

HOSPICE VOLUNTEERISM IN RESIDENTS OF A
SKILLED NURSING FACILITY

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by

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ABSTRACT

Volunteering within their community greatly benefits older adults, contributing to increased optimism, self-perceived health, and feelings of connectedness. However, most of the literature examines the volunteerism of community dwelling seniors, with few studies examining the experiences of older adult volunteers living in care facilities. The present study aims to compare the motives and experiences of community dwelling volunteers with a sample of four residents of Bayside Care Center that participated in hospice volunteer training. Two focus groups were conducted with the residents following their training, and the recorded contents were transcribed for qualitative analysis. Results indicated that this group of older adults exhibited similar motivations to community dwelling seniors in the existing literature. However, due to delays in the program's implementation, the present study was unable to examine whether hospice volunteerism resulted in similar benefits for this population.

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CHAPTER 1

Introduction

A common theme in my psychology coursework dealing with aging has been the challenge older adults face in finding a sense of purpose as they transition from their working years and adjust to the physical and social changes that come with aging. This is particularly stark in residents of nursing homes and other care facilities, where the transition is even more dramatic and can leave them feeling cut off from their communities. One way to help with this is to find meaningful activities in which seniors in care facilities can feel productive, helpful, and accomplished, even when they are unable to live independently.

An influential study by Langer and Rodin (1976) demonstrated that instilling a sense of personal control in residents of a senior home was predictive of increased well being; the group of seniors given plants to take care of reported higher activity levels and overall happiness than those whose plants were tended by the nursing staff. These changes were corroborated by accounts from the nursing staff, and an increase in the mental alertness of seniors in the responsibility-induced group was also observed (Langer & Rodin, 1976). Van Willigen (2000) observed that seniors who reported volunteering in their community reported better health than those who did not engage in these activities. In addition, participants who were elderly volunteers reported greater increases in subjective well-being than those who were younger volunteers. Health problems have been identified as one of the largest barriers to volunteerism in the senior population (Petriwskyj & Warburton, 2007), and this needs to be taken into consideration when examining volunteer opportunities for elders in care facilities.

I first became interested in studying the psychology of aging during my enrollment in a course titled Psychology of Death offered at Cal Poly. During this time, I became aware of the

challenges many people face as they age in maintaining optimism and a sense of purpose, as well as being able to look back on their lives with satisfaction. This led me to pursue a minor in gerontology and an internship at a skilled nursing facility in my hometown of Arroyo Grande. My time working in the activities department at the Arroyo Grande Care Center has affirmed what I had learned about the importance of personal choice and community involvement for the health and wellbeing of seniors. Activities such as “Green Thumbs,” where the residents tend to a wheelchair-accessible farm behind the facility and sell harvested food in order to donate the money, give them feelings of competence and positivity.

The present study examines the qualitative effects of a hospice volunteer training program on the well-being of seniors residing in a skilled nursing facility. This group of seniors lives at Bayside Care Center and elected to participate in volunteer training provided by Wilshire Hospice in San Luis Obispo. I conducted a total of two focus groups with the seniors after their participation in the classes. The first focus group was given a month after completion, and the second approximately three months post-training. These focus group interviews were transcribed and examined for qualitative changes participants described from their experiences. Participation in the hospice program was hypothesized to contribute positively to perceived well-being and increased feelings of control and competence. The seniors did express improvements in well-being and feelings of positivity after graduating from the training program, however due to delays in the group’s placement I was unable to assess their experience of volunteering.

The purpose of this study was to assess how participation in this program impacted the seniors’ quality of life and sense of purpose. Volunteering at hospice is a unique way for seniors to provide support to others in need and remain active members of their community. This study hopes to contribute to the literature on aging, as well as provide immediate feedback to Bayside

Care Center and Wilshire Hospice concerning the effects senior participants experienced from the training.

CHAPTER 2

Literature Review

Through the natural course of aging, elders face many challenges, such as the loss of loved ones and transitioning into retirement. Rowe and Kahn (1997) define successful aging as having “low probability of disease and disease-related disability, high cognitive and physical functional capacity, and active engagement with life.” The third component, active engagement in life, involves both participating in meaningful activities as well as maintaining social connectedness. These components were echoed in a Florida study by Duay and Bryan (2006), where a small sample of primarily community dwelling seniors was interviewed about their thoughts on aging. They identified engaging with others, coping with changes, and maintaining both physical and mental health as the most important components of aging successfully. The most commonly identified themes in a sample of Australian seniors from both community and institutional settings included maintaining health, enjoyable activities, and personal growth (Knight & Ricciardelli, 2003). The life changes facing institutionalized elderly can be particularly hard, as evidenced by a higher average occurrence of depression, lower optimism, and overall poorer health found in this subgroup (Reker, 1997). Following is a review of the literature on identified components of successful aging, focusing on their influence in the lives of institutionalized elderly.

Personal Control

When their health declines, seniors may begin limiting their activities, or substituting new pastimes in place of the old. In a Canadian study examining coping strategies utilized by seniors diagnosed with osteoporosis and osteoarthritis, “selection and compensation processes were associated with perceptions of a loss of independence, greater feelings of dependence,

helplessness, and, in some cases, lower coping efficacy across most domains of activity” (Gignac, Cott, & Badley, 2000). Feelings of dependence were also higher for respondents who reported more instances of receiving help. In the domain of personal care, Gignac et al. (2000) noted receiving help was correlated with higher perceived helplessness and more emotional difficulty coping with the change in their abilities. Roe, Whattam, Young, and Dimond (2001) found seniors requiring lower levels of personal care tended to have an easier time adjusting than those who required more extensive help with activities such as dressing and showering. Help was better received when elders were able to retain some control through being involved in decisions about their care. In addition, there appeared to be a gender difference in attitudes, where the women interviewed seemed to be more bothered by the loss of independence and invasions of privacy than the men. While Gignac et al. (2000) interviewed community dwelling seniors, Roe et al. (2001) examined a mixed sample of both community dwelling and institutionalized elders.

Langner and Rodin’s (1976) ground-breaking study on personal control showed the importance of maintaining feelings of choice and responsibility for institutionalized elders. To examine the effects of responsibility and choice, Langner and Rodin (1976) gave one group of elderly residents a talk on personal responsibility in which their influence over care decisions (such as the organization of their rooms) was emphasized, then these residents were given an opportunity to choose a plant to care for. The control group received a similarly structured talk, but the content focused on the responsibility of the staff for resident care and, at the conclusion of the talk, members of this group were handed a plant for their room and told the nurses would take care of it for them. At the conclusion of the study, the group given responsibility over their own chosen plant reported higher increases in happiness as well as in physical activity (Langner

& Rodin, 1976). These self-reports were compared to accounts given by the nursing staff, and the staff's estimates correlated significantly with resident reports.

Sense of Purpose

A meta-analysis looking at the effect of meaning in life on psychological well being in the elderly found feelings of purpose declined on average as individuals age, related to losses such as retirement from the workforce and declining health (Pinquart, 2002). Individuals who maintain a stronger sense of purpose tended to be in better health, have more meaningful social contacts, and report higher levels of subjective well being. Sources of purpose in life identified in the meta-analysis included employment or involvement in a valued role, frequent contact with friends and family, and perceptions of physical competence (Pinquart, 2002). Using data from 530 interviews collected between 1992 and 1999, and 269 interviews collected between 2002 and 2003, Krause (2004) examined the effect of stress resulting from changes in roles on the self-concepts of the elderly. Changes in highly valued roles were found to negatively affect health primarily through damage to elders' sense of meaning. This suggests that finding meaning in stressful life events could be a buffer to the oftentimes negative health consequences of these changes.

Nygren et al. (2005) found significant correlations between sense of purpose in life with higher levels of resilience, sense of coherence, and self-transcendence in a sample of 125 Swedish seniors over 85. Sense of purpose was also positively correlated to the ability to adjust to life changes in an Australian sample, as well as having a higher rating of satisfaction with life (Knight & Ricciardelli, 2003). Interestingly, purpose in life correlated to a higher sense of perceived mental health in the older women of Nygren et al.'s (2005) study, but this effect was not found to be significant among the male senior participants, possibly due to differences in

coping mechanisms between men and women that were not adequately addressed within the questionnaires. Reker (1997) investigated existential predictors of depression in both community dwelling and institutionalized elderly. Different variables were found to be significant for the two groups: personal choice had more of an effect for community-dwelling elderly, while having a sense of purpose and an optimistic outlook on life were stronger buffers for those elderly living in institutions.

Connectedness

Isolation has been identified as a risk for poor health outcomes in the elderly (Rowe & Kahn, 1997), and quality contact with friends and relatives fosters stronger feelings of purpose and meaning (Pinquart, 2002). Though the oldest old tended to report smaller social networks than their younger counterparts, Lang and Carstensen (1994) observed the number of very close friends was fairly stable between different age groups, suggesting the network size primarily shrinks through the loss of social acquaintances. In addition, having a circle of close friends was important for retaining a sense of social integration for both community dwelling and institutionalized older adults that have few surviving family members (Lang & Carstensen, 1994). Park (2009) observed perceptions of a friendly atmosphere, such as caring staff, have beneficial effects on the psychological well-being of nursing home residents independent of involvement in social activities.

Bailis and Chipperfield (2002) examined the effect of positive social identity, “the favorable evaluation of oneself as a member of social groups or relationships,” on the health and self-esteem of the elderly using data from the Aging in Manitoba (AIM) Longitudinal Study. Positive social identity was observed to have a mediating effect on the interaction between perceived control over health and perceived quality of health. The positive effect of social

identity was stronger for seniors who felt they had little control over their health, and weaker for individuals with higher perceived control (Bailis & Chipperfield, 2002). Emotional support from friends and family also help to buffer the stress resulting from changes in valued life roles, such as “provider of the household” (Krause, 2004). Clarke, Marshall, Black, and Colantonio (2002) observed the mediating role of social support on the effects of disability on the well-being of community dwelling stroke survivors. Having sufficient social resources helped foster resilience in these elders, helping them cope with lingering disability after the stroke.

In nursing home populations, having poor quality social relationships is correlated with shorter survival (Cohen-Mansfield, Marx, Lipson, & Werner, 1999), and residents who have higher levels of social engagement tend to have higher one year survival rates independent of health-related factors (Kiely & Flacker, 2003). Not only do social support and social integration affect survival, but these are also important for the quality of life of elders residing in care facilities. Drageset et al. (2009) found maintaining meaningful relationships with others contributed positively to the mental health of nursing home residents, and residents’ social functioning was aided by opportunities to help others. In a sample of American transitional rehabilitation residents and long term residents of a Veterans Affairs Medical Center, perceived support from peers was correlated to lower depression symptoms and higher motivation and positive affect (Carpenter, 2002). Carpenter (2002) also found that the perceived quality of social relationships appeared to be more important for residents’ well-being than the reported size of their social group.

Unfortunately, living in a care facility can limit residents’ interactions with family and friends living outside (Bonifas, Simons, Biel, & Kramer, 2014) and some nursing home residents describe their relationships with their peers as largely superficial or distanced (Buckley &

McCarthy, 2009; Bonifas et al. 2014). Buckley and McCarthy (2009) interviewed a small sample of female elders from a care facility in southern Ireland, exploring residents' perceptions of their interactions with staff, other residents, and their friends and families outside the facility. Overall these residents reported feeling closer to facility staff than to other residents, and residents' sense of connectedness was higher if they believed the staff understood their needs. The cognitive ability of fellow residents played a large role, with participants reporting they were "fearful of outbursts" and felt disconnected from residents with lower mental capacity (Buckley & McCarthy, 2009). The subjects interviewed by Bonifas et al. (2014) identified mealtimes as the primary setting for fostering friendships with peers, and that yelling, squabbles, and other outbursts during this time was a stressful barrier to socializing with other residents.

Community Involvement

Though hours of employment drop after retirement age, older adults still contribute to their community through informal help to friends and family as well as through volunteer work (Rowe & Kahn, 1997). Duay and Bryan (2006) noted "over half of the participants indicated that they received a great deal of satisfaction when they gave of their time to friends and community members." Much of the literature on senior volunteerism has utilized samples of community dwelling older adults (Jirovec & Hyduk, 1999; Duay & Bryan, 2006; Petriwskyj & Warburton, 2007; Anderson et al., 2014). This may be due to transportation limitations of care facilities or the health and functional limitations of individuals, since seniors living in these facilities are often in poorer health than independent community dwelling seniors. Health problems can be a significant barrier to participating in volunteer work (Petriwskyj & Warburton, 2007).

Formal volunteering for agencies, such as a local Food Bank, has been found to socially benefit both older adult volunteers and clients of the service, especially when it involves face-to-

face interaction between volunteers and clients (Onyx & Warburton, 2003). Volunteering has also been associated with better self-reported health, fewer functional limitations, lower symptoms of depression, and lower mortality (Hunter & Lin, 1980-81; Anderson et al., 2014). In Anderson et al.'s (2014) review of the literature, reduced symptoms of depression were most strongly associated with volunteering. Positive associations were also found with positive affect, life satisfaction, and improved social network. Van Willigen (2000) compared both senior and young adult samples, and observed seniors who volunteer experience higher increases in reported life satisfaction and perceived health on average than younger adult volunteers. Senior volunteers also experienced a further increase in benefits from volunteering for more than one organization, while young adults experienced diminished benefits. Though Van Willigen (2000) found volunteering seniors reported significantly better health than their non-volunteering peers, Jirovec and Hyduk (1999) only observed an association between volunteerism and psychological health, not physical health.

Married senior volunteers tend to volunteer at a higher intensity than their peers who are not married (McNamara & Gonzales, 2011). In the case of couples where both individuals volunteered, McNamara and Gonzales (2011) observed these seniors were more likely to volunteer and less likely to stop volunteering than seniors who were not married. The main barrier to volunteering identified in this sample was providing care to a spouse or parent. Van Willigen (2000) noted the senior volunteers participating in the Americans Changing Lives (ACL) survey were much more likely than young adults to volunteer at senior centers, possibly providing more opportunities for them to interact with their age-mates. Some important motivations for seniors to volunteer include wanting to remain active in meaningful ways, as a form of self-help (Perkinson, 1993), to develop new skills, and to feel useful or needed

(Petriwskyj & Warburton, 2007). Senior retirees participating in the SmartWorks project cited the opportunity to learn and apply new skills as well as make new friends as the best part of their experience (Bronstein & Mason, 2013). However, these seniors also stated in the focus group that they felt their skills could have been better utilized as volunteers if the agency had more well-defined roles for them. A third theme identified by Bronstein and Mason (2013) was the seniors' emphasis on needing to work with staff that was responsive to their needs.

Black and Kovacs (1999) compared young and older adult hospice volunteers in terms of the roles they played within the hospice program. Direct patient care services were more likely to be performed by younger volunteers, while older adults were more likely to be performing fund-raising or clerical services. Because they did not directly address motivations for activity selection, Black and Kovacs (1999) did not make any conclusions regarding the reason for this difference. They postulated it might possibly be due to the fact that non-direct services are more often performed in groups with other volunteers, as opposed to individually with clients. Though a large proportion of hospice volunteers of any age express the work is emotionally distressing, the majority report being satisfied with the volunteer experience (Payne, 2001). Motivations for hospice volunteerism are similar to those of other volunteer activities, such as easing other's burdens and helping families (Black & Kovacs, 1999). The top three things hospice volunteers identified as most satisfying about their work in Payne's (2001) sample -- primarily adults over 50 years of age -- were personal growth, working with others, and helping families.

The Current Study

The present study examined the motivations, benefits, and challenges experienced by a small group of senior residents of Bayside Care Center that had recently become hospice volunteers. Bayside Care Center is a Compass Health skilled nursing facility located in Morro

Bay, California. Compass Health (2015) is a healthcare provider servicing the Central Coast of California, and runs multiple assisted living and skilled nursing homes in this area. The hospice training was provided by Wilshire Health and Community Services (2015), a California non-profit organization that offers a range of services, including Wilshire Hospice, to the San Luis Obispo and Santa Barbara counties. The typical training program implemented by Wilshire Hospice involves a minimum of 20 hours of training, including role play, guided imagery, and other exercises (Steve Willey, personal communication, February 20, 2015). Training sessions usually run for four hours. This program was altered in order to accommodate the limitations of the participants from Bayside Care Center. Steve Willey (personal communication), the instructor of the classes, condensed topical material to provide information directly relevant to supporting fellow residents, such as those who have few visitors and are bed-bound, and limited the sessions to an hour at the longest.

The ultimate goal of providing this training for Bayside residents was to provide them an opportunity to give care to others and remain productive despite their limitations (Matthew Lysobey, personal communication, March 3, 2015). This study aims to test the findings of Black and Kovacs (1999) and Payne (2001) in a sample of nursing home residents to observe whether this population is driven by similar motivations and experiences similar effects from hospice volunteerism as community dwelling seniors. Similar to the method of Bronstein and Mason (2013), a focus group format was utilized to stimulate discussion on the topic and provide feedback information for Compass Health and Wilshire Hospice concerning the program.

CHAPTER 3

Method

Participants

Of the five senior adults attending the hospice program, one did not complete the program. A second declined to participate in the first focus group, but gave consent to participate in the second. The four participants were residents of Bayside Care Center, Morro Bay, all over the age of 55. Two of the participants were female, two were male. For privacy purposes, the gender of quoted speakers will not be disclosed.

Procedure

The first focus group took place at Bayside Care Center on December 19, 2015 at 11:00 am in a small side room. Participants were given copies of the informed consent form, which was then read aloud to them before they were asked if they had further questions. Once the participants gave their consent, nametags were passed out and the participants were asked to introduce themselves. Participants were also asked to reintroduce themselves once recording commenced in order to aid coding speakers during transcription. Participants were asked a total of six questions over approximately 55 minutes. One planned question was skipped for time. The session was recorded on a Sony digital recorder, with a backup recording captured simultaneously on an Asus netbook. The recordings were then transcribed for qualitative analysis.

Focus group two occurred at Bayside Care Center on February 25, 2015 at 1:00 pm, and took place in the facility's conference room. A fourth volunteer, who had previously declined to participate, arrived at the focus group and gave verbal consent to be included in the transcription. A total of five questions were asked in the second focus group over the course of 50 minutes.

Recording equipment used in this meeting was identical to that used in the first focus group, and the same transcription procedure was used.

Transcription

On the transcripts, participants were coded using a number and letter combination: 1J, 2C, 3K, and 4N. The letters used in these combinations are different than the letter initials of their real names. The researchers were coded as researcher 1 and researcher 2. Names of any individuals mentioned by name were replaced with their relation to participants or the facility (e.g., staff worker). During transcription, all “um” and “uh” utterances were omitted. The duplicates of repeated words were also omitted. Pauses longer than three seconds in duration were coded as an ellipsis, and sections that were not caught clearly on the recorder were marked [inaudible]. When participants referred to each other without directly using their name (ex. “you”), the participant’s initial code appears in parentheses. For the first focus group, one intermission and two interruptions were noted on the transcription in brackets, but their content was not included. Smaller interruptions were also omitted. For the second focus group, two small sections were omitted because they concerned the volunteer who did not complete the training and did not give consent to participate in the study. These sections were marked [contents omitted]. Copies of the completed transcripts were given to the participants for review, showing only their individual contributions during the recording. Any content they wished removed was marked [contents retracted] upon the final transcript, and original recordings of the focus group were destroyed following final review.

CHAPTER 4

Results and Commentary

Following is a brief overview of each focus group, including the questions asked, a summary of the discussions, and commentary on participant input. There is also a brief summary of each focus group after the question overview. Participants are identified using the initials corresponding to their coded initials on the transcript. Focus group 2 contains feedback from an additional participant, 4N, who previously declined to participate in focus group 1. Complete transcripts of the focus groups are available upon request.

Focus Group 1

Question 1: Please describe your initial thoughts and motivations for participating in hospice training. In response to this question, all three participants expressed their interest in helping others, especially people going through crises. They had been through their own tough times and empathized with the hardships and loneliness of others. The hospice training was another outlet for them to reach new people, similar to how they try to get to know others at the care center who are going through difficult times. As participant 3K expressed, “I feel like I was already doing pretty much what hospice is all about; watching people, caring about people.” For Participant 1J, helping others gave an opportunity to focus on the hardships of another person instead of personal troubles. These motivations are in line with the literature on seniors’ motivations to become active volunteers (Perkinson, 1993; Petriwskyj & Warburton, 2007). 1J also mentioned initially joining the program in order to provide support for 3K, before becoming engrossed in the program. This information was revealed later in the focus group and not as a direct response to the first question.

Question 2: What were some of your expectations at the start of the program? The primary expectation identified by the participants was having opportunities to connect with other people and provide support for them during the end of their lives. They expected this would involve some give and take, but mostly being there for people who needed to get things off their chest or feel like others care about them. However, as 1J stated, “none of us are going to connect one hundred percent of the time.” 1J went on to express the expectation of making new friends through the experience that would be like family. Of the three, 3K stated not having any expectations about the program, though 3K found the classes amazing and interesting.

Question 3: How have your expectations, if any, been met or challenged now that you have completed your training and gone through the classes? At this point in the process, participant 2C wondered what the next steps were going to be. 2C was ready to begin, but unsure how far the program wanted them to go as volunteers and how they would be introduced to clients. Though 3K had not identified any expectations for the program, 3K expected the appointment for the focus group was actually when they were going to be assigned to clients by Wilshire. These concerns and confusions are similar to volunteers’ desire for role clarification observed by Bronstein and Mason (2013).

Question 4: What have you found to be the most rewarding part of your experience? Both 1J and 3K agreed that the entire experience at that point in time had been very rewarding. It provided a sense of personal meaning and purpose, helping them feel like they had so much more to offer in their lives. 2C added, “Just because I’m in a wheelchair doesn’t mean that I’m handicapped.” Through the experience they felt a new way to give back to others, and it fostered the optimism to focus more on what they can still do for others rather than what they can no

longer do. The participants also agreed some of the benefits were difficult to put into words, though “you may know it before you know.”

Question 5: What have you found to be the most challenging part of your experience with hospice training so far? Participants had a hard time identifying difficulties in their experience when asked directly, however two challenges mentioned in other portions of the focus group were strain and role confusion. Suggestions of possible challenges were provided upon the request of 2C. These suggestions included 1) needing to listen rather than give advice, 2) keeping client’s experiences confidential, and 3) respecting one’s own limits. In response to the first suggestion, all three expressed they understood the importance of listening rather than jumping in as “fixer-uppers.” The second suggestion generated more discussion, and brought forth the related challenge of gaining client’s trust. 1J felt clients would be reluctant to open up unless they felt comfortable and “get to know you,” which might require some sharing of either their own or another person’s life experiences in order to express understanding. For the issue of confidentiality, 2C was more cautious and thought sharing too many personal details would be inappropriate. 3K was not worried about confidentiality: “If I was talking to you and we were by ourselves... it’s between you and me. And everybody knows it... they know I will not say anything.” The final issue explored in the focus group was that of physical and psychological limits. 3K felt this issue would not be very difficult, because 3K believed Wilshire would simply put them with another person if they were experiencing more than they could handle. In contrast, 2C seemed to be more concerned. 2C recalled combativeness and other interpersonal incidents experienced with fellow residents that made 2C “stand back and say, there, the big word: limit.”

Question 6: What do you feel is needed going forward with your volunteer experience as a group? 1J identified two things that were important for them to have; direct

observation of the process before working with clients, and more knowledge about Wilshire hospice procedures as well as their expectations for volunteers. At this point, 2C reported already asking about shadowing, but had not yet received an answer from Wilshire staff. 2C also worried about the strictness of being assigned to one person, because others might not have people helping them. 1J was not worried about this, confident any of the three of them would be able to adjust and provide support where it might be needed. 2C agreed, but worried they might “get in trouble” if they did not stay with their assigned client. All three participants also requested clarification on using the word “hospice” because of its loaded meaning. 3K was under the impression that Wilshire did not want them calling themselves “hospice volunteers,” and 3K produced a nametag that said simply “[3K] Resident Volunteer.” 1J felt it might be better for others if “hospice” was not used as a label because it could bother people, and 2C agreed the label was not necessary.

Summary of focus group 1. All three volunteers expressed great enthusiasm for the program throughout the focus group. The atmosphere was comfortable, and 1J, 2C, and 3K seemed to be well adjusted to their residence at Bayside. Though there was some confusion on the implementation of their training, participants were optimistic about the experience overall. They also shared their experiences within Bayside Care Center interacting with and providing support for fellow residents. Most of these examples concerned residents opening up to them when a bond of trust was established. Some themes that appeared within the focus group included personal meaning and connectedness with others. Because these themes also appear within the literature on volunteerism (Black & Kovacs, 1999; Petriwskyj & Warburton, 2007), a question concerning the influence of these specific themes on participant motivations was asked in the second focus groups.

Focus Group 2

Question 1: How has input you received from experienced hospice volunteers affected your impression of the hospice training program? All four participants agreed the meeting with the hospice volunteer brought in by their instructor was helpful and validating. In 1J's words, "He told us more or less what to expect." They had trouble remembering when the meeting occurred at first, but reminded each other about the event. When asked if there were any notable examples the volunteer had shared with them, 2C related a discussion they had about coughing. At first, 2C thought it might be appropriate to take cough drops, but the volunteer stated it would be most appropriate to excuse oneself from the room to avoid worrying the patient. 2C said during the focus group she now agrees with the volunteer, recalling an experience where 2C had been shooed away by another resident who thought 2C coughed too much.

Question 2: To what extent do you feel the following have affected your decision to participate in hospice training; A) Having a sense of purpose? Both 3K and 1J stated this was not a reason that motivated their participation specifically, because "we were basically doing the same thing as hospice, only out here" (3K). However, it seems as if in this capacity they do feel their support is needed within the resident population of their facility. Participant 4N did not feel this reason affected 4N's decision to participate. **B) Having a sense of personal control?** There was some confusion as to whether this question had to do with controlling others, but once participants understood the question only concerned personal control over their own decisions they expressed that this was not a large part of their motivations. According to 1J, "there was nothing really else to do here." 2C did not like the word 'control,' and felt it was not related to 2C's motivations. Participant 4N also did not feel personal control was part of 4N's motivation.

4N then said “I never graduated from any program in my whole life,” and cited this as his primary motivation to join the classes. This seems to have more to do with a sense of personal accomplishment, but contains some implicit suggestion of controlling one’s decisions. C)

Connectedness with others? Connectedness resonated a lot more with participants. 1J even expressed the wish that we had asked about this motivation earlier in the focus group, because “for me, it’s more of 100%.” 3K and 2C agreed. Of the four themes asked, this seemed to be the most vividly favored. However, discussions concerning this theme were cut short by personal difficulties recently experienced by some of the participants, which more directly pertains to the third question and are addressed there. **D) Staying involved in your community?** Though the question was posed to participants, no direct answers were given as to how much community involvement affected their initial motivations. All four participants expressed frustrations with the limited progress of the program, and did not feel their current involvement in the program was doing anything meaningful.

Question 3: Some challenges you mentioned in the first focus group included emotional strain and confusion about how your roles are defined as volunteers. What are your current thoughts on these? This question was not directly asked to the participants to avoid making them repeat their situations, because these issues were brought up before the question was reached. Participant 1J, who experienced the most difficulties, was directly relieved not to be asked to repeat. All four participants related that, other than the classes, “there’s not been another thing that’s gone on” (participant 3K). They had asked about shadowing and being placed, but neither occurred since the first focus group. After learning this information, researcher 2 asked whether it was a bad thing if the classes were the end of their participation. In the words of 4N, “It’s not a bad thing. It’s not anything.” When asked whether they felt this

program created a set of empty promises, both 1J and 4N agreed. Of the participants, 2C tried to be the voice of optimism, but even 2C agreed there was very little progress. While 4N and 3K seemed more mildly irritated with the lack of progress, 1J was more strongly affected. 1J had a sense that following the classes that the roommates assigned in 1J's room were often dying. 1J felt this was intentional on the part of Bayside, though that was not confirmed. The situation as perceived caused a great deal of emotional stress for 1J and diminished 1J's interest in the program dramatically. "I need time to refocus and regroup myself," 1J stated, but felt this was impossible when living with them in the room. 3K agreed with this description of the situation, adding "1J is getting totally messed up. Mentally, emotionally, it's getting to 1J." This situation, and the issues brought up by it, was so salient it dominated conversation for the remainder of the focus group. It highlighted the communication issues between Bayside and the resident volunteers, as well as the unique limitations and challenges presented to volunteers in care facilities that may not be present in community dwelling volunteer populations.

Question 4: What advice would you give to anyone thinking about participating in hospice training? The consensus from 3K, 4N, and 1J was that the program itself was wonderful, but the implementation was inadequate on the part of Bayside. For 1J and 3K, the lack of support they perceived from the facility diminished their enthusiasm for the program and made them reluctant to recommend it to fellow residents. "I would say it's a wonderful thing to do" said 1J, "if you're not in this kind of facility." 2C disagreed, and expressed the willingness to recommend the program to anyone who was interested. 2C felt this program, like anything else, has its positives and negatives, and it's better to focus on the positives.

Question 5: What supports might you need to continue to be active with this program? Because of a brief commotion that occurred at the end of the focus group, this

question was not directly answered. Participants did express their needs for more support from Bayside earlier in the discussion, and suggestions discussed earlier included having the opportunity to shadow. In order for 1J, 3K, and 4N to remain active in the program, the facility would need to provide better communication to them about their roles and how they will be placed with clients. By the conclusion of the focus group, only 2C was resolutely determined to stay with the program as it was.

Summary of focus group 2. The atmosphere of this focus group was very different from that of the first. There was greater tension between participants, and overall the content of discussions contained more negative experiences. While the participants shared many positive interactions with fellow residents in the first focus group, they discussed recent and past problems with residents and staff within the second, particularly difficulties with room assignments. Though 2C tried to be the voice of positivity, 2C was visibly less at ease than in the first focus group and showed emotional distress during discussions of 1J's situation. The primary themes that emerged from this focus group were frustration and strain. Some of this may have come from stressful changes in their environment at Bayside, as well as lack of progress for the program.

CHAPTER 5

Discussion and Recommendations

As a whole, the resident volunteers of Bayside Care Center found the hospice training classes to be an interesting and rewarding experience. On the flipside, implementation of the program fell short of their hopes and expectations. The first portion of the hypothesis, that volunteers from care centers would be driven by similar motivations to community dwelling seniors, was supported. The motivations of these participants were consistent with Black and Kovacs' (1999) findings, with helping fellow residents and connecting with others among the top motivations. However, because the participants were not placed before the second focus group and had no direct experiences with clients, Payne's (2001) findings concerning the benefits of hospice volunteerism could not be examined with this population. Similar to the seniors participating in Bronstein and Mason's (2013) focus groups, resident volunteers felt confusion about their role definition. While Bronstein and Mason's (2013) sample expressed feeling underutilized, participants such as 1J and 3K felt an outright lack of direction from Bayside. 1J expressed in the second focus group session, "There doesn't seem to be much interest in getting us any further than we already got."

Between the two focus groups, there was a visible change in participant energy levels and the enthusiasm they expressed for the program, which seemed to be a factor in sentiments such as that expressed above. When they first came together, all volunteers were excited about the program, although there was some confusion about their roles and the trajectory of the program from that point. Focus group 2 found the group no less confused and increasingly frustrated with the lack of progress. 1J mentioned dropping out of the program on three separate instances within the hour. Hospice training instructor Steve Willey (personal communication, February 20,

2015) indicated the original intent of the program was to organize a group of residents to provide support for bed-bound residents of their own facility, some of whom might be on hospice. However, this seems to have been poorly expressed to the participants and inadequately organized by the facility. In addition, the placement process was delayed due to Steve Willey's health, as well as cases of illness within the residents of Bayside Care Center in mid January 2015 (Lysobey, personal communication).

Following the second focus group, a conference call was conducted with Bayside facility director Matthew Lysobey to discuss the general findings. We also brought up the concerns 1J expressed about recent room assignments, and were assured 1J's situation was being actively addressed and the room assignment had nothing to do with 1J's participation in the hospice training. Because of the problems encountered in the implementation of the program, as well as concerns expressed by the participants, a primary suggestion is that the use of a less intensive program offered by Wilshire may be more beneficial for future groups. Wilshire has multiple programs for older adult volunteers, such as Caring Callers and Senior Peer Counseling. Caring Callers involves building support systems for seniors who are home-bound by providing weekly in-home visits to talk with them and participate in activities (Wilshire, 2015). Senior Peer Counseling is a program Wilshire (2015) uses to train volunteers over 55 years of age to provide weekly counseling sessions to seniors seeking support through challenges they are facing. These programs might be adjusted to care facility volunteers by providing services to bed-bound residents or organizing activities volunteers can bring to their rooms (e.g., a movie) during weekly visits. Caring Callers and Senior Peer Counseling also have the benefit of being free of the "hospice" label and its accompanying associations with death, which was a point of concern for the Bayside volunteers.

Based on the input from the focus groups, the information exchanges with Steve Willey and Matthew Lysobey, and my own observations and research, the recommendations for future Bayside programs of this type include:

- Providing volunteers with clearly defined roles as early as possible
- Structuring the program with frequent meetings to check in with participants
- Communicating the trajectory of the program more clearly
- Utilizing less intensive programs as models (e.g., Senior Peer Counseling)

Following these recommendations may provide for a more straightforward and rewarding experience for the volunteers and organizers.

One strength of this study's qualitative method is the ability to get a more detailed picture of participant's individual experiences and attitudes concerning the training program. It also provided useful feedback to both Compass Health and Wilshire Hospice concerning the program's effectiveness and participants' impressions of the process. Their support of the focus group method and interest in the results was also important in that it allowed participants an outlet for expressing both the positives and negatives of their participation to this point. This research also contributes documentation of the motivations and experiences of a small sample of senior resident volunteers, a population few studies have examined. The focus group model could be built upon in future research by incorporating larger samples from diverse facilities for comparison.

Limitations to this study include having a very small sample from a single care facility. Initial plans were to organize a focus group to take place before or during training for comparison purposes, but this was not coordinated in time to implement. In addition, gathering information in a focus group format might have limited responses because of the social

atmosphere as well as time limitations. Some participants were less vocal than others and offered fewer and shorter answers to questions posed to the group. It may have been beneficial to conduct interviews with every participant to get their individual responses for each question. The room in which the first focus group occurred was not very secluded and the session was interrupted on multiple occasions. Though the room in which the second focus group was conducted offered more privacy, the layout spread participants in a way that made it harder for some to hear the questions. Future research should carefully select the setting of groups and interviews to minimize these issues.

Nursing home populations are often more limited in terms of physical ability and transportation availability than community dwelling volunteers, making implementation of a hospice volunteer program more difficult within this population. Within the first focus group, participants expressed wanting to find ways to be productive despite their limitations. They seemed to have greatly enjoyed the educational elements of the training program. Providing further educational opportunities for residents might be another avenue for care facilities to provide engaging and meaningful activities for seniors. Because studies examining volunteerism in nursing home residents are very few in number, future studies might examine successful care center programs to identify potential areas for volunteerism and peer support. Direct comparisons to community dwelling older adult volunteers in the same area as care facilities under study may also be an important area for future research.

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