in their written answers to the open-ended questions than at baseline. For the most part, these well-being measures did not appear to be correlated with lifestyle factors such as exercise and spiritual practice. There is evidence that volunteering to serve can even improve lifestyle factors. The volunteer's meditation practice increased at the beginning of volunteering compared with six months prior, and five of eight cigarette smokers quit during the year.

The most compelling evidence that being with dying individuals can be a transformative experience was with the fear of dying findings. The volunteers rated themselves as having high to moderate fear of death six months before volunteering, and this decreased after the training. Some of the volunteers stated that dealing with their own fear of death was a major reason for volunteering. Much of the training was focused on having the volunteers face their own mortality through exercises such as losing what was most valuable to them and envisioning one's own death. Fear of death decreased as the volunteers continued to serve throughout the year, and this may have been due to their being with dying residents, which they rated as the most fulfilling aspect of their service. Lower fear of death has been found as a predictor of persistence in volunteering in a prospective study of 75 hospice volunteers.<sup>17</sup>

Consistent with the findings of this study, Amenta and Weiner<sup>18</sup> found fear of death to correlate with anxiety and other measures. Using Templer's<sup>19</sup> Death Anxiety Scale and the 16 Personality Factor Questionnaire,<sup>20</sup> they found that fear of death was positively associated with anxiety, suspiciousness, and proneness to guilt and negatively correlated with ego strength. The consistent correlations between fear of death and the well-being measures suggest that fear of death may affect everyday well-being. These results were consistent for each of the well-being measures across time, suggesting a reliable finding. The General Health scale showed this relationship the strongest. The subscales of the General Health scale suggest that anxiety and depression were most highly correlated with fear of death. Perhaps this is just a generalized fear or depression, indicating that those who are most anxious or depressed are also most anxious about their own mortality. But the subscales of anhedonia and insomnia suggest that it is more than a generalized anxiety. Fear of death, at least for those who come in contact with death, may be related to the inability to have fun and even ability to sleep. It is axiomatic in Buddhist philosophy that accepting one's own death makes living more fulfilling. Given Western society's glamorization of youth and subsequent avoidance and fear of death, more work should be done in other populations to examine whether accepting our mortality can increase our well-being.

There may be a clue in the contrast between the high- and low-well-being score volunteers for how fear of death could have such a pervasive effect on well-being. The qualitative answers to

the question about why the subjects volunteered showed that the volunteers who had the lowest well-being scores had self-focused reasons for volunteering. They were volunteering "to discover new parts of myself" and "It is a place I can practice." Those who had the highest well-being scores were more altruistic, "To make a contribution if I can." The self-centered theme of low-well-being-score volunteers also surfaced in their answers about what was least satisfying about their hospice experience. The low-well-being-score volunteers indicated either personal "self-centered obsessions," their "own impatience," or interpersonal experiences "hostile and defensive hospital staff." The higher well-being-score volunteers cited the environmental factors such as "too busy in the AM shift" or "parties." Black and Kovacs found that volunteers with the greatest anticipation of receiving psychic benefits may be the least likely to sustain their participation.<sup>21</sup>

Numerous studies have shown a negative relationship between self-focus and well-being. For example, among patients with coronary heart disease, those who use more self-references (I, me, my, and mine) in speech have higher levels of anxiety and depression,<sup>22</sup> they report more distress to the pain of cold water,<sup>23</sup> and they are most likely to die when they have suffered a heart attack<sup>24</sup> than individuals who used fewer self-references. For these people, death could present a greater threat to the loss of self than those who identify less with the little self as all of who they are. In the context of hospice care, the self-centered person will have more difficulty entering the transpersonal realm for both caregiver and the dying individual. In the Tibetan Buddhist view, the altruistic intention to work for the benefit of others, rather than just for one's own, results in happiness because human beings are dependent on the cooperation of one another for survival.<sup>25</sup>

The contemplative care approach's emphasis on cultivation of mindfulness, equanimity, deep listening, and compassion appear an ideal fit for dying patients' needs for slower care, to be listened to, and to have control over their lives.<sup>26</sup> Conversely, dying individuals have gifts of changing those for the better who become deeply involved with them. Dying individuals have much to teach caregivers about the human condition and the *bar do* state between death and rebirth. Every patient is an individual microcosm with a unique set of conditions, circumstances, and experiences from which a caregiver can learn.<sup>25</sup> Guenther<sup>27</sup> points out that "inner" hearing, by its very innerness, "can dissolve separation, and that "in the act of listening the experiencer not only opens herself up to another presence, but also allows herself to be affected by this presence." When resonating in synchrony, the caregiver-patient relationship is not only receptive to change but is also fertile ground for transformation.<sup>25</sup> Trust and harmony between a caregiver and a patient provide a sense of physical and psychological comfort and safety that may ease the patient's anguish in the process of dying and the caregiver's fear of dying.

The limitations of the study are varied. First, because of the one-group design, it is not possible to know how the contemplative approach to training and supporting hospice volunteers compares with conventional hospice training programs. The fact that more candidates sought to volunteer than could be trained and the high retention rate after their first year's commitment is

a strong recommendation for the program. A second limitation is that the death anxiety measure was based on single items rather than a validated scale. The fact that the fear of the process of death is highly correlated with the transition provides modest support for their reliability. A third limitation is that one cannot infer that fear of death may directly affect well-being; the direction of causality could be the opposite; those who are anxious may be anxious about many aspects of their lives, including their own mortality. It could be that they reflect a general malaise with the human condition.

In deciding to care for the dying, these volunteers submitted themselves to one year of challenging experience in the spirit of applied Buddhism. We see that, through developing relationships with dying people and other volunteers at ZHP, a safe space is created to confront death and explore one's own capacity to make a difference in someone's life. By undergoing this experience as a community, the volunteers spread healthy patterns of living to each other, enabling personal transformation and a healthier lifestyle. Having come face to face with suffering, pain, loss of function, and death, the volunteer's task to bring an open heart and loving intention to each resident allows practicing the principles of compassion and love in concrete ways. The fruit of their labors is a blessing community wide.

### Acknowledgments

We gratefully acknowledge the Zen Hospice Project Volunteer coordinators Eric Poche and Zuza Engler for helping to develop and complete the Hospice Volunteer Performance Scale and to Kate Sadowsky and Jennifer Haber for their assistance in data collection; Don Blanchard, Paula Singh, and Kathleen Sempell for their assistance in data entry and management; and Dr. James Pennebaker for linguistic inquiry and word count analysis.

### REFERENCES

1. Chöpel Gl. *Dhammapada*. Oakland, CA: Dharma Press; 1985.
2. Smith ED, Stefanek ME, Joseph MV, et al. Spiritual awareness, personal perspective on death, and psychosocial distress among cancer patients. *J Psychosocial Oncol*. 1993;11:89-103.
3. Paton L. The Sacred Circle: a conceptual framework for spiritual care in hospice. *Am J Hospice Pall Care*. 1996;13:52-56.
4. Walters T. The ideology and organization of spiritual care: three approaches. *Pall Med*. 1997;11:21-30.
5. Bollwinkel EM. Role of spirituality in hospice cares. *Ann Acad Med Singapore*. 1994;23:261-263.
6. Halifax J. *Being With Dying: Contemplative Practices and Teachings*. Audio cassette. Portland, ME: Audiophile; 2001.
7. Longaker C. *Facing Death and Finding Hope: A Guide to the Emotional and Spiritual Care of the Dying*. New York, NY: Doubleday; 1997.
8. Rinpoche S. *The Tibetan Book of Living and Dying*. San Francisco, CA: Harper; 1994.
9. Moore N. Forging a spiritual bond: the Zen Hospice Project. *Altern Ther Health Med*. 1996;2:3.
10. Boyce B. Zen Hospice Project profile. *Buddhadharma Magazine*, Spring 2003.
11. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. *Psychol Med*. 1979;1:139-145.
12. Reed PG. Self-transcendence and mental health in oldest-old adults. *Nurs Res*. 1991;40:5-11.
13. Celli DF. Manual: *Functional Assessment of Chronic Illness Therapy (FACIT) Scales*. Chicago. Center on Outcomes, Research, and Edu-

- 
- cation, Evanston Northwestern Healthcare and Northwestern University; 1997.
14. Pennebaker J, Francis ME, Booth RJ. *Linguistic Inquire and Word Count (LWC)*: Mahwah, NJ: Erlbaum; 2001.
  15. Murrant G, Strathdee SA. Motivations for service volunteer involvement at Casey House AIDS Hospice. *Hosp J*. 1995;10:27-38.
  16. Scott JP, Caldwell J. Needs and program strengths: perceptions of hospice volunteers. *Hosp J*. 1996;11:19-30.
  17. Lafer B. Predicting performance and persistence in hospice volunteers. *Psychol Rep*. 1989;65:467-472.
  18. Amenta MM, Weiner AW. Death anxiety and general anxiety in hospice workers. *Psychol Rep*. 1981;49:962.
  19. Templer DI. The construction and validation of a death anxiety scale. *J Gen Psychol*. 1970;82:165-177.
  20. Cattell RB, Eber HW, Tatsuoka MM. *Handbook for the Sixteen Personality Factor Questionnaire (16PF)*. Campaign IL: Institute for Personality and Ability Testing; 1970.
  21. Black B, Kovacs PJ. Direct care and nondirect care hospice volunteers: motivations, acceptance, satisfaction and length of service. *J Volunt Adm*. 1996;14:21-32.
  22. Scherwitz L, McKelvain R, Laman C, et al. Type A behavior, self-involvement, and coronary atherosclerosis. *Psychosom Med*. 1983;45:47-57.
  23. Scherwitz L, Berton K, Leventhal H. Type A behavior, self-involvement and cardiovascular response. *Psychosom Med*. 1978;40:552-661.
  24. Scherwitz L, Buehler J, Grandits G, Graham L. Self-involvement and coronary heart disease incidence in the Multiple Risk Factor Intervention Trial. *Psychosom Med*. 1986;48:187-199.
  25. Coberly M, Shapiro SI. A transpersonal approach to care of the dying. *J Transpersonal Psychol*. 1998;30:1-37.
  26. Owen-Still S. Spiritual Caregiving. A philosophy for the volunteer-intensive hospice program. *Am J Hosp Care*. 1985;2:32-35.
  27. Guenther H. The complexity of the initial condition. *Intl J Transpersonal Stud [Voices of Russian Transpersonalism, Vol 4]*. 1997;16:52-70.

---

## Appendix A

### Hospice Volunteer Evaluation

Volunteer Coordinator Name \_\_\_\_\_ Date \_\_\_\_\_

Volunteer Name \_\_\_\_\_ Months since training    *please circle* 4 8 12

*Please review the criteria for making judgments of volunteer qualities. In making your ratings, please try to discriminate with each question, first to make fine distinctions on the scale, and secondly to exclude any questions where you do not have an opportunity or basis for making a rating. Your highest rating of 7 should be comparable (in that specific quality) to the most outstanding member of your volunteer community. Similarly, the lowest rating could be the lowest rating of anyone in the community, and the average is in the middle.*

This volunteer:

**1. Behaves responsibly in volunteer role** (*shift time, works with attendants and nurses*)

|            |      |           |         |           |      |           |    |
|------------|------|-----------|---------|-----------|------|-----------|----|
| 1          | 2    | 3         | 4       | 5         | 6    | 7         | NA |
| Not at All | Poor | Below Avg | Average | Above Avg | Good | Excellent |    |

*(Each of the following questions uses the same 7-point scale.)*

**2. Behaves appropriately in volunteer role** (*shows initiative, all-around volunteer effort*)

**3. Develops a relationship between mindfulness and caregiving** (*develops mindful practice, uses hospice to awaken*)

**4. Shows awareness to death and dying** (*examines responses to suffering and own impulses*)

**5. Shows community value** (*attends monthly meetings, participates w/ volunteer journal, shift change meetings*)

**6. Understands hospice and palliative care approach**

**7. Manages pain and symptoms** (*notices changes in symptoms and conveys to nurse/attend*)

**8. Demonstrates knowledge of bedside care skills** (*as needed feeds, makes bed, transfers, repositions, bathes, toilet*)

**9. Brings and sustains calm presence** (*ability to respond with calm in challenging situations*)

**10. Bears witness to suffering and demonstrates an empathetic response** (*sits with residents, offers emotional and spiritual support to family, friends, and can receive emotional support when appropriate*)

**11. Listens empathetically** (*attentive to meta-message, gives whole self to listening, respects confidentiality*)

**12. Maintains clear boundaries with self and others** (*engages and disengage physically, emotionally, challenges self*)

**13. Demonstrates awareness of family dynamics** (*empathic listening to family, supports residents and family in grief*)

**14. Shows spiritual concerns for dying patient and family** (*inquires into spiritual concern, finds support*)

**15. Touches skillfully** (*respectful, gentle, deliberate touch, proactively offers massage*)

**16. How would you assess the individual's overall skills as a volunteer?**