

# Biopsychosocial Stressors for Service Providers Assisting Clients Facing Death

Marissa Happ\* and Mark Stone

Aurora University, Aurora, IL, US.

## \*Correspondence:

Marissa Happ, Aurora University, Aurora, IL, US, Tel: 630-947-8932.

Received: 01 November 2019; Accepted: 29 November 2019

**Citation:** Marissa Happ, Mark Stone. Biopsychosocial Stressors for Service Providers Assisting Clients Facing Death. Nur Primary Care. 2019; 3(6): 1-5.

## ABSTRACT

*The Hospice movement brought a new paradigm that challenged society's perception of terminal illness; death became accepted as the final stage of life and new awareness emerged that changed the treatment modalities available for patients facing death. Clients today find support from trained volunteers as death approaches and after it takes place. It is crucial to consider the needs of volunteers to ensure that appropriate supports are in place for them as well as the clients they serve.*

*The Volunteer Assessment Survey (VAS) was constructed to evaluate the status of service providers. The VAS consists of 32 statements addressing eight specific topics pertinent to their motivation for service. A subsample also completed a narrative report. The findings indicate the biopsychosocial status of the volunteers.*

## Keywords

Bereavement, Hospice, Volunteers.

## Introduction

The inevitability of death is a universal reality affecting humanity. The drive to preserve life has always been the foundation of medicine; the medical advances of modern research have afforded us the opportunity to increase the life expectancy decades beyond that of our ancestors.

Across the centuries, art and science have sought to understand the complexities of human existence. Though medical advances in the United States since WWII have lengthened life expectancy from 65.7 [1] to 78.8 [2], the reality of mortality remains. Reese [3] notes, however, that prolonged life does not assure quality of life and essential emotional support is not always present for those facing end-of-life issues. Hospice and bereavement volunteers place themselves at the heart of human experience when assisting clients facing death and it is imperative that their needs are understood.

Hospice and bereavement workers carry significant stressors but continue to serve. The biopsychosocial model [4] considers the biological, psychological, social, environmental and behavioral

aspects of the patient; problems in any of these areas may impact health outcomes. It is important, then, to consider the needs of the hospice and bereavement worker whose unpaid work is often intense and emotionally challenging.

## Applicable Theories

The hospice and bereavement volunteer seek to provide the holding environment described by Winnicott [5] by offering the unconditional positive regard of which Rogers [6] speaks. While these two aspects of therapeutic work are essential to the building of a supportive relationship with the client, the volunteer must first believe that there is meaning in doing so. The "tragic optimism" illustrated by Viktor Frankl [7] is perhaps the attribute that best equips the volunteer to engage the terminally ill and the bereaved; if done successfully, the client has the opportunity to master the ego-integrity outlined by Erikson, and despair is defeated [8].

The volunteer working with end-of-life issues needs to be equipped emotionally, clinically and spiritually to face the complex issues presented by his/her client(s) and extensive training for this work is essential. The ability to be comfortable with the reality of death is crucial for hospice and bereavement workers, yet it often runs contrary to the mindset of the western world.

## Methodology

According to Creswell [8], mixed-methods research is an approach which gathers both quantitative and qualitative data with the assumption that combining both types of data provides a more complete picture of the research problem than either approach alone. Participants were asked to complete the Volunteer Assessment Survey (VAS) that provided quantitative data; a subgroup of volunteers who had fifteen or more years of service were invited to complete a short narrative yielding qualitative data.

The Convergent Parallel Mixed Methods design allowed the researcher to gather both sets of data and analyze them separately before comparing results to determine if the findings confirmed or disconfirmed each other. The side-by-side comparison enabled the researcher to first report the quantitative findings, followed by the qualitative findings; with a comparison of the two sets of data.

This mixed-method study included both the post-positivist and the constructivist worldview [8]: the quantitative survey examined discrete variables related to the research questions; the qualitative question allowed the subgroup of volunteers to share the subjective meaning of their experiences as hospice and bereavement volunteers over time.

## Sample

The sample consisted of patient care and bereavement care volunteers working directly with patients undergoing chemotherapy or receiving palliative care from a hospice agency as well as the individuals, families and groups who had lost a loved one.

At the time the study was conducted, 44 of the 70 direct service volunteers agreed to participate in the research project. This was a convenience sample of easily accessible participants, some of whom had been hospice and bereavement volunteers for more than fifteen years.

## The VAS

The Volunteer Assessment Survey (VAS) explores biopsychosocial stressors in the volunteers and captures some of their thoughts on spirituality, bereavement, mortality, volunteerism and fortitude. These quantitative data, together with the qualitative essays from a subgroup of volunteers with fifteen years of service (or more), provide insight into the experiences and beliefs of hospice and bereavement volunteers who serve for reasons deeper than that of monetary compensation.

## Quantitative Analysis

Participants were instructed to answer yes or no to each statement according to how strongly it reflected (or did not reflect) his or her own beliefs. Internal reliability ( $r = 0.89$ ) of the VAS was established earlier by piloting the instrument to 221 social work students ages 24 to 67 collected over several semesters.

Rasch analysis of the VAS was used to analyze the characteristics of the instrument itself and to determine misfits of any item beyond a standard deviation of 2.0. The responses to each statement were

measured by percentages for each category. A t-test was used to determine the differences in the mean scores between men and women, and ANOVA compared the mean scores within the three age groups and four categories of years of volunteerism.

## Qualitative Analysis

Qualitative data were gathered from a subgroup of participants. Saldaña [10] suggests that qualitative data can prioritize the participant's voice and honor it. For the hospice and bereavement volunteers in this study, the narrative question allowed the participants to reflect on their work. An open-ended question asked participants if personal experiences had influenced the desire to work in the area of death and bereavement and to share why they volunteer in this capacity.

These written narratives were coded and analyzed according to recurring themes. Initial analysis identified key words and phrases and grouped them into descriptive code clusters. The next stage used short quotes that matched the respective codes with the numbers of participants whose statements reflected those specific codes, as were the number of quotes generated by the participants as a whole. Forty-four (44) VAS surveys were collected. Seven (7) submitted written a narrative in addition to completing the VAS.

## Rasch Measurement Analysis of the VAS

Analysis of the VAS followed the strategies outlined in the Best Test Design by Wright and Stone [11] and utilized computer software in Winsteps [12]. Rasch measurement utilizes the Rasch logistic formula (1) to relate the raw scores of the VAS to measures:

$$\text{Raw score} = \sum_i \frac{e^{(b-d_i)}}{1 + e^{(b-d_i)}} \quad (1)$$

Formula (1) can be utilized to analyze the characteristics of the instrument, i.e. item analysis. In this formula,  $b$  signifies the person responding and  $d_i$  an item of the VAS. This formula transforms each raw score to a measure. Item and person measures are accompanied by item statistics produced by WINSTEPS software [12].

Item analysis indicates misfit values for INFIT and OUTFIT where INFIT examines misfit close to the score and OUTFIT examines misfit at a distance from the score. The infit item mean was 1.00 and the outfit mean was 1.03 showing that the item sequence indicated no statistically significant misfit. Item point-biserial coefficients ranged from .01 to .29 with only three coefficients greater, two at .48 and one at .54 indicating no high correlation between an item and the total score.

Figure 1 is a map of the VAS. Left of the vertical dividing line is the measured logistic location of each respondent.  $M$  is the mean and  $S$  and  $T$  indicate one and two standard deviations respectively from the mean. Each # indicates two respondents. Each dot indicates one respondent. The distribution of the respondents is very narrow compared to the distribution of the items indicating that the items were relevant to the sample.

Right of the vertical dividing line are the item locations of the VAS

shown by their measured values together with their codes. Figure 1 indicates as a map how the items are located by the measured logistic space between any two items of groups of items. From the total variance of the measures (scores) of persons at 100%, the VAS accounts for 84.8% of the total variance with only 15.1% unexplained variance. These values were computed from a principal components analysis of the VAS items using WINSTEPS software. In summary, the VAS appears a valid and useful instrument with high reliability inasmuch as its internal reliability coefficient was reported at 0.98 for this sample in this application.

**Figure 1:** Person and item map of the VAS.

As noted earlier, the VAS contained 32 statements to which each participant responded. These statements were constructed by eight categories each of which provided information for the comprehensive profile of the hospice and bereavement volunteer. Each category is summarized below with percentages for each category.

**Biological Stressors**

These data suggest that while only 7% of the participants currently face medical issues they consider serious, 52% report family medical histories which suggest vulnerability to medical conditions and 64% carry at least some level of concern regarding their current state of health. Though medical illness does not appear to be a current major stressor in the lives of the participants, only 18% report family histories void of serious medical conditions which leaves the remaining 82% conscious of their vulnerability to health issues.

**Psychological Stressors**

These data suggest that 100% the participants experience stable moods and do not report struggling in this area. With 90% of the participants reporting effective methods of self-care, only 7% report discouragement in their attempts to maintain balance in life. This suggests that the participants in this study experience psychological health and bring these strengths into the therapeutic relationships they foster with their clients.

**Social Stressors**

These data suggest that social stressors are low in the lives of the volunteers, with only 7% reporting complicated relationships unresolved at this time. Though 46% report their circle of friends to be “rather small”, this does not necessarily denote isolation; 95% report a community of supportive friends which highlights the importance of social capitol in terms of quality instead of quantity.

**Spirituality**

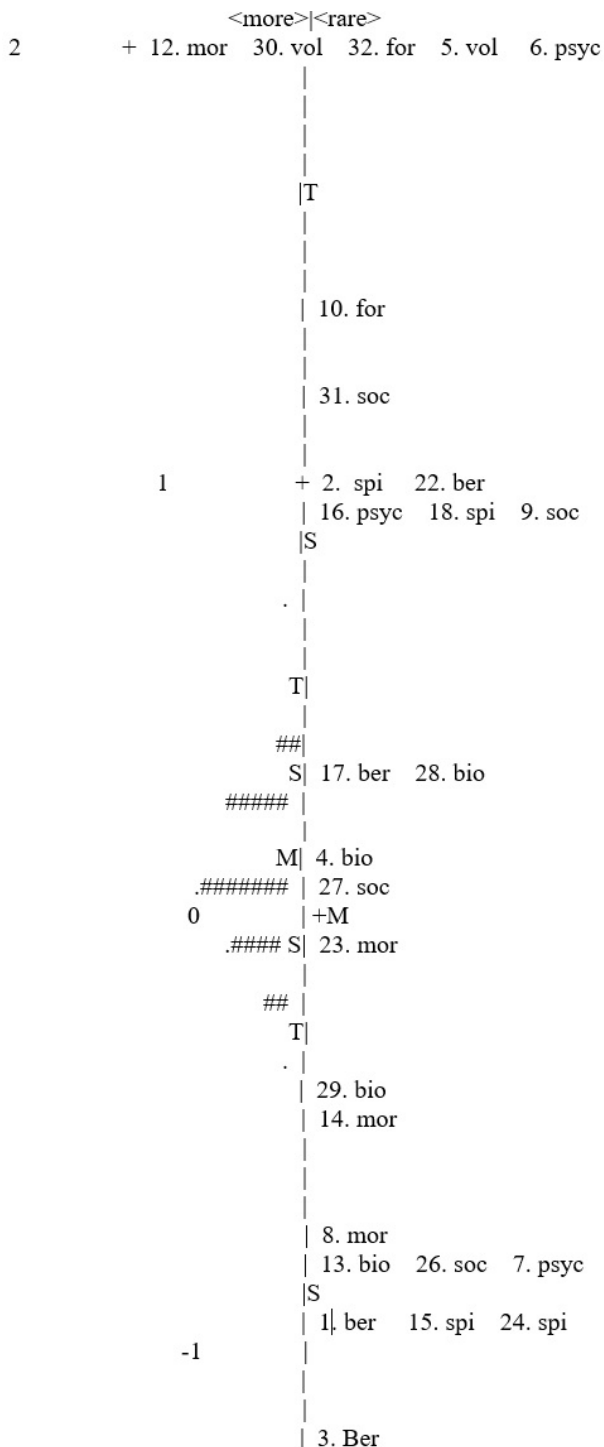
These data show that 93% of the volunteers believe that spirituality is an important part of their lives and many of them identify a Higher Power they call God. Because the term spirituality is often interpreted as denoting religious beliefs or affiliation, it would be interesting to see if these data would change if the concept of transcendence were used instead.

**Bereavement/Loss**

These data show clearly that 97% of the volunteers have lost loved ones and 65% have experienced the loss of particularly supportive and affirming loved ones. None report trouble understanding the losses of their clients, and 95% stated that the losses faced by their clients resonate with them as volunteers.

**Mortality**

These data suggest an acceptance of mortality with 100% of the volunteers comfortable with the fact that all living things die. Yet on a personal level, one’s own mortality brings a host of thoughts



and behaviors: 16% find thoughts of death frightening and 10% avoid thinking about their own end-of-life issues. These are not large numbers, but they point to the very real existential material faced by human persons (volunteers and clients) facing death. The 36% who report they consider their own end-of-life issues quite often (also not a large number) suggests that 64% do not: the researcher wonders if that which appears to be avoidance might in fact be the transformative freedom that emerges when one is truly comfortable with death and thereby becomes less preoccupied with it as well.

### Volunteerism

These data showcase the spirit of the volunteers: Hospice and Bereavement work is complex and demanding yet 100% find it rich and meaningful and believe that giving-back is important. None considered it a low priority and none felt inclined to ignore others in need.

### Fortitude

These data portray an element of the volunteers' core beliefs that lie at the heart of their volunteerism. 97% believe that their own sufferings actually equip them to bring comfort to their clients, with 100% of them stating that they try to bring hope to their clients even if they themselves carry personal sufferings of their own. None of them believe they are useless if they are suffering or that personal suffering disqualifies them from effective service. None of them have allowed their own concerns to prevent them from serving in this capacity.

### Descriptive statistics and statistical analysis

A t test was conducted for a VAS score difference by sex. For 31 females (mean =83, SD = 3.74) and 12 males (mean = 83, SD = 4.34) and t statistic of 0.34 with p = 0.73 against a critical two-tail test of 2.1 was not statistically significant.

ANOVA was used to test for VAS score differences for the three age groups and the four groups designating years of service. The VAS scores among the three age groups was not statistically significant with F = 0.002652 and F critical at 1.65 (d.f.= 1,34, p = 0.99). The VAS scores for the four groups by age of service was not statistically significant with F = 0.0259 and F critical at 1.65 (d.f.- 1,34, p = .98).

The three highest scores were correlated to the three lowest scores producing Figure 2 which shows an almost perfect correlation with R2 = 0.97. This strategy was introduced by Rasch [13] and exemplified by Wright [14] which indicates that measures are clearly linear when the data fit the Rasch logistic model. Wright's presentation, over fifty years ago [14], featured two cumulative ogives constructed from test responses (not given here). The first one showed the test scores for two groups clearly differing in their ability as indicated by two clearly separated ogives. The second figure plotted these same scores, but now according to their Rasch "person-free test calibration" measures. In the first figure, the plot of the two ogives was different for both groups, and the differences easily observed. The second two figures, each with the same data,

utilized a different approach. Furthermore, the range of these "calibrated values" exceeded the range of the observed estimates.

Such plots and outcomes are now the classic demonstration of Rasch's model applied to test data when data fit the model. The differences between the two tests can be divided by the measurement error to produce a standardized difference, and Wright summarizes saying, "These alternative estimates of ability (Figure 1 vs. Figure 2) seem to be aiming at the same thing." But the first figure and values indicate the impossibility of a relationship while a Rasch model calibration provides an almost perfect replication. The measuring model in the presentation gave the odds of success,  $On_i$  by the product of person ability,  $Z_n$ , and the item easiness,  $E_1$  yielding  $On_i = Z_n E_1$  using Wright's notation for that time. The probability that a person with ability  $Z_n$  will succeed on item easiness  $E_1$  is  $Z_n E_1$  divided by one plus the product,  $P_{in} = Z_n E_1 / (1 + Z_n E_1)$  – the Rasch model.

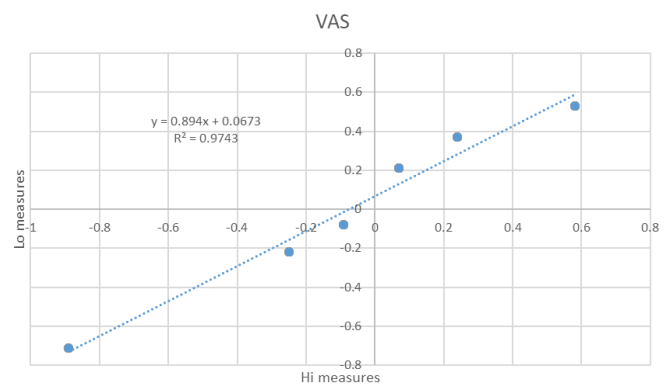


Figure 2: VAS low measures vs. high measures.

In summary, the mean for all participants showed no significant differences, suggesting a highly homogeneous group, even though both sexes were included in the study, ages of participants ranged from 20 to 60+ and years of service ranged from < 5 to > 25. Biopsychosocial factors did not represent major obstacles in the lives of the hospice/bereavement volunteers. Though over half reported a family history suggesting vulnerability to illness and 64% had at least some concern about their current state of health, these concerns have not prevented them from serving as volunteers.

Psychological stressors were low with all reporting mood stability and 90% stating the employment of effective methods of self-care. Social stressors were also low with 90% reporting healthy relationships and 95% stating that they had a community of supportive friends.

93% of the participants reported spirituality as important in their lives and 90% believe in a Higher Power they identify as God.

Bereavement and mortality, two major components of hospice and bereavement work, both brought high scores among the participants, with 97% reporting the loss of loved ones and 95% a unique understanding of the loss(es) faced by their clients. 100% reported that they are comfortable with the fact that all living



things die.

All participants reported that hospice/bereavement volunteerism is a rich experience and that they believe giving back is an important part of a life well-lived. All attempt to bring hope to their clients and believe that their own sufferings actually equip them to do so.

### Qualitative Data

From hospice and bereavement volunteers with more than 15 years of service, seven (7) narratives were collected, each approximately one paragraph in length. Each handwritten document was typed verbatim and coded.

100% of the participants reported that their own personal experiences had influenced their desire to work in bereavement, and all seven reported that these experiences had involved death.

In every case, experiencing loss had been a formative experience which, according to each volunteer, had been instrumental in his/her decision to become a hospice/bereavement volunteer. Of the seven respondents, three reported having gone through cancer themselves and believed this, too, had influenced the desire to volunteer in the field of hospice and bereavement.

To analyze the second part of the question, structural coding was employed to glean information from each narrative as a “grand tour” overview [10]. First-cycle coding noted recurring words, concepts and themes from the participants. Phrases like “giving back”, “helping others”, “rewarding”, “fulfills me”, “faith” and “felt called” were used repeatedly and helped create a collective picture of the volunteers’ thoughts about their work. These words and phrases were tabulated for each volunteer.

In the second-cycle, focused coding was used to categorize these data and group them together in thematic clusters.

Among the seven participants, there were thirteen references to spirituality and faith; one participant identifying faith as the underlying reason for her desire to serve in this capacity. Two participants identified God as the source of their volunteerism with others mentioning spirituality in terms more abstract such as “feeling called” or “being placed in the right place at the right time”. In every case, spirituality was described as a reality beyond oneself.

There were fifteen references to the deep personal fulfillment experienced by volunteering. More than half reported that they believed that they have received far more than they have given after decades of service, suggesting humility and gratitude.

In summary, the seven narratives provided statements which denoted recurring themes of altruism, fulfillment and spirituality. The largest theme, however, was that of mortality and bereavement, with 34 total references from the seven participants. The themes reflected in the volunteers’ narratives confirm the quantitative data that the volunteers are comfortable with death, that spirituality is an important aspect of their work and that one’s personal suffering does not prevent them from voluntarily extending support to clients experiencing loss and grief.

### References

1. <https://u.demog.berkeley.edu/~andrew/1918/figure2.html>
2. <http://www.npr.org/sections/health-shots/2016/12/08/504667607/life-expectancy-in-u-s-drops-for-first-time-in-decades-report-finds>
3. Reese D. Hospice social work. New York Columbia University Press. 2013.
4. Engel G. The need for a new medical model. Science. 1977; 196: 129-136.
5. Winnicott D. Mother and child a primer of first relationships. New York, NY: Basic Books. 1957.
6. Rogers C. On becoming a person A therapist's view of psychotherapy. Boston: Houghton Mifflin. 1961.
7. Frankl V. Man’s search for meaning. Boston, MA Beacon Press. 1959.
8. Erikson E. Childhood and society. New York, NY: Norton. 1950.
9. Creswell J. Research Design. CA Sage. 2014.
10. Saldanã J. The coding manual for qualitative research. New York: Sage Publications. 2013.
11. Wright B, Stone M. Best test design. Chicago MESA. 1979.
12. Linacre M. WINSTEPS A software program for Rasch measurement. Perth, Australia: SWREG. 2015.
13. Rasch G. Statistical models for some intelligence and attainment tests. Chicago: The University of Chicago Press. 1980.
14. Wright B. Sample-free test calibration and person measurement. Invitational Conference of Testing Problems. Educational Testing Service, Princeton: NJ. 1967; 28.