Bereavement Volunteers in Hospice Settings:
Challenges in recruiting, training and retaining

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Abstract
The area of this research is specific to how selected hospices utilize volunteers in bereavement support services. The purpose of this mixed method study was to explore hospice volunteer recruitment practices, the volunteer training programs they provide that are specific to bereavement and how their programs support the volunteers to retain their service to the agencies. A self-created survey was sent to a sampling of sixty-five bereavement and/or volunteer coordinators randomly selected from the National Hospice and Palliative Care Organization’s hospice provider directory (NHPCO, 2016). The results of this study identified common practices hospice agencies utilize to build a volunteer base to support the client system within their program.

Keywords: Volunteers, Bereavement, Recruitment, Training, Retaining, Support
Bereavement Volunteers in Hospice Settings: Challenges in recruiting, training and retaining

Volunteers in hospice agencies across the world play a vital role in filling in the gaps where service and cost-effectiveness are key components of end-of-life care. According to the National Hospice and Palliative Care Organization (NHPCO), it is estimated that in 2014, 430,000 hospice volunteers provided 19 million hours of service here in the United States. While volunteers take on various duties such as clerical and fundraising efforts, 60.8% of volunteer hours are dedicated to assisting with direct support, including bereavement services (NHPCO, 2015).

Background

As per United States Medicare guidelines, hospices are required to provide bereavement support services to patients and their families before, during, and for up to thirteen months post-death as one of the Conditions of Participation, or CoP (NHPCO, 2008). Since bereavement support is not billable once a patient has died, the agency must bear the burden of cost to provide services for the surviving family members. Additionally, Medicare mandates the utilization of volunteers as a non-core service provision (NHPCO, 2009). To meet these requirements and to help alleviate costs and the social worker’s ever-increasing caseloads, it seems only practical for hospice agencies to integrate volunteers into the bereavement support program. However, bereavement and volunteer coordinators face many challenges in the recruitment, training and retention of bereavement volunteers.
Historical Context

The philosophy of hospice prides itself in the practice of advancing patient and family centered care. As with any business, it can be a struggle meeting regulatory needs and balancing costs without compromising high quality care.

Volunteers have been an integral part of all hospice agencies since its grassroots movement in the 1960’s. Hospices have continued to offer services for the terminally ill and children and adults dealing with grief free of charge through the dedication and support of professional and hospice trained volunteers and community donations. The National Hospice and Palliative Care Organization (NHPCO) reported that in 2014 the percentage of hospice patients covered by the Medicare Hospice Benefit was 85.5% (2015). All core services are reimbursable except bereavement support for the families once the patient has died. With the social worker’s ever-increasing caseloads, shrinking bereavement departments and a small base of trained bereavement volunteers, there are families and caregivers who are not receiving the much needed (and promised) support in their journey through grief and loss.

Social Context

Hospice of North Idaho (HONI), which serves three counties in Northwest Idaho, reported over 800 deaths in 2015. While close to 100 volunteers are actively assisting in the operations of HONI in our community, there are less than 5 who are connected with any one bereaved family member (M. Neel, personal communication, October 2016). This translates a need to serve a large population of bereaved individuals and families who may be experiencing difficulties functioning within their daily lives. Clients may develop normative symptoms related to their grief, such as difficulty eating or sleeping,
anxiety, and heavy sadness. However, due to our culture of medicalization of life events, many people seek the care of a physician. Research has indicated that the use of volunteers in hospice bereavement support has been effective in reducing bereaved people’s use of medical services compared to an unsupported group (Payne, 2001). Costs are thus reduced within agencies, medical insurance premiums and within society as a whole.

**Problem Statement**

The problem is that hospice agencies struggle to meet Medicare guidelines in terms of time and cost. The use of volunteers in bereavement services could fill in the gaps and prove to be cost effective. However, my preliminary research indicated various problems in recruiting and training practices along with retaining and supporting bereavement volunteers.

**Purpose Statement**

The purpose of this mixed-method study was to explore hospice volunteer recruitment practices, the volunteer training programs they provide that are specific to bereavement and how their programs support the volunteers to retain their service to the agencies. The results were expected to identify common experiences and an understanding of what challenges hospice agencies face in building a volunteer base to support the client system within their program.

**Significance of the Study**

Based upon the literature and data that has been reviewed, there is an assumption that it would be economically beneficial for hospice agencies to build a strong base of volunteers trained to deliver bereavement support services. According to the NHPCO
2014 National Summary of Hospice Care, hospice volunteers provided 60.8% of direct patient support, yet there is no information that indicates volunteer bereavement support to the families and primary caregivers post-death as mandated by Medicare (2014). Additionally, it is reported that 91.6% of hospice agencies offered ‘some’ level of bereavement services (2014), yet is not clear who (nurses, social workers, chaplain, bereavement counselor) provided what service (calls, mailings, visits). As per Medicare guidelines, bereavement support must be provided for up to thirteen months after the patient has died, which Medicare does not reimburse. This presents a financial burden on the agency and work overload on the professional staff. Again, there is an assumption that solidifying a program with a base of trained bereavement volunteers would satisfy many needs.

This study was designed to examine the utilization of volunteers in bereavement support services. The participants selected to complete the survey provided data telling how volunteers in their regions are recruited, trained and retained. The results can be used to inform the development of volunteer bereavement support in hospice agencies and may present support for future research for those seeking Medicare policy change.

Research Question

RQ1: How do hospices utilize volunteers in bereavement support services?

Definitions

The following definitions are used for this study:

1. Bereavement – the extended period of adjustment to loss.
2. Bereavement support services – counseling (provided by professionals only), calls, mailings, visits, support groups and social events provided by supervised volunteers and professionals (Payne, 2002).

**Theoretical Framework**

The attachment theory presents the theoretical framework that best informs bereavement research as it relates to early attachment styles, the continuing bond with the deceased and meaning reconstruction theory.

John Bowlby, also known as the father of the attachment theory, gives clinicians a conceptual framework in which relationships between the deceased and the bereaved can be explained. Bowlby believed that a person’s response to loss is associated with the attachment style formed during infancy and childhood. He held the opinion that our emotional and behavioral patterns are relevant to our early attachment in that individuals display the same emotional and behavioral stress in their reaction to separation through a death as we do in our childhood (Stroeb, 2002). Contemporary bereavement studies have drawn on Bowlby’s later work in grief and loss by highlighting the period of adjustment after experiencing separation through death. As a result, Stroeb reports that models of intervention have evolved to include “strategies of care” in the course of bereavement rather than the “prevention of separation” (2002, p. 131).

The concept of this theory relates to the continuing bond with the deceased and the relation between coping during the bereaved’s extended period of adjustment and meaning reconstruction, or finding a new purpose in living their lives after losing a loved one (Field, Gao, & Paderna (2005); Neimeyer, Baldwin & Gillies (2006). Field, et.al.
explains that although we are physically separated by death, the emotional attachment is a life-long connection (2005).

Payne (2001) reports that over 70% of hospice volunteers are previously bereaved. Related research on bereavement volunteers used the conceptual framework of the meaning construction theory addressing the elements following a death which include “the capability of griever to make sense of the loss, to realize growth or benefit that the experience of loss may have brought them, and to reorganize personal identity in the context of loss (Supiano, Cloyes & Berry, 2014, p83). Meaning making involves the process of redefining the self and finding new ways to engage with the world (Servaty-Seib, 2004). This research hypothesizes, based on the attachment theory of continuing bonds, that volunteering is how some people cope with their own loss and that helping others through the grieving process gives them a new purpose to life (meaning reconstruction).

**Literature Review**

Research studies conducted on hospice care commonly place a strong emphasis on the value of bereavement support in helping families and caregivers navigate through the grieving process after losing a loved one. Medicare requires hospice agencies to provide a bereavement program as well as volunteer documented hours. The use of trained volunteers in bereavement programs are a cost benefit to hospice agencies and provide a peer supported benefit to the population they serve. The literature identifies the needs of volunteers in bereavement programs in regards to training and support in order to sustain a strong volunteer supported program.

**Related Literature**
Regulations and Cost. The Medicare Hospice Benefit was established in 1982 to provide beneficiaries access to high-quality end-of-life care. Behind the philosophy of hospice is the belief that everyone deserves compassionate care and has the right to die pain-free and with dignity regardless of the ability to pay. Support is provided for the patient’s loved ones as well. Among medical personnel and social workers, bereavement counselors and trained volunteers participate in the patient’s plan of care as part of the interdisciplinary team. The value of bereavement support is emphasized by the Centers for Medicare and Medicaid services (Dean, Libby, McAuley & Van Nostrand, 2014). As per United States Medicare policy guidelines, hospices are required to provide bereavement support services to patients and their families before, during, and for up to thirteen months post-death as one of the Conditions of Participation, or CoP (National Hospice and Palliative Care Organization, NHPCO, 2008). Funds are allocated only for the patient’s length of service which means that bereavement support services for the families and caregivers are not covered by Medicare once a patient has died (Dean, et.al., 2014; Foliart, 2001). Therefore, the cost to provide bereavement services for the surviving family members falls upon the agency for up to one year.

Although Medicare guidelines outline the minimal standards of bereavement care that hospice agencies must meet, there is little guidance on the nature or delivery of these services (Dean, et al., 2014, Payne, 2002), leaving much to the discretion of hospice agencies. In addition, since reimbursement rates are not tied to the level or quality of care, there remains little financial incentive to provide more than the minimal benefit (Barry, Carlson, Thompson, Schlesinger, McCorkle, Kasl, & Bradley, 2012). Dean et.al. points out that families and caregivers may miss the opportunity for much needed bereavement
support when only minimal support is offered by professional staff with high caseloads and untrained volunteers (2014).

**Value of Volunteers.** Volunteers have been an integral part of all hospice agencies since its grassroots movement in the 1960’s. Hospices have continued to offer services for the terminally ill and children and adults dealing with grief free of charge through the dedication and support of professional and hospice trained volunteers and community donations. According to NHPCO data, it is estimated that in 2014, 430,000 hospice volunteers provided 19 million hours of service here in the United States. While volunteers take on various duties such as clerical and fundraising efforts, 60.8% of volunteer hours are dedicated to assisting with direct support, including bereavement services (NHPCO, 2015).

**Training and retaining.** A common thread found in research implies that there are many challenges in the hospice setting from the initial assessment to the delivery of bereavement services. In an evaluative study of hospice-based bereavement support services in Ireland, the researchers point out the need for more research to inform service planning and delivery, considering it “unethical to introduce services for the bereaved that are not well-founded and evaluated” (Roberts & McGilloway, 2008, p612). Volunteers who are involved in bereavement support should be carefully selected, trained and supervised by qualified professionals.

Research illustrates a discrepancy in accredited training programs for bereavement staff and volunteers (Agnew, Manktelow, Haynes & Jones, 2011). Volunteer coordinators not only face the challenge of recruiting and training volunteers but retaining them as well. Skoglund (2006) reports that “from the moment a program
trains a group of volunteers, the focus should be on retention” (p.217). In other words, it is important for volunteers to feel good about their role and to feel supported for them to remain committed to their assignment.

In a study done on understanding grief experiences of hospice caregivers, an effective training program included instruction by professional and experienced volunteer mentors, or peers. In addition to teaching boundaries with patients, caregiving volunteers were supported with on-going training, included in the interdisciplinary meetings on the plan of care and supported in dealing with their own grief (Supiano, Cloyes, & Berry, 2014). Payne (2001) reports that over 70% of hospice volunteers are previously bereaved which underscores the need for support to prevent compassion fatigue. Further research is recommended to address bereavement volunteers “need for or attitudes about agency assistance” (Dean, et.al.,2014, p.90).

Summary

Based on the research that has been reviewed, the common theme appears to be that properly trained and supported volunteers can serve to meet Medicare guidelines, prove to be an economic benefit to hospice agencies, provide compassionate peer-to-peer care to the bereaved and, in addition, give meaning to their own lives after a loss. This research can benefit hospice agencies that are faced with these particular challenges to develop effective bereavement programs.

Methodology

In an effort to explore the role of volunteers in bereavement services in hospice agencies from an outsider perspective, this study collected data from survey responses from a randomly selected sample of hospice providers listed in the National Hospice and
Palliative Care Organization directory (NHPCO, 2016). Building upon prior qualitative research designs that collected data from direct interviews with hospice volunteers (Payne, 2002), this mixed-method design sought to identify common themes among hospice agencies in development of their volunteer bereavement programs based on their recruitment and training practices and to measure the rate of retention. Previous research conducted through interviews with hospice volunteers has indicated that the needs of bereavement volunteers include ongoing training and formal and informal support from both professionals and their peers (Payne, 2001; Skoglund, 2006). The results of this survey study were anticipated to find the correlation between volunteer retention rates and agency training and support practices.

Research Design

This study was conducted as a mixed method design. The qualitative and quantitative components include a descriptive analysis of the data collected from a self-created survey completed by randomly selected hospice agencies in the states of Idaho, Oregon and Washington listed in the NHPCO directory (2016).

This study sought to identify hospice agencies experiences with bereavement volunteers (the independent variable), and what the relationship is between recruitment, training and support practices with the retention rates (the dependent variable) of volunteer involvement in their agencies.

Participants and Setting

The participants for this study were bereavement and/or volunteer coordinators selected from the National Hospice and Palliative Care Organization (NHPCO) directory of hospices in the states of Idaho, Oregon and Washington (2016). Out of the 130
hospices listed in those states, 50% were randomly chosen by systematically selecting every other one. The selected 65 hospices are Medicare certified and have an active bereavement program in place. Only those that met those specific guidelines were invited to participate in this study. This ensured that the agencies selected are presumably meeting the minimum Medicare Conditions of Participation mandates for both volunteer participation and bereavement services for hospice agencies (NHPCO, 2008, 2009) that are relevant to this study.

**Instrumentation**

A self-created survey was generated through SurveyMonkey, an online survey service company. The survey questions were designed to produce a cross-sectional examination of hospice agency practices in their use of volunteers in their bereavement departments.

**Research Questions.** The following research questions were asked on the survey:

1) Do you use volunteers to deliver bereavement services?
2) What is your method of recruitment?
3) Do you have a volunteer training program specific for bereavement support?
4) How long do bereavement volunteers usually remain with the program?
5) How does your agency support volunteers in the bereavement program?

**Data Collection**

Upon Institutional Review Board approval, participants that were collected from the National Hospice and Palliative Care Organization’s directory of providers were emailed an invitation to participate in this study with informed consent and the assurance of anonymity. The invitation included the URL to complete an online survey set up by
the researcher through SurveyMonkey, an online survey service company (https://www.surveymonkey.com/). The results were collected and recorded in the SurveyMonkey software as each participant completed and submitted the survey. The recorded data was collected and secured on the researcher’s password protected computer for analysis.

Data Analysis

Data was recorded on tables and graphs created from the survey results to detect common themes. Notes were taken on the participant’s answers to the open-ended questions on the survey and color coded to identify the responses.

Limitations

Demographic variables not included in this study should be considered for future research; such as, the agencies geographic location (rural, urban or mixed) and the size as related to total annual patient admissions. Other limitations include agency ownership (an independent hospice, part of a hospital system, home health agency or nursing facility), and the hospice’s tax status (non-profit versus for-profit).

Analysis and Findings

Analysis

This research was conducted as an online survey. Email invitations to participate in this study were sent to sixty-five hospices from Idaho, Oregon and Washington who were randomly selected out of the National Hospice and Palliative Care Organization’s directory (NHPCO, 2016). Twenty-four volunteer and/or bereavement counselors responded anonymously to the researcher’s survey questions that were specific to the use of volunteers in the delivery of bereavement support services in their hospice agencies.
Participants were asked whether volunteers were used for bereavement support and, if so, what methods their agencies used to recruit, train and support the volunteers. This research was a mixed method design that consisted of four nominal quantitative questions and two qualitative questions. To identify emerging themes from the participant’s responses to the qualitative questions, the researcher used a thematic analysis method by reviewing and color-coding patterns within the collected data.

**Findings**

Out of the 24 responses, 20 (83%) answered that volunteers were used to deliver bereavement support services at their hospice agencies; whereas, 4 (17%) replied that they did not.

**Table 1: Do you use volunteers to deliver bereavement support services?**

![Use of Volunteers for Bereavement Services](image)

The second question on the survey asked what methods agencies use to recruit bereavement service volunteers. The 22 respondents to this question reported one or more recruitment methods, including: pulling from the pool of existing volunteers who serve their agency in other departments (41%), word of mouth (27%), advertising through newspapers, flyers and social media (36%), presentations at community events (14%),
and reaching out to caregivers and family members who have received services in the past (14%).

Table 2: What is your method of recruitment?

<table>
<thead>
<tr>
<th>Method of bereavement volunteer recruitment</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pull from existing pool of volunteers</td>
<td>9</td>
<td>41%</td>
</tr>
<tr>
<td>Word of mouth</td>
<td>6</td>
<td>27%</td>
</tr>
<tr>
<td>Advertisement</td>
<td>8</td>
<td>36%</td>
</tr>
<tr>
<td>Community presentations</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>Former bereavement program recipients</td>
<td>3</td>
<td>14%</td>
</tr>
<tr>
<td>Total responses</td>
<td>n=22</td>
<td></td>
</tr>
</tbody>
</table>

Part A of Question 3 asked the participants whether their agency offered a volunteer training program specific for direct bereavement support. From 23 responses, 17 (74%) replied yes and 6 (26%) answered no. The 17 who replied yes were asked in Part B to describe the bereavement volunteer training program the agency provides. 53% replied that volunteers attend module-based classes facilitated by a licensed professional. It is mentioned in several replies that the classes offer in-depth training on the grief process and the different methods to lend support to the bereaved. 29% replied that volunteers interested in direct bereavement support work one-on-one with the agency’s bereavement coordinator or chaplain, using a self-study curricula. 18% replied that
volunteers with experience in bereavement group participation, along with professional
guidance, are considered good candidates for working with the bereaved.

Table 3: Describe your agency’s bereavement volunteer training program.

<table>
<thead>
<tr>
<th>Bereavement Volunteer Training Programs</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionally facilitated classes</td>
<td>9</td>
<td>53%</td>
</tr>
<tr>
<td>Self-study curricula</td>
<td>5</td>
<td>29%</td>
</tr>
<tr>
<td>Support group participation</td>
<td>3</td>
<td>18%</td>
</tr>
</tbody>
</table>

Total responses n=17

Participants were asked in Question 4 how long their agency’s volunteers usually remain in the bereavement support program. Out of 21 total responses, 20 (95.24%) replied that their volunteers are retained for 12 months or more, with only 1 (4.76%) report of 6-12 months.

Table 4: How long do volunteers usually remain in the program?

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6 months</td>
<td>0</td>
<td>0.00%</td>
</tr>
<tr>
<td>6-12 months</td>
<td>1</td>
<td>4.76%</td>
</tr>
<tr>
<td>12 months +</td>
<td>20</td>
<td>95.24%</td>
</tr>
</tbody>
</table>

Total responses n=21
This significantly high retention rate suggests a strong correlation to the support system hospice agencies provide for their bereavement volunteers. Question 5 asked how the agencies support the bereavement volunteers. Table 5 shows that 77% of the 22 respondents provide ongoing training, individual supervision and volunteer support groups. Individual support alone was reported by two agencies (9.09%) and volunteer support groups reported by 1 (4.55%), while 2 (9.09%) agencies replied that none of the above were provided.

**Table 5: How does your agency support the volunteers in the bereavement program?**

<table>
<thead>
<tr>
<th>Support Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Groups</td>
<td>4.55%</td>
</tr>
<tr>
<td>Individual Supervision</td>
<td>9.09%</td>
</tr>
<tr>
<td>Ongoing Training</td>
<td>0%</td>
</tr>
<tr>
<td>All above</td>
<td>77.27%</td>
</tr>
<tr>
<td>None</td>
<td>9.09%</td>
</tr>
</tbody>
</table>

Lastly, the participants were given the opportunity to add any comments to the survey. Gratitude and praise for their bereavement support volunteers was the most common theme from the 11 comments.

- “*Volunteers are a vital part of our bereavement support services*”.
• “Volunteers provide an additional dynamic of comfort, care and love to our patients and their families”.

• “We LOVE our volunteers! We couldn’t offer our services without our volunteers.”

• “Our bereavement volunteers are highly valued”.

• “Hospice bereavement volunteers are a special kind of people, a tribe of angels for sure”.

Other comments included pride in the fact that their hospice agencies were able to provide “lots of support and education” for the dedicated volunteers that assist them in bereavement support to the families grieving a loss of a loved one.

Participants also reported that many of their volunteers have professional degrees who are self-guided. Various duties specific to the bereavement support volunteers were explained by more than one respondent, such as; facilitating peer support groups, volunteering at bereavement camps for kids, and reaching out by making calls or visits to those who prefer a more private setting.

Discussion

The researcher’s findings from the survey offer significant support to previous bereavement research studies discussed in the literature review. A high volunteer retention rate is indicative of a strong support system. Tables 4 and 5 show that volunteers who are offered training specific to bereavement and who are strongly supported by the professionals within the hospice agencies with ongoing training, individual supervision and peer support groups are more likely to feel valued and remain in the program for longer periods. For agencies struggling to meet the conditions of
participation guidelines for bereavement services set by Medicare, the results of this study suggest that the use of volunteers maintains the potential to alleviate costs, meet staffing challenges, and to provide quality services to the bereaved.

Limitations

With 3,680 hospice agencies in the United States (NHPCO, 2016), this study was limited to a small sampling in the scope of national geographic demographics with just 24 respondents from three Pacific Northwest states. Due to the random selection of hospice agencies from the National Hospice and Palliative Care Organization’s (NHPCO) directory, it is important to note that the researcher did not differentiate between specific variables such as hospice ownership (for-profit vs. non-profit), size (i.e., patients per day), patient to staff ratio, religious affiliation, and/or financial status regarding revenue from Medicare. These variables should be considered for future research.

Recommendations for Future Research

The participants in this research study were hospice volunteer and/or bereavement coordinators who were asked in a survey about their recruitment, training, and support practices specific to the delivery of direct bereavement support services to caregivers and family members of hospice patients who have died. This researcher recommends a similar study to include a sampling of bereavement volunteers to measure the satisfaction of their experiences in an attempt to aid agency performance.

During the course of this study, the researcher discovered that gaps in the delivery of bereavement services from some agencies stem from a financial standpoint. As noted earlier, hospice agencies are mandated by Medicare to provide bereavement services for the primary caregivers of a patient for up to 13 months after the date of death, as needed.
However, under current Medicare policy, once a patient has died agencies cannot be reimbursed for these services. This equates to a burden of cost on the agency in terms of both financial and quality of services. Further research on the actual cost of professional staff hours to deliver quality services and to train and supervise bereavement volunteers would be beneficial to those seeking a change in current Medicare reimbursement policy regarding family bereavement services.

There is an importance for continued research on hospice bereavement services due to the value of bereavement support and because of the emphasis placed on such services by the Centers for Medicare and Medicaid Services (Dean, et al, 2014). This study sought a solution to the problem of hospice agencies meeting the needs of the families who have lost a loved one while meeting the Medicare Condition of Participation guidelines. The findings have the potential to aid future research for those seeking policy change and may be used to inform the development of volunteer bereavement support in hospice agencies.

**Conclusion**

The hospice philosophy prides itself in the practice of providing compassionate end-of-life care and bereavement support. As with any business, it can be a struggle meeting regulatory needs and balancing costs without compromising the quality of care. The contributions of dedicated bereavement volunteers are a vital part in meeting those challenges.
References


Neel, M., MSW. Hospice of North Idaho. neelm@honi.org. Personal communication: October, 2016.


