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Expression of Hospice Culture at Volunteer Training

Meghan Letters

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University of Portland

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Abstract

This project describes the organizational culture of hospice. Hospice is not a single organization or a building but it is a way of caring for patients who suffer from terminal illnesses and are not expected to live for more than six months. Volunteers are a crucial part of the care provided to these patients. Volunteers go through extensive training to be able to serve this population and their families. This project uses participant organization as the method of finding how the culture of hospice is expressed to new volunteers at the volunteer training and what organizational truths are conveyed. Program recommendations are made for improving future trainings.

Introduction

Hospice work is not for everyone. It is a calling that few hear. My first experience with hospice was not the first day I walked into Legacy's Hopewell House in Portland, Oregon. Nor was it the first day of Volunteer Training. My father was diagnosed with terminal lung cancer when he was 71 years old. I was a freshman in high school. Since my grandmother had been a hospice nurse and volunteer for many years, my family was welcoming to the idea of bringing Dad home and setting up a hospital bed in the living room. I am the youngest of seven kids and my dad was the middle of eight. My large family lived for weeks with Dad dying in the living room.

This introduction of the idea of hospice care stuck with me. The nurses, chaplains and volunteers who came to us during that time were a special group. I knew there was something different about them. The hospice people always walked in with reverence and confidence. I remember feeling such a contrast between them and most other people, even friends, who would walk into our home in those weeks as if they were stepping on eggshells or like they had never been in our front hallway before. Outsiders would whisper with shoulders clenched and look around as if something had changed. To them, death was already there in our home and they were unable to act normal or converse with us about anything naturally. The hospice people brought a calm understanding to our situation. They helped us recognize the profound and universal experience we were going through together. They were there for Dad's well-being, but they were also there for our sanity. This was the wonderful way they did things. This project focuses on what the culture of hospice is and how it is expressed to new volunteers at training.

My interest in hospice care stems from encounters with these organizations when my father was dying as well as with both my grandparents. Though not very religious, I do believe everything happens for a reason. I believe if I was given an expertise in my personal life, I have an obligation to utilize the knowledge I gained to help others. So for my Service Learning Capstone, I looked at the Community Coalition Hospice Volunteer Training with intention of working at Hopewell House, an inpatient hospice facility run by Legacy Health System. The coalition is made up of five hospice agencies working in the Portland metro area. Like many other volunteers at the training, my personal experiences with death lead me to want to volunteer at the same time as furthering my academic knowledge of hospice and the organization's culture.

The goal of volunteer training was two-fold. The coalition worked hard to present the culture of hospice but also provided a space for new volunteers to examine their own selves with regards to the work they will be doing. In this way, volunteers will be armed with knowledge of the organization, an understanding of their role in it and an ability to confront the variety of difficult situations they might encounter with grace and maturity. The six sessions are designed to introduce new volunteers to the culture by teaching the clinical skills needed to care for the dying and the principles, philosophy and goals of the national hospice movement. Intertwined with this were activities meant to explore each volunteer's understanding of death, suffering and their own personal loss story. This task was not easy. This project is intended to depict the culture of hospice presented at the volunteer training, assess the effectiveness of how that culture was expressed, and propose areas of improvement for future training sessions in terms of their ability to affirm and make that culture even more transparent to newcomers. This project will

provide background on the hospice movement, examples of communication research done on hospice organizations and some theoretical frameworks used to analyze the training sessions. The method and work plan are described in detail before the description of hospice culture. The analysis is broken down into four categories with examples from the training to illustrate each one. The project concludes with future research considerations and recommendations for the training program.

Background

Relatively speaking, the hospice movement is new to health care. It wasn't until the late 1960's that the word "hospice" was used to refer to care of dying patients. Since then, the movement to fight our death-denying culture has been slowly taking hold with hospice home programs and inpatient facilities popping up all over the country. Legislation has been passed to provide federal funds for hospice care patients as well as extension of Medicare to patients not wanting to extend their lives but wishing to receive comfort care (www.NHPCO.com). The National Hospice and Palliative Care Organization estimated that over 400,000 volunteers in the United States spend their time caring for people who are in the end stages of terminal illness and their families (as cited in Palanalp & Trost, 2008). Volunteers are a substantial part of any patient's care while on hospice. They not only serve patients and families as a link to information about disease processes but they can provide a compassionate listener who is available for whatever task is needed at the moment.

Academic studies have looked at the communication issues that volunteers face while in the patient's home (Palanalp & Trost, 2008) as well as developed multiple

training programs for basic skills needed (Coffman & Coffman, 1993; Foster, 2002 as cited in Planalp & Trost, 2008). Communication skills training is important because volunteers are placed in sensitive situations which sometimes require expert negotiation skills and counseling. While the culture of hospice is unique and complex, little research has been done to describe the language, rites or rituals that surround hospice care. More importantly, little research has been done to provide explanation of what guides new volunteers as they start their journey into these organizations. The training is extensive and initiates volunteers into a world of death, disease, suffering and emotional stress. Because of the intensity of this world, it is relevant to look at how the concept of hospice care and the culture of the hospice organization is expressed to new volunteers.

Managing culture is of special interest to corporations who wish their employees to exhibit the mindset of the business environment. Managers in the for-profit sector can gain a competitive advantage by providing a clear and unified work environment. Not only does a corporate identity provide uniqueness to a business but it also allows for the internal community to gain cohesion, which leads to job satisfaction and high productivity (McAleese & Hargie, 2004).

McAleese & Hargie (2004) provide five guiding principles aimed at assisting managers in creating and maintaining a corporate culture. These principles can be utilized in managing any environment or organizational identity. The first principle is to establish a cultural strategy. This is more than just a business plan or company guidelines. This is where managers build and then share the “mission, vision and values” of the organization (McAleese & Hargie, p. 162, 2004).

To help them accomplish this, the second principle suggests developing cultural leaders. These are employees or volunteers who exhibit the culture and profess it to others within the organization and to outside clients or customers. Communicating effectively and precisely with these leaders and other staff is also important in managing an established culture. The task of talking with and listening to employees helps make the internal community feel valued.

The fourth principle advocates for reward systems to be implemented in order to validate internal participants in the corporate culture. The monetary value of rewards is irrelevant but more important is the symbol of appreciation being expressed to people who legitimize the rhetorical vision of the group. If the culture is effectively understood within the organization, the fifth principle follows logically. McAleese & Hargie (2004) suggest the importance of communicating the culture with all dealings with customers across all levels of the organization. This puts pressure on managers to nurture the culture within the organization so that all participants can express it to the external audience. Though managing an organizational identity and environment might be a bit different than creating one for new members of the organization, the same principles can be used to evaluate the expression of hospice culture during the training.

Pacanowsky (1988) attempted to describe the culture of a corporation by conducting qualitative research in which he participated in the unique culture of W.L. Gore and Associates. The company had gained notoriety for their “lattice” organization structure. The label “lattice” signifies the unrestricted communication of the company and lack of a hierarchy. The researcher began as an outside observer but was quickly asked to be part of an ad hoc task force, which thrust him across the line into

participation. Hospice volunteer training has already been studied in a similar fashion but with the focus of understanding the communication skills taught by the program.

Worthington (2008) attempted to identify how volunteers were prepared to work with people who are dying and their families. The researchers used an exploratory case study approach. Two researchers participated in the training sessions, collected copies of all material handed out and wrote descriptions of all activities and lectures. Analysis consisted of quantifying the appearance of communication skills training or tips. This approach allowed researchers to identify areas of improvement or need for further examination.

Symbolic convergence theory can be used as a foundation to study the expression of culture. Ernest Bormann (1972) and a team from University of Minnesota introduced this theory as an explanation of the group cohesion that is created when stories or “dramas” are shared within groups. A speaker tells a story that is legitimized by the group around them. There is a psychodynamic chord that strikes the audience, which proves they want to be associated with the group and involved in the collective mindset. The agreement of the group presents norms that the rest of the group complies with (if they choose to continue in the culture). Any public communication to the group can be studied for themes, which can be organized into fantasy chains. These themes can be extended to “rhetorical visions,” which prescribe acceptable behaviors (Bormann, 1972). Narratives are the basis for expressing this kind of collective knowledge.

Bormann (1972) worked mostly to describe the creation of fantasy themes within zero history groups, or groups that have no past. Critics argue this method assumes homogeneity and ignores the nature of naturally occurring groups (Olufowote, 2006). If

research is meant to describe and analyze groups that already exist, have a past and an external environment, the diversity of the group must be taken into account. Bona fide group theory can be used as a boost to the scope of symbolic convergence theory. Bona fide group theory breaks the traditional idea that group boundaries are rigid and impermeable and takes into account the larger context in which groups exist (Olufowote, 2006). The research approach here is extended from the laboratory to the real world and strengthens the scope of symbolic convergence theory. The assumption is that groups exist within an environment that affects them. Researching these kinds of groups is more appropriate if the goal is to express the organizational culture.

Proposed Approach and Work Plan

Hospice can be studied from any of several productive perspectives. There is room in this large, international movement for communication studies to be done on every aspect of the services these organizations provide. If I was interested in interpersonal communication, I could study the relationship between family members and the nurses, volunteers and social workers that come into their home. If group communication was my focus, the interdisciplinary team meetings would provide a wealth of communication challenges and problem solving skills to be studied. Interviews with members of the group could be done to explore areas of strength and opportunities for improvement. If I was interested in public messages, the image of death and hospice in society could be looked at through mention of hospice practices and organizations in publications over a period of time. There are also opportunities for quantitative research

to be done on the number of volunteers and workers who have personal experience with hospice as well.

This report's interest is in the culture of hospice. In my experience, people involved with hospice seem indoctrinated with good energy. It would be a coincidence if everyone I have dealt with in my life from a hospice organization just happened to be a kind, loving person. This leads me to believe that it is the organization that nurtures that energy. Just as any business or organization has a corporate environment, non-profits work with common beliefs, norms and philosophies. Culture is a symbolic social energy that drives the heart of an organization (Glastetter & Kleiner, 1989). Culture is shared meaning. It is a group or a community's common way of understanding and reacting to the world around them. It is "the way we do things around here." Pacanowsky (1988) described culture as the whole sense-making process of a group. This means that culture is the way that the people in the group understand the outside world as well as the environment they share together. Others (Kraybill, Nolt & Weaver-Zercher, 2007) have used the term "repertoire" to describe this process of becoming aware of and proficient in a specific culture. Just as musicians build up a body of music they can play at any given time, such is our ability to adapt and be able to perform within the environment around us instinctually. We expand our repertoire so that it extends the past and present patterns we have been taught (Kraybill, Nolt & Weaver-Zercher, 2007).

Method

To fully understand what the culture of hospice is, I embarked on both an academic study and a personal journey. I committed to attend the Community Coalition Hospice Volunteer Training for a total of twenty-five hours. To supplement my

introduction to hospice culture, I took a work-study position as an office assistant to the volunteer coordinator and chaplain at Hopewell House. The time spent in the office was separate from the volunteer training and only used to gain access to more information as well as insight from my mentor. At the volunteer training, I looked at what language was used, what norms were created for the volunteers and what rituals were presented.

This project was designed to be a case study on one hospice training program. Just as Worthington (2008) used one training program to suggest areas of strengths and weaknesses of hospice training programs in general, I have done the same. In doing so, I understand the events that I witnessed might not be common to all hospice training programs. This is part of the risk of studying groups in natural settings and making recommendations to the greater environment. I do assume there is a reasonable amount of cohesion between this specific community coalition and the international hospice movement. I assume that there are similar language patterns used to describe the values and norms of working with terminally ill patients and their families in Oregon as there are all over the country.

The planned approach is based around observation, participation and documentation. The first journals were written before the volunteer training, when the volunteer coordinator and chaplain oriented me to the office assistant position I had taken on with the work-study program. My early field notes and journal entries chronicled some mundane tasks, but also reflect my initial impressions and observations of hospice culture at Hopewell House, an inpatient hospice facility. The following six journal entries explained the activities and discussions I witnessed as a participant-observer at the Community Coalition Hospice Volunteer Training program. These journals contain my

observations, feelings, questions, and beginning of the theoretical framework I used to describe and analyze hospice culture.

I took notes during the training not only about the content to the presentation but also about the structure of the environment I was witnessing. I wrote journal entries after each day of training and then went back to make academic connections. I related the scholarly journal articles to the format of the hospice organizations. I looked for patterns in the content of the presentations that might extend beyond the volunteer experience and represent the larger hospice culture. Symbols that represent “The Hospice Way” were taken into account as embodiments of the culture. I also took notes about narratives given to express concepts. Storytelling seemed to be a tool used by most of the presenters. Through my notes as well as the handouts and manual given to me, I was able to comprehend and describe the culture of hospice as expressed and performed at this site. In light of the academic research surrounding this topic, I will assess the effectiveness of the tools used to express the culture. Then, based on a compilation of best practices, suggestions can be made for improvement.

Hospice Culture

Hospice is a special kind of care designed to provide sensitivity and support for people in the final phase of a terminal illness. Hospice care seeks to enable patients to carry on an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality at home or in a home-like setting.

(Manual, 11)

This quotation is expressed explicitly as the philosophy of hospice. It explains the mission of this organization and its intended care for its patients. Underneath the explicit language of the training and the manual, I have identified four statements that come through as hospice truths. These truths are the different rhetorical visions that are created and maintained through “fantasy chains” (Bormann, 1972). Multiple stories were told during the training to express each of these. As a new volunteer, I was told at hospice, “We are a team;” “We provide comfort;” “Each of us is on a personal journey and that’s fine;” and “We are professionals.”

We are a Team

The cooperative nature of hospice was expressed in multiple instances. The first encounter with this theme for the new volunteers was the first day of training, when the Eight Principles of Hospice Volunteering were introduced. Number seven clearly states, “You are part of a team.” We were told not to bear the burden of the whole situation on our shoulders. The design of hospice is intended to spread the workload between the interdisciplinary team and allow people to specialize in specific services. Patients are not left with one kind of care but provided with a variety of experts to handle the variety of pain that might be experienced as they get closer to death. On page 5 of the training manual, there is a box titled “What Makes Hospice Care Different?” The interdisciplinary approach is mentioned in this box and was noted by the trainers as paramount to the way hospice works. In the letter given to Hopewell House volunteers, the volunteer coordinator and chaplain begins by welcoming us to the “community.” This letter goes on to explain an interdisciplinary team that meets regularly to discuss

important information about patients in order to provide the highest quality of life to our patients.

As an office assistant, I was able to sit in on one of the interdisciplinary group meetings. The meeting is open to every member of the care team and happens weekly. At the training, we were told that we are welcomed to attend these meetings if we ever feel it necessary. The charge nurse who is responsible for admitting patients leads the meeting. Registered nurses, who spend more time in direct care, speak about each patient, their status and then open discussion up to the rest of the group. Not every participant of the meeting speaks about each patient. Everyone had to sign each patient's paperwork. This keeps everyone who works in patient care informed and responsible equally. Someone informing the group that a patient died interrupted the meeting. This was not an unusual occurrence at Hopewell House and that was obvious in the language the group used. It was decided that the group would go to the patient and assist the family when the meeting was over. Someone also mentioned that the patient's pastor wanted to be notified, which the chaplain volunteered to do. Rather than dwell on the death that had happened, the group was planning ahead and began thinking about how they needed to move people around to accommodate the week's planned events and other patient's needs. When the news was brought up that the patient had died, after a short time of logistical discussion, the site manager, piped up with a cheery tone and said, "Well, let's move them around then!" Everyone giggled and seemed to appreciate the moment of common bonding.

The fact the volunteer training is put on by a community coalition suggests that hospice works in teams. The agencies which make up the coalition are from different

health care companies who, technically, are competitors. This was put aside for the betterment of the new volunteers. For a group to be effective, they must work together as a team. The final day was a perfect illustration of this concept. We were asked to find teams to role-play with about 5 or 6 other people. Each team was given a scenario to discuss and questions to answer. The scenarios asked us to put ourselves into the situation and describe what we would do, based on the Eight Principles of Volunteer Training and the many hours of lectures from experts. As a team, we discussed what our initial reactions to the situation were and how we might be inclined to act. We then turned our attention to finding the best practices we had been taught. We were asked to work as a team to present what we would do to the rest of the volunteers and lead the group in a discussion. It was made clear that members of the group were expected to participate and help unpack the situation.

The Sense of a Goose was included in the training manual on page 9. This is a poem that illustrates the importance of working together as a team. The poem appears at the beginning of manual, which indicates this truth is paramount for volunteers to understand if they are to be successful in the hospice culture. The formation of flying geese is related to working together in a team. The uplift from the bird in front helps the bird behind and the whole group fly farther. “People who are part of a team and share a common direction get where they are going quicker and easier because they are traveling on the trust of one another” (Manuel, pg 9). This truth was expressed in poem form, which makes it easy for the new volunteers to digest. Poems and narratives show examples of the principle and allow audience members to imagine themselves in the situations. This makes the principle more tangible and memorable.

We Provide Comfort Care

I thought of this theme as the clinical side of the training. As hospice caregivers we were expected to provide palliative care, or care that is not meant to cure any disease process but increase the quality of the patient's life. The Hopewell House chaplain explained to me that the facility was considered a mini-hospital. Doctors and nurses are available to make medical decisions to comfort the patient. But, we as volunteers, also have to be aware of the medical processes, norms and worse case scenarios. Like a few others at the volunteer training, I am not trained as a nurse. There were sections of the training focused on bringing non-nurses up to the level of basic medical caregivers. The second half of the first day was intended to introduce volunteers to the different kinds of diseases hospice patients face. We were given the logistical knowledge needed to care for people who are dying.

This theme can be illustrated by a personal experience to supplement the volunteer training. It is common for hospice volunteers and nurses to give patients baths. This service is meant to make the patient feel like they are a dignified part of their family or decrease their self-consciousness. My father was only on hospice for less than a week. During that time, a nurse came specifically to wash him. As my mother looks back on the presence of that woman, she could only describe her as an angel. I remember the woman as a young nurse who spoke softly if at all. She also showed us how to sponge Dad's lips. This was meant to give him some hydration but also was pleasurable to him. This woman was focused on what would make Dad feel good but also aware of how to teach us to serve Dad while he needed comfort care.

In the training, we were given some tips on what to do for comfort care. Along with what will happen to people as they die, we were given things to do for them to help them have a better quality of life. This handout was given out to the Hopewell House volunteers and was organized by sounds and symptoms of active dying. Under each are suggestions of things to do to make the patient more comfortable. For example, it is common for patients to develop a throat rattle or gurgle while mouth breathing. It is suggested to move the patient into a side position with plenty of pillow support. This might relieve the blockage if there is any or drain secretions. Other tips were cleaning the mouth and keeping lips moist with Vaseline or Chapstick. Some suggestions were less practical and designed to let the volunteer be accepting of the patient's behavior. It is also common that patients will want to sleep a lot and desire to be left alone. This is hard for the families and sometimes the volunteers. The suggestion was to let the patient sleep. "Remember that at this time being with is often more important than doing anything. Let yourself sit in the room and just be there quietly" (Comfort Care Handout).

The nurse who gave the lecture on Pain and Symptom Management on day two of training spoke about how hospice controls pain in the most non-invasive way possible. Pain was explained as a multidimensional experience. As volunteers, we were told to be aware of spiritual, social, physiological and physical pain a patient might be experiencing. Listening skills are essential in assessing this element of the patient's needs. The volunteer's role is to be present and listen to the patient. We were asked to encourage the patient to examine the pain they are in and what it might mean. We were instructed to listen to the patient's concerns, observe behavior that might indicate comfort is not achieved, respond to the patient by repositioning or providing a quiet environment,

and report the pain rating scale according to agency procedure. Caring for the whole patient makes it easier to alleviate pain from all areas, not just traditional physical pain.

Anger, anxiety, depression, isolation, fearful memories, boredom and other psychological factors can in fact lower a patient's pain threshold. On the other hand, a positive outlook, a supportive family, empathy from nurses and physicians, forgiveness, diversion and sleep will all raise the pain threshold and decrease the pain experiences.

(Manual, 53)

One of the most surprisingly interesting lectures in the training came from a woman who was a speech pathologist. Her role in the training was to discuss communication challenges that arise when working with patients who are confused, disoriented, agitated or unable to verbalize effectively. She talked about the clinical side of what different diseases can do to a person's ability to use language as well as tips on working with people who are hard to understand for various reasons. She showed us devices that can be used to help the patient communicate. For example, if a patient is suffering from Multiple Sclerosis, which is a neurological disorder, it is likely they will lose their articulation skills, experience memory decay and the volume of their voice will decrease. White boards and phrase books can be used to communicate basic needs. Memory books can be made to help the patient remember important people or events. And speech-generating devices and volume enhancement aids are available which amplify the vibrations in the patient's throat so their voice can be audible. We were able

to see all the aids so if we come in contact with a patient who uses one of these to communicate, we will be aware of its function and better able to serve them.

The speaker inspired us to be very patient with these people. She told a few stories about homes she had visited. One woman was not willing to let her touch her throat, which was important to see if she needed to be fitted for a speech device. As much as she tried, this patient would not let her do her job so she said that she began doing a little show so the patient would warm up to her. There was joking involved and finally the patient said she would allow the examination. The presenter said that sometimes you have to put on a song and dance and laugh a little before the patient will accept your presence in their world. Making the patient comfortable can take on many meanings.

Each Of Us Is On A Personal Journey And That's Fine

The Hospice Volunteer training is meant not only to provide information about the organization, the philosophy of hospice care and the clinical needs of the patients. It is also meant to provide space for the volunteers to come to terms with their own experiences with death and their personal loss story. The third of the Eight Principles of Hospice Volunteering is, "Know your own stuff." By dealing with the things which have happened to you, you are more available to serve the family and patient to which you have been assigned. This theme also can be organized and discussed as a symbol of the organization's need to be professional.

This truth was manifested in a few different spots in the training manual but was most clear during an activity one of the chaplains led for us on the third day of training. She was speaking on spiritual care and introduced her topic by using a quote from

Chaplain Horace Duke, who serves the Veteran's Medical Hospital. "The most important factor in your care of patients is your death. Unless you can come to terms with that, your care will be sorely lacking." She discussed the view of death in our society in contrast with how hospice views it. Rather than procrastinating and putting the topic off, we were encouraged to stare death straight in the eye. This points to the value of self-analysis. To do this, we were asked to take part in "Mr. Karma's Disease Lottery." This was an activity where we each picked a card out of a hat. On each card was a disease common to hospice patients. Everyone was asked to imagine that they had just been given this diagnosis and would be dying of this disease. We were all asked to sit with the information and think about what our reactions would be to this kind of information.

I, personally, was hugely affected by this activity. Somehow, I picked "Brain Tumor" out of the hat. This is a coincidence since my older brother has been fighting a brain tumor for almost three years. The closeness of this diagnosis helped me realize how possible it was to have this disease. I thought about what my mom would say if she found out another one of her children would be fighting this horribly intrusive cancer. I felt the pain of having to watch my family take care of me, the youngest child, as I went through the dying process. I also felt scared to have a tumor change my personality or destroy my motor functions. I, surprisingly, also felt some relief. I knew I had enough information about this disease to fight it. Since my brother's diagnosis, my family and I have learned everything possible about brain tumors, research programs, surgeons, chemotherapy, and alternative means of treatment. I felt if I were already armed with information then I would be a step ahead of being able to fight my disease. I was less

scared getting a cancer diagnosis than I would have been if I had gotten a disease of which I knew nothing.

After we all took some time to internalize the diagnosis we were given, we were asked to share. People around the room were able to talk about what they felt and how they would go about confronting the disease. Some people were concerned with finding the right doctor; others were worried about their family or their children. It was interesting to hear from people who had gone through diseases before. One woman, who had fought breast cancer a few years ago, was able to share her story with the group and testify to what it really feels like to be told you have a terminal illness. This technique was hugely successful. It would have been easy for the organization to tell the volunteers they should deal with their own death and come to terms with their own mortality. This activity was a physical way to show people what it would be like to be in the shoes of some of our patients and deal with the personal emotions we are likely to see expressed. This activity went beyond telling a story to illustrate the principle by giving the volunteers an opportunity to tell their own stories. This not only allowed the volunteers to find their own story but also to share with the group.

Sharing did not just happen in the official activities. How I interacted with other volunteers became an example of this principle. This did not happen right away but after I was asked a few times what brought me to hospice, I began asking the question. People seemed to be interested in the path that brought each of us to this training. As I have had a life of preparation for hospice work, others seemed to feel the same. The first person I met in the training was a woman named Gail. We were both lost while attempting to find the room where the training was held and began chatting as we searched. After we

decided which way to go and exchanged names, she asked me what had brought me to hospice. I told her I had admired the organization because of their work with my dad, my grandpa and my grandmother, who had been a hospice nurse for many years. Gail had worked as an administrator in a nursing home but had experienced hospice personally when her mother was dying. The common experience of losing someone felt like the psychodynamic cord that Bormann (1972) described in his fantasy theme analysis. We both had decided to use the loss in our life as a jumping off point to doing good work. “What brought you to hospice?” was also a question asked of the veteran volunteers who came to talk to us on the first and last days of training. All had experienced a death close to them that hospice made easier. These mini stories can be added to the fantasy chain since each time a similar story is told, there is understanding and acceptance of the experience from the audience.

Another side of this theme is the allowance of hospice culture for the patients to have their death be whatever they want it to be. The video shown on the morning of the first day of training introduced the idea of hospice. The video used language that described death as a process and a journey we all take. The role of hospice, and therefore hospice volunteers, is to be a companion on that journey. We are not meant to steer the ship but merely guide it in the right direction. Throughout the training, we were told not to impose our beliefs or values on the families we visit or attempt to change any patient’s opinions. Number six of the Eight Principles of Hospice Volunteering reminds us that, “You don’t have to fix it.” Utilizing this principle allows the volunteer to be accepting of whatever path the patient wants to take in their dying process. If the patient wants to sleep, let them sleep. If the patient wants to smoke cigarettes, we are to allow them to

smoke cigarettes. The training instilled in us judgment is not welcomed in the hospice culture.

We are Professionals

The personal nature of care hospice provides is at the forefront of the minds of new hospice volunteers. Many people come to this work as a way of giving back to an organization that had helped them through the death of a loved one. For those of us in this situation, the professional side of the organization is less central than the heartwarming care. But as new volunteers or representatives of the organization, we were told to know our boundaries as volunteers. This concept was covered the first day of training and revisited multiple times. At first, I felt that it was discussed too early in the training since we had not learned what our role was quite yet. In retrospect though, it does seem to make sense to express to the volunteer what their role is not before they build what the volunteer role is in given situations. The first and second of the Eight Principles of Hospice Volunteering are, “Know your role” and, “Know what your role is not.” By defining these both early in the training, volunteers are able to think of their time with the organization as a professional service and not a way to relieve personal pain or desires.

One of the handouts given to us on the first day of training is titled, “Boundaries: ‘Good Fences Make Good Neighbors.’” This handout defines what boundaries mean in the service setting. “Boundaries allow you to be fully present for the patient’s needs while retaining your own sense of wholeness and integrity” (Boundaries Handout). Unlike a friendship, which is a mutually beneficial relationship, the caregiving relationship is one where the patient’s needs are met by the volunteer during scheduled

visits only, as defined by the care plan, under strict confidentiality, just as anyone else's would be and under compliance with national health care regulations. The differentiation between a personal and a professional relationship is clearly expressed in two easy-to-read charts. This handout was designed to be a reference for volunteers if they ever question whether or not they are still within professional boundaries. It also includes a page with "questions to consider in examining potential boundary issues" (Boundaries Handout).

This theme is important to the hospice culture for two main reasons. First, the hospice organization has legal responsibilities to the patients and deviation from the standard practices would most likely violate national Medicare regulations or at least the trust of our patients and their families. The second reason that keeping a professional relationship is important is for the volunteer. The emotional stress that can be felt with hospice volunteering is obvious. It is sad to watch patients experience the dying process and be with families in the middle of grief and heartache. This can be a heavy burden to bear. The volunteer training is meant to give new volunteers the tools to do the work they are called to do while still nurturing themselves. Volunteers are encouraged to keep a professional distance so they do not become drained or diminished from patient care. This theme is an overarching theme, which came up in many different parts of the training.

The handout from the speech pathologist included some notes about maintaining boundaries. The essence of this section was to be respectful of the patient's situation and their own journey. She encouraged volunteers to avoid talking about their own lives or issues. Her suggestions are reminiscent of number four and five of the Eight Principles

of Hospice Volunteering, “It’s not your family.” and “It’s not your death.” The focus of hospice service is the patient. Because of that, volunteers must remember to keep a professional distance while assisting the patient in achieving a pain-free end of life, even if we would choose something else for our own personal situation.

Closing

The ways in which the culture of hospice was expressed to the new volunteers at the Community Coalition Hospice Volunteer Training program was largely successful. The use of narratives, poems, tips, and activities seemed to instill in these volunteers the culture of hospice so that they are equipped to represent it to the families and patients with whom they come in contact. “The Hospice Way” was expressed to address the clinical side of patient care and the emotional responsibility of all those who come in contact with the special population that hospice serves. Comparing what I have learned about hospice and McAleese and Hargie’s (2004). Five Guiding Principles of Culture Management results in an affirmation of this program’s effectiveness. The culture strategy has been defined and artifacts of this are given to the volunteers in the form of the volunteer manual and handouts.

Having these reminisces of the training is a product of effective communication within the organization. Even months from now, I can look back at my manual if I have any question about what “The Hospice Way” involves. The training gave the new volunteers cultural leaders to look up to by allowing veteran volunteers to speak with us at the beginning and the end of the training experience. The coalition measured their own cultural performance by eliciting evaluations from the new volunteers throughout the

training. This gives them insight into what worked and what might be approved upon for the next training.

Limitations

My method was as meticulous as possible. The limitations of this project are in me as a researcher. I acknowledge the validity of the research is based on my unbiased documentation. As a participant observer, I attempted to balance taking part in the activities and doing research about what was going on around me. The training was focused on leading the volunteer through a self-study so they would be more aware of their own personal loss story. The highly personal nature of the training felt difficult to embrace at the same time as attempting to do reliable research. For future research, multiple participants must be used in order to neutralize the personal aspect of the training and document a common introduction to the culture.

The discussion of culture does not include every example of the theme. I attempted to choose examples that best illustrated the concept being presented. I did not choose the method for this project until I had attended a few training sessions. This left the beginning of my field notes a bit incomplete. I attempted to use my journals to fill in the holes but also realize having a consistent methodology from the beginning would better the validity of my research. This will be taken into account in future research.

Program Recommendations

My recommendations for improvement of this program are minor. The experience behind the seasoned experts and volunteer coordinators who put the training on is far beyond my knowledge and insight. I do rely on relevant research literature to suggest a technical improvement that hopefully would enhance the current content.

Currently, the training is a lot of information expressed in a short amount of time. Especially for someone who has not been clinically trained, the information about diseases and medical situations was overwhelming. It is understandable that the program does not go through some of this information in more detail, likely because of time and budget constraints. To alleviate this problem, perhaps some of the training could be made available online so new volunteers could work through it at their own pace. Having the personal journey exploration in person is important and should not be moved to an online setting but logistical information about pain management or disease processes might be more effective online. This would also leave more room in the live training for more communication training or grief counseling training.

My own personal indoctrination into the hospice culture was both educational and enlightening. I feel like I have gained tools to be able to deal with the varied situations that might arise while volunteering at Hopewell House. I feel like this is only the beginning of my work with an amazing organization and this project has given me the foundation to be both a volunteer as well as a researcher of the culture. I have become aware of these truths: We are a team, We provide comfort care, Everyone has their own journey and that's fine and We are professional. Though I have not fully had the opportunity to express the culture I have become a part of, I feel confident that I will be able to act with as much compassion, reverence and competence as the hospice people who served my family members and inspired me to volunteer.

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