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Understanding the holistic impacts of hospice care on individuals who access their services

by

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Honours Thesis

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Abstract

The number of deaths in Canada is expected to rise significantly, which will create the need for end of life care. Hospices support this need by offering care on clinical, social, and spiritual dimensions. We examined the level of satisfaction with hospice support and services in dying individuals, as well as if any demographics or themes influence the level of satisfaction. We also analyzed dying individuals' level of satisfaction with hospice volunteers. The participants were six dying individuals living in the community who were either self-referred or received outside referral to a hospice. From there the participants were given a pre-survey during the initial intake from a hospice caseworker. Approximately five weeks after the introduction of hospice services the participants received a post-survey. Overall, the participants reported a high level of satisfaction with support and services received from the hospice, and an overall high level of satisfaction with the hospice. On the other hand, the participants reported that they would have benefited from hospice support and services at an earlier time in their terminal illness.

Understanding the holistic impacts of hospice care on individuals who access their services

Hospices provide support to dying individuals and their loved ones based on clinical, social, and spiritual care. The purpose of a hospice is to ease suffering and to help increase the quality of life for dying individuals. Additionally, a hospice helps to celebrate the life of dying individuals, but also accept that death is a normal process (Canadian Institute for Health Information, 2007). The number of deaths in Canada is increasing significantly (Statistics Canada, 2012), because of the growing population and is likely to rise again in the future because of an aging population (Statistics Canada, 2009). As a result of this the need for end of life care is going to rise dramatically and the need for scientific evidence to support the effectiveness of hospice services is required to demonstrate the benefits hospices have in individuals' lives. Additionally, hospices are typically publically funded and require quantitative and qualitative data showing their effectiveness to ensure continued growth and funding.

Previous research on this subject examined the level of satisfaction of hospice services from the perspective of bereaved family members rather than dying individuals (Claxton-Oldfield, Gosselin, Schmidt-Chamberlain, & Claxton-Oldfield, 2010), and individuals dying in residential hospices (Nelson, 2006). Also, this research has been primarily conducted in the United States of American rather than Canada (Deemer, 2004, Deemer & Sauer, 2002), and due to the differences in the health care systems American and Canadian hospices may not be comparable. In this study, our goal was to examine the level of satisfaction from dying individuals in the community who access hospice support and services in Canada, and the level of satisfaction with the volunteers who facilitate the support and services. The hospice support and services include complementary and wellness services such as hair styling and esthetics, reiki, massage therapy, social support, pet therapy, bereavement support groups and volunteer

visiting. There is also an analysis of the demographic information and themes that influence an individual's level of satisfaction.

The needs of dying individuals have been assessed to understand how to best help them. Reynolds, Henderson, Min, Schulman, and Hanson (2002) looked at the unmet needs of dying individuals and found that these individuals require more emotional support, pain management, communication surrounding their death, and assistance with personal hygiene. Morasso et al. (1999) found that dying individuals have 11 different needs that can be categorized into two different dimensions: psychological needs and health related needs. In regards to psychological needs dying individuals require: emotional support to address their personal fears and worries, a sense of self-fulfillment and to find satisfaction in life, better communication with loved ones about their illness, and occupational functioning meaning the need to carry on with regular activities. Health related needs in dying individual include: symptoms and bodily functions managed, improved and preserved, food that meets taste, appetite, amount and eating habit requirements, quality sleep, personal care, financial support for any treatments, knowledge about terminal illness and an understanding of how to pursue health related activities that improve one's quality of life. Overall, this shows that the needs of dying individuals are incredibly diverse and require holistic care to meet these needs.

Offering complementary therapies and wellness programs is the norm for many hospices, and it is growing in popularity to offer these services in palliative care settings. Specially trained volunteers typically run these services, and hospices feel they are an essential component to the care they offer and have many benefits for dying individuals and their caregivers (Demmer, 2004). This calls for the need to research and therefore understand the benefits of offering complementary therapies, wellness services and volunteer support in palliative care settings.

The previous research on this subject shows that accessing hospice support and services comes with tremendous benefits. These benefits include: adaptive coping techniques for pain management, a heightened sense of wellbeing (Nelson, 2006), providing a viable alternative treatment for symptom management, and overall helping to enhance the quality of life in dying individuals (Vandergrift, 2013). Research shows that individuals who utilize hospices have a high level of satisfaction with them, but individuals who receive complementary therapies such as music therapy and massage therapy are typically more satisfied than individuals who do not (Demmer, 2004).

The different complementary therapies have been assessed to determine the benefits. According to Polubinski and West (2005) massage therapy can significantly reduce the level of pain in individuals in a hospice setting, lower the feeling of anxiety, and increase the feeling of peacefulness. Pet therapy is beneficial for both patients and staff at hospices; it adds to the home-like atmosphere, as well as can help to increase social interaction between individuals in a hospice facility (Phear, 1996). Music therapy has been shown to be highly successful in lower the level of pain, increasing physical comfort and increasing the level of relaxation in dying individuals (Krout, 2001). Finally, reiki can be beneficial for a terminally ill individual by enhancing the quality of his or her life (Bullock, 1997).

Several studies have examined the personalities of individuals who volunteer at hospices and the motivations behind choosing to volunteer there. Claxton-Oldfield and Banzen (2010) analyzed the personality characteristics in regards to the 'Big Five' and the level of empathy in hospice volunteers. In comparison to the average person hospice volunteers scored significantly higher on the following traits: agreeableness, extraversion, and openness, but also scored lower on neuroticism. Additionally, hospice volunteers have been shown to have significantly higher

levels of empathy when compared to the average population of people. Overall, these traits help hospice volunteers to stay calm in stressful environments and have the ability to talk and be at ease with death and dying. These traits help the volunteers to effectively deal with the emotional demands of working with dying individuals and the bereaved (Claxton-Oldfield & Banzen, 2010).

Research shows that hospice volunteers donate their time because of an innate desire to help others, and because they feel like they are truly making a difference in others' lives (Planalp, & Trost, 2009). Hospice volunteers give caregivers of dying individuals the opportunity for respite and provide emotional support during an incredibly difficult time. Overall, they are rated as being very beneficial and important by not only bereaved family members (Claxton-Oldfield, et al., 2010) but also by nurses in hospices and palliative care settings (Claxton-Oldfield, Hastings, & Claxton-Oldfield, 2008). Considering the majority of hospices' support and services are run by volunteers it is essential that these individuals are compassionate and with an innate desire to help others. Additionally, these qualities would increase the level of satisfaction with a hospice's support and services. Nevertheless, volunteers receive limited training and it is important to evaluate their level of effectiveness with the support they provide.

Previous research shows the negative impact the caregiving role has on a caregiver of a dying individual and the importance of hospice support and services to help him or her during this time. Haley, LaMonde, Han, Burton and Schonwetter (2003) reported that there are higher levels of depression in the caregivers of dying individuals and lower levels of satisfaction with life. Caregivers with higher levels of stress, declining health, and with little to no social interactions typically have the highest level of depression. Social interactions such as activities

and support are associated with a greater sense of satisfaction with life. Additionally, lower levels of depression are found in caregivers who have the ability to find satisfaction in their caregiving role. The ability to find satisfaction in this role may be increased with respite and support provided by a hospice. According to Bialon and Coke (2012) caregivers of dying individuals take on a large burden and many stressors with the caregiving role. Many of these individuals have struggled with the inability to manage stress and with balancing taking care of themselves and the dying individual. The caregiving role is incredibly physically and emotionally demanding and can create a great deal of stress in a caregiver's life and the life of the dying individual. This stress is associated with worsening health and weight changes. This negative effects on the caregiver's life could in return negatively impact their ability to support and care for the dying individual. The impact this role has on the caregivers of dying individuals creates the need for a holistic approach to help the caregivers that includes educational, social, religious and spiritual, and emotional support.

The support and services provided by hospices can help to buffer a caregiver against depression by providing them with respite, social activities and services that help to support his or her overall psychological and physical well being. This in turn may help to ease a caregiver's burden, which will allow him or her to be the best support possible for a dying individual (Bialon, & Coke, 2012). This research furthers the need to have more evidence showing the impacts of hospice care, which will allow a hospice to have scientific evidence proving their effectiveness and support further funding for operational costs.

Hospices play an important role in individuals' lives in many different ways. Hospice support and services may be a critical component to allow individuals to die at home. According to McGrath (2001) dying at home is incredibly valued by dying individuals and their caregivers

and this comes with many benefits including being comfortable in an environment away from noise and medical equipment and a greater sense of control in the life of the caregiver. Gunn, Morag, Stephen and Chris (2004) found that the caregivers of individuals who died at home had better bereavement outcomes, and that bereavement had a smaller toll on physical health when compared to caregivers of individuals who died in a hospital setting. Additionally, when the caregivers perceived that the dying individual did not greatly suffer he or she had a better outcome with his or her bereavement. Hospice support and services can add to the overall quality of life of dying individuals and their caregivers, which may allow them to die at home and reduce the level of suffering. This research looks specifically at the impacts of hospice support from individuals who are dying at home, making this important research to support the theory of this study.

Aside from complementary therapies and wellness programs and services, spiritual support is an important aspect of hospice care. A previous report showed that hospices help to facilitate the dying process like a spiritual journey, which may contribute with the level of satisfaction in the bereaved (Mcgrath, 2001). Nurses in palliative care settings report that providing spiritual support is an important part of the job. This helps to build the sense of trust and the personal connection between the nurse and the patient. Additionally, nurses report that spirituality is an important part in developing a sense of presence in being with, and listening to the patient's needs on a deeper level (Bailey, Moran, & Graham, 2009).

Religious and spiritual beliefs are important tools an individual can use to endure his or her impending death. Cicirelli (2011) looked at the level of depression in terminally ill individuals and found that individuals with healthy religious views used them as an adaptive, positive coping tool to soothe fear and anxiety about death. One of the ways that spirituality can

be used to help dying individuals and their caregivers is through meaning making. Adamson and Holloway (2012) argue that personal meaning is a vital part of individual spirituality and it is an important part of adapting to grief and bereavement. Counsellors and coordinators at hospices help a dying individual explore his or her spirituality allowing him or her to find meaning and ease in life and death. There is a small amount of the existing literature that supports the important role that faith, religion and spirituality have in the death and dying process as well as grief and bereavement (Cicirelli, 2011; Adamson & Holloway, 2012). Little is known about the level of satisfaction in dying individuals regarding the spiritual services provided at hospices.

The existing research shows that hospices provide support on a variety of different levels; satisfaction of hospice support and services must be assessed on these levels. Several important dimensions surrounding hospice care and the qualities of employees and volunteers have been determined, which influences the level of satisfaction with hospice support and services: the level of “warmth, friendliness and caring”, receiving “holistic care”, the overall “excellence of care”, “satisfaction with the dying experience”, and “spiritual issues”. An individual’s level of satisfaction is heavily influenced by his or her perception of the personality of a hospice volunteer or employee. Individuals who represent a hospice should be sincere, non-judgmental, and provide dying individuals and their caregivers with a comfortable and caring environment (Mcgrath, 2001).

Furthermore, hospices are expected to provide holistic care, which includes counselling and 24-hour care without charge for services. Additionally, for a high level of satisfaction services need to be directed towards the dying individual and his or her significant other(s). The care is expected to be excellent in the sense that it should be practical and meaningful. Also, the support provided should be given by professional individuals who are efficient and available.

Greater satisfaction with the dying experience is associated with the ability to die at home rather than in a hospital setting, which hospices' support and services may be critical for this. In regards to the spiritual dimension, satisfaction with hospice support is influenced by allowing the dying process to happen in a spiritual and faith based way if that is what the dying individual desires (Mcgrath, 2001). This shows the importance of hospices offering support in a holistic manner and on a variety of different dimensions. Additionally, it shows that it is necessary to measuring an individual's level of satisfaction with a hospice on a variety of different dimension.

Based on the previous research hospice support and services have tremendous benefits for dying individuals and their caregivers. Complementary therapies and wellness support and services in hospices have obvious positive impacts for the individuals who access them. But the previous research looks at the level of satisfaction from the perception of bereaved family members rather than the dying individuals themselves. Additionally, little is known about demographics that may influence the overall level of satisfaction in dying individuals.

Thus, complementary therapies, wellness support and services and hospice volunteers have the potential to create a high level of satisfaction in dying individuals who access these services. To date, no studies have examined the level of satisfaction in Canadian dying individuals in the community who access hospice support and services, as well as the level of satisfaction with hospice volunteers including a volunteer visiting service. This provides a unique perspective into the impacts and benefits of utilizing hospice care. Our overall purpose was to examine the level of satisfaction in dying individuals and to understand what influences this.

The hypothesis of this study is that accessing hospice services creates positive and beneficial impacts for dying individuals and their caregivers. The objective was to produce data

showing the positive impacts that hospice care creates in individuals' lives. It will allow hospices to understand what programs and services are of benefit for their clientele and can be used to support funding for operational costs. Additionally, this research will add to the body of literature that shows the impacts that hospice care has on individuals who access their services and identify any areas of weaknesses. It will examine any age and gender differences and how that affects the level of satisfaction with hospice support.

The participants of this study are individuals who are either self referred or receive outside referral to receive hospice support and services. When a participant received an initial assessment the caseworker at the hospice gave him or her the pre-survey to determine what programs and services would help to increase the participant's quality of life. The survey includes demographic information and an assessment of the individual's current emotional and physical support. Approximately five weeks after the introduction of hospice support and services the participants received a post-survey, which looked at the level of satisfaction with the services provided from the hospice. There is a final analysis to determine if any demographic information such as gender, and age influence an individual's level of satisfaction.

Method

Participants

The participants of the study are terminally ill individuals over the age of 18 who live in the community and utilized the support and services of St. Joseph's Hospice of London (SJHL). The only exclusionary criterion in the study if the participant dies before he or she receives the post-survey and has the ability to complete it.

The client caseworker at SJHL recruits the participants in the study. Each terminally ill individual that comes into contact with the hospice is assigned to one of the two client

caseworkers. The participants were either self referred to the hospice, or received outside referral from a physician, friend, family member, or another organization that is associated with the hospice.

The hospice identified 18 individuals who were willing to participate in the study, two of the individuals died before completing the study, one individual was admitted into long-term care before completing the study, six individuals completed the post-survey, and nine individuals did not complete the study for unknown reasons. Of the six participants who completed the study four of them were female, and two were male. One of the individuals was between the ages of 61-70, two were between the ages of 71-80, and one was between the ages of 81-90. Five of the participants identified as Caucasian and one as African American.

Materials

The guidelines for introducing the survey (Appendix A) is a guideline for the caseworkers to introduce the study to potential participants. The consent form (Appendix B) introduces the study by giving the title of the study, introducing the researchers and how to contact them, and inviting the individual to participate in the study. It explains the benefits of the study and the importance of having further research in this area. Additionally, it explains what is required of the participant in regards to the time commitment and the questionnaires. The consent form emphasizes that participation is completely voluntary and an individual can withdraw at any time, there are no known psychological consequences for participating in the study, services provided from SJHL will not be affected by participation, and that the individual is not required to answer any questions he or she finds objectionable or uncomfortable to answer. It also asks that the individual provide his or her signature, the date, and his or her name. Finally,

it gives the contact information for the caseworkers and the executive director at SJHL, and the Association Academic Dean at King's University College.

The pre-survey (Appendix C) gathers qualitative data to understand how SJHL can best serve the terminally ill individual. It begins by collection demographic information by asking the participant's gender, age, ethnicity, whether he or she is the client or the client's caregiver and first language. It is administered verbally by the caseworker during the initial meeting. It contains seven open-ended questions. Examples of the questions include: "Would you benefit from having more support to share your beliefs and explore your spirituality (religiosity, faith or personal beliefs)?" and "Would you benefit from more support to complete activities and errands (e.g., going shopping, to the pharmacy or scrapbooking)?" This survey has been adapted from (Ewing, Grande, 2013)

The post-survey (Appendix D) begins by asking the same demographic information as the pre-survey. It contains 14 questions: 11 of these questions measure the participant's level of satisfaction with hospice support and services using a seven point likert scale (from 1 = "Entirely Disagree" to 7 = "Entirely Agree"), two questions are open-ended and gather feedback about services, and the final question asks how the participant was referred to the hospice. Examples of the questions measuring satisfaction include: "I am satisfied with Hospice staff and volunteers' sensitivity to the changes and difficulties I am facing", and "I would recommend St. Joseph's Hospice services to others". It measured qualitative information by asking open ended questions such as "What would you have changed about your Hospice experience?" and "Do you have any suggestions on where Hospice could provide more awareness about their services?". The first 11 questions on the scale were adapted from (Miceli, & Mylod, 2002). The final questions were

specially designed by the caseworkers at the hospice to gather important information to ensure they are meeting the need of their clients.

When the participant receives the post-survey by mail he or she will also receive a thank you letter (Appendix E). This letter gives thanks to the participant for his or her participation in the study and advises him or her that his or her participation helps SJHL to understand how their services benefit individuals, and advises him or her that this research will add to the body of literature showing the effects of hospice care.

When the participant receives the post-survey and the thank you letter, he or she will also receive a pre-paid return envelope to send the post-survey to the hospice. The participants are not compensated for their participation in the study. All support and services provided by SJHL were provided with no fee.

Procedure

After the individual was referred to SJHL and he or she made the initial contact with the organization an appointment was made to meet with either one or two client caseworkers. He or she met with his or her client caseworker in his or her home, the hospice facility, or an outside location such as a café.

During the initial meeting the client caseworker asked the individual if he or she is interested in participating in the study following the guidelines. The guidelines for introducing the study is a guide for the client caseworkers to introduce the study to potential participants. This guide includes five steps that outline a simple explanation of the study, the time it takes to participate in the study, and the requirements of the participant. Additionally, this guideline guides the client caseworker to explain that there are no known risks for participating in the study, the study is completely voluntary, support and services provided by SJHL will not be

affected by participation in the study, and that all of the results from the study are completely confidential. It also guides the client caseworker to advise the individual how to obtain psychological support if participation in the study causes any feelings of distress.

If the individual agreed to participate in the study the client caseworker gave him or her the consent form, ensured that he or she understands the form and had him or her write his or her signature, name and the date on the form. After the consent form is understood and signed the client caseworker verbally administered the pre-survey. The client caseworker wrote down the responses from the participant. If the individual did not agree to participate in the study the client caseworker continued with the assessment as usual and the individual received the appropriate hospice support and services.

After the first interview with the participant the client caseworker analyzed the responses from the pre-survey to understand what support and services would enhance the quality of life for the participant and recommend appropriate support and services at SJHL. Support and services include: massage therapy, volunteer visiting, reflexology, reiki, therapeutic touch, pet therapy, support groups and other complementary therapies offered by the hospice.

Approximately five weeks after the introduction of hospice support and services in the participant's life he or she received a post-survey in the mail with a thank you letter. This letter gives thanks to the participant for his or her participation in the study and advises him or her that his or her participation helps SJHL to understand how their services benefit individuals, and advises him or her that this research will add to the body of literature showing the effects of hospice care.

When the participant received the post-survey and the thank you letter, he or she also received a pre-paid return envelope to send the post-survey to the hospice. The participants are

not compensated for their participation in the study. All support and services provided by SJHL were provided with no fee.

Results

Design

The independent variable in this study is the demographic information of the participants. This includes: gender, age, ethnicity, and first language. The dependent variable is the participant's level of satisfaction with the support and services he or she received from the hospice. This is a cross sectional study, as the level of satisfaction with hospice services is only collected at one point in time. All the participants in the study will receive support and services from the hospice.

Analysis

The hypothesis in the study is that accessing hospice services creates positive and beneficial impacts for dying individuals. This was determined by analyzing the level of satisfaction in each participant. The 11 questions in the post-survey that measure satisfaction on a likert scale have been broken down into four categories: the first category includes questions one, three, four and six and measures an individuals' overall level of satisfaction with hospice services, the second category includes questions two and five and measures an individuals level of satisfaction with the hospice volunteers, the third category measure an individuals level of satisfaction with staff and volunteers and if an individual feels their needs were met and includes questions seven, eight, nine and ten, and the final category includes question eleven and measures an individuals perception of if he or she felt that he or she received the services from the hospice at an appropriate time. The mean and standard deviation was calculation for each category. The total level of satisfaction with hospice support and services was measured by

calculating the mean and standard deviation of the total individual 11 questions from the post-survey. This allowed the researcher to understand which aspects of hospice support and services receive a high or low level of satisfaction from the participants. A high mean indicates a high level of satisfaction, but on the other hand a low mean shows a low level of satisfaction.

The first category that measured the participants' overall level of satisfaction with hospice care was relatively high ($M = 6.58, SD = .90$). The second category that measured the participants' level of satisfaction with hospice volunteers was relatively high ($M = 6.92, SD = .20$). The third category that measured the participants' level of satisfaction with staff and volunteers and needs met was also high ($M = 6.95, SD = .10$). The fourth category measured the participants' level of satisfaction with timing of services and was low ($M = 4.5, SD = 2.59$). Finally, the participants' level of total satisfaction was relatively high ($M = 6.59, SD = .41$).

There was another analysis completed to understand if there are any factors that influence an individual's overall level of satisfaction with hospice support and services. There was a correlational analysis completed to understand if there is a relationship between the demographic information collected and the level of satisfaction with hospice support and services. Pearson's correlation coefficient r was calculated to determine if there is a relationship and the strength of the relationship between the two variables. Based on the high positive correlation between age and level of satisfaction if there were more participants in the study it would be likely that as age increases so does level of satisfaction with hospice services (Table 1). Otherwise, there were no significant correlations between gender or ethnicity and level of satisfaction with support and services.

Table 1: Correlation between measures

	Overall satisfaction with hospice	Volunteer satisfaction	Staff/volunteer satisfaction
Measure			
Age	.410	.388	.388
Note. *p<.01, **p<.001			

A reliability analysis was conducted on the post-survey to determine if this is a reliable scale. The first category was found to be a reliable measure, Chronbach's Alpha is $\alpha = .66$. The second category was found to be a reliable measure, Chronbach's Alpha is $\alpha = 1.00$. The third category was also found to be a reliable measure, Chronbach's Alpha is $\alpha = .95$. Finally, a reliability analysis was conducted on the entire scale. Overall the scale was found to be unreliable, Chronbach's Alpha is $\alpha = .37$. Removing question 11 significantly improves the reliability of the scale, Chronbach's Alpha is $\alpha = .78$. There are two reasons why removing question 11 improved the reliability. First, this item is negatively correlated with the other items on the scale. This shows that it does not measure what the other items are measuring. Second, it has the lowest total correlation of all the items, $r = -.27$. Considering this was the one category that the participants were not satisfied with the support they received, it would not correlate with the other items where the participants were extremely satisfied.

The post-survey included open questions where the participants could include feedback regarding their experiences with the hospice. Overall the participants had wonderful comments about their time spent with the hospice. One individual wrote, "I find peace and comfort in your Quiet Room. Sometimes, I just sit by the food area and enjoy a cup of tea. I have used the pedicure and massage services – your volunteers are wonderful!". Another individual commented, "I have had two wonderful visits from the client caseworker who is a wonderful resource and answered all my questions! She is so sweet and very tuned into my needs and found

for me a super volunteer who comes to play games! So I tell all my friends about how luck I am to be part of your hospice!”. Based on the comments it is obvious that the hospice makes a positive and beneficial impact on the individual who access its support and services.

One of the questions asked about how much earlier an individual would have benefited from hospice support and services. One of the participants commented “I would have benefited from your services at least two months earlier. As a matter of fact I had no idea that this service was available. Thank goodness it is.” Another individual commented on her lack of knowledge of hospice services, “I have been in London since 1975 but had never heard of your organization”. This shows that there seems to be a lack of knowledge about hospice support and services, and how there needs to be more public knowledge, which will allow individuals in need to become aware and access services sooner.

Discussion

The present study hypothesized that dying individuals in the community who received hospice support and services would report a high level of satisfaction with the hospice. Furthermore, the study set out to understand if there were any demographics such as gender and age that was effect an individual’s level of satisfaction with the hospice.

Overall it was found that dying individuals in the community have a high level of satisfaction with hospice support and services. Additionally, it was found that if there was more participants in the study it would be likely that as age increases so does level of satisfaction with hospice support and services. Gender and ethnicity did not have a significant effect with the level of satisfaction. On the other hand, individuals were not satisfied with the timing they received hospice support and services; individuals reported that they wished they had received support and services earlier and that they were previously unaware of what the hospice offers.

The first category of satisfaction looked at individuals' overall level of satisfaction with the hospice. This category had a high level of satisfaction, which is not surprising considering the previous research on this subject. According to Bretscher et al. (1999) hospices may improve the quality of life for dying individuals by supporting their emotional, spiritual and physical needs. Furthermore, these support and services may offer a sense of relief in an individual's fear surrounding death. Additionally, a large-scale study by Connor, Teno, Spence and Smith (2005) found that family members of individuals who utilize hospice services have an exceptionally high level of satisfaction with the care that their family member received.

The second category measured the individual's level of satisfaction with hospice volunteers and the support and services they provided. This category reflected a high level of satisfaction. Block et al. (2010) found an association between a hospice's use of volunteers and bereaved family members' level of satisfaction with the end-of-life care received by their terminally ill loved one; the more the hospice used volunteers the higher the bereaved family members' level of satisfaction was. These volunteers have been shown to be incredibly friendly, warm and sympathetic extraverts who enjoy working with and being with others (Caldwell & Scott, 1994). Previous research shows that individuals who receive complementary therapies have a higher level of satisfaction with hospice services than those who do not (Demmer Sauer, 2002). Considering desirable hospice volunteers administer the complementary therapies individuals are likely to have a high level of satisfaction with the volunteers and the services they provide.

The third category measured the satisfaction level with staff and volunteers while looking at if an individual feels that his or her needs were spiritually and emotionally met and if they would recommend hospice support and services to others. A high level of satisfaction was found

in this category. Considering the hospice offers holistic support and care for dying individuals on a spiritual, emotional and physical level this is not surprising. The individuals in the study indicated a high level of satisfaction and a strong sense of gratitude for the support and services they received. The comments provided by the participants reflect the important and beneficial role that the hospice played in supporting them during their terminal illness.

The final category measured the level of satisfaction with the timing of receiving support and services from the hospice. The category had a low level of satisfaction and individuals indicated that they would have benefited from receiving hospice support and services at an earlier time. Rickerson, Harrold, Kapo, Carroll and Casarett (2005) found that family members of individuals who died in a hospice who had longer lengths of stay there felt they received greater benefits than those who did not. The results of this study may transferable to dying individuals in the community who receive hospice support and services; individuals who receive support and services for a longer period of time may have greater benefits than those who do not. A study by Teno et al. (2007) showed that when bereaved family members perceived that their dying loved one was referred to a hospice “too late” they felt that there was unmet needs for their loved one and in turn there was an overall lower level of satisfaction with the hospice. We need to grow a greater understanding of when hospice support and services would be best suited to enter a dying individual’s life and how to make individuals aware of these services at an earlier point in their illness.

Overall individuals had a high level of satisfaction with the hospice and the support and services they received. The hospice offers support on many different dimensions that have been determined to be important for dying individuals, which likely influenced an individual’s overall level of satisfaction. First, the hospice offers spiritual care, which can be an important part of the

dying process (Mcgrath, 2001; Cicirelli, 2011; Adamson & Holloway, 2012). Next the hospice offers a variety of complementary and wellness therapies, which can play an important role in improving the quality of life for dying individuals (Deemer, 2004; Nelson, 2006; Vandergrift, 2013). Furthermore, hospices seem to draw special individuals who are incredibly compassionate and enjoy being with and working with others (Claxton-Oldfield, Hastings, & Claxton-Oldfield, 2008; Planalp, & Trost, 2009; Claxton-Oldfield and Banzen, 2010). Hospices can help to ease a caregiver's burden, which in turn can allow him or her to be more supportive to his or her dying companion (Mcgrath, 2001). Finally, hospice support and services may provide the care that an individual needs to be able to die at home, which might be important to a dying individual and his or her caregiver (Morag, Stephen & Chris, 2004).

Implications for future research

Many of the participants in the study indicated that they would have benefited from receiving hospice support and services at an earlier time. Future research needs to be conducted to understand when hospice support and services would be best suited to come into an individual's life. Additionally, more research needs to be conducted on how to best educate communities on hospices, which would allow individuals to be better aware of the support and services available. This could in turn make hospices more known to their communities, increase their amount of clients and bring them clients who are at an earlier stage in their terminal illness.

Another implication for research would be to look at different life factors and see if there are any correlations between them and an individual's level of satisfaction. Some of these factors include: level of support in an individual's life, marital status, socioeconomic status, and religiosity. A greater understanding of how these factors influence an individual's level of

satisfaction with hospice support and services may allow hospices to better tailor their support and services to suit their clientele.

Conclusion

To conclude, the participants of this study reported that they were extremely satisfied with the hospice and the support and services they received. This is important because it ensures the hospice's continued funding from major funders that expect data showing their effectiveness. Additionally, this research shows how hospices can positively impact dying individuals living in the community and their wellbeing. Overall, it is important that this research continues to ensure that hospices are effective and continue to strive towards providing the best possible care to their clients. This research can be used to promote hospice care, which in turn could increase the usage of hospices and improve the quality of life for a larger number of dying individuals.

Limitations

There are several different limitations in this study that need to be considered for future research. The first limitation is the small number of participants. A larger sample size of participants would better reflect the diversity in our population and give more accuracy in the statistical analysis. Additionally, it could possibly lead to a significant and positive correlation between age and level of satisfaction with hospice services.

Another limitation is the psychological state of the participants in the study. These individuals have a terminal illness and only have a short time before they die. They are facing issues with their declining health and may be suffering from pain and loss of physical abilities. A participant may be preoccupied with his or her impending death and may not be able to provide an accurate reflection of his or her experience. Additionally, a participant may be overwhelmed with his or her life circumstances and completing the study will likely not be a priority.

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Appendix A

Guidelines for Introducing Survey

- 1) Explain that it is a research study being conducted by King's University College
- 2) Describe what is involved
 - a. Completing 2 surveys
 - i. One at the initial contact
 - ii. Another survey approximately 5-6 weeks after accessing services at St. Joseph's Hospice
 - b. Surveys will take approximately 15 minutes each to complete
- 3) Let them know that there are no known risks for being involved in the study.
 - a. There is support if an individual does become distressed
 - b. They can get support from St. Joseph's Hospice
- 4) Explain that the study is completely voluntary
 - a. If an individual does not want to answer any specific questions they are not required to
- 5) Emphasize that participation or not participating in the study will not affect any services from St. Joseph's Hospice
 - a. Results are kept completely confidential

Appendix B

Dr. Wendy Ellis
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Vanessa Eyre
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October 28, 2015

Dear Sir or Madam,

We are a student and a professor in the Department of Psychology, at King's University College at the University of Western Ontario. We are conducting a research project titled "Understanding the Holistic Impacts of Hospice Care on Individuals Who Access Their Services" and we would like to invite you to participate.

The purpose of this study is to have a greater understanding of what support an individual would benefit having from St. Joseph's Hospice of London and his or her experience of using these services. This study is meaningful because researchers know very little about the effects of hospice care on individuals in the community. Also, further research on this topic will support hospices to provide the best possible care by meeting the needs of individuals.

This study will take place from fall 2015 until the spring of 2016. Individuals will be asked to answer a questionnaire before they access Hospice services, and complete a questionnaire approximately 5-6 weeks after accessing Hospice services. Each questionnaire will take approximately 15 minutes to complete.

Participation in our research project is voluntary and you may decline participation or withdraw your participation at any time without any negative consequences. There are no known psychological consequences from participating in this study. Your identity will be kept confidential in any report or presentations that result from our study. Additionally, participation in this study will not affect services received from St. Joseph's Hospice of London in any way. You are not obligated to answer any questions that you may find objectionable or feel uncomfortable answering.

Sincerely,

Vanessa Eyre

Wendy Ellis

I have read and understand the attached letter regarding the study entitled “Understanding the Holistic Impacts of Hospice Care on Individuals Who Access Their Services”. Additionally, I agree to participate.

Date: _____ Name: _____

Signature: _____

For support please contact one of the following individuals during regular business hours (Monday – Friday from 8:30am – 4:30pm) at 519-438-2102

Janet Belchamber, Client Services Coordinator, St. Joseph’s Hospice
Maura Neale, Caseworker, St. Joseph’s Hospice
Julie Johnston, Executive Director, St. Joseph’s Hospice

For concerns regarding ethical misconduct please contact the Associate Academic Dean at King’s University College:
Dr. Renee Soulodre-La France – 519-433-3491, extension: 4424

Appendix C

Name: _____

Demographic Questionnaire

Please circle the answer that best describes your current situation

1. My Gender: Female Male

2. My Age Range: 18-30 31-40 41-50 51-60 61-70 71-80 81-90 91-100+

3. My Ethnicity: Caucasian African American Hispanic Asian
Aboriginal Other: *Please Specify* _____

4. Status: Client Caregiver

5. First Language: *Please Specify* _____

6) Would you benefit from more support to complete activities and errands (e.g., going shopping, to the pharmacy or scrapbooking)?

7) Are you concerned that your caregiver does not take enough time for himself or herself?

Appendix D

Name: _____

Demographic Questionnaire

Please circle the answer that best describes your current situation

1. My Gender: Female Male

2. My Age Range: 18-30 31-40 41-50 51-60 61-70 71-80 81-90 91-100+

3. My Ethnicity: Caucasian African American Hispanic Asian
Aboriginal

Other: *Please Specify* _____

4. Status: Client Caregiver

5. First Language: *Please Specify* _____

To what extent do you agree with the following statements?

- 1) St. Joseph's Hospice was sensitive to my schedule when arranging the initial meeting with Hospice staff.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 2) St. Joseph's Hospice visitor support was available during the days and times of my preference.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 3) I was provided adequate information about St. Joseph's Hospice to make informed decisions and choices about what support I would receive.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 4) I had no difficulty arranging additional services from St. Joseph's Hospice (e.g. programs or complementary therapies).

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 5) I am satisfied with the overall support received from St. Joseph's Hospice. This might include volunteer visitor or other types of support.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 6) I am satisfied with Hospice staff's concerns for my privacy.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 7) I am satisfied with Hospice staff and volunteers' sensitivity to the changes and difficulties I am facing.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
 5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 8) Hospice staff and volunteers demonstrate(d) sensitivity to my emotional and spiritual needs (religiosity, faith and personal beliefs).

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
 5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 9) I would recommend St. Joseph's Hospice services to others.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
 5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 10) Communication with Hospice volunteers and staff was/is easy and I am confident that my needs and/or concerns are heard and addressed.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
 5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

- 11) I feel that I would have benefited from receiving hospice services at an earlier time.

1 – Entirely Disagree 2 – Mostly Disagree 3 – Somewhat Disagree 4 – Neither Agree or Disagree
 5 – Somewhat Agree 6 – Mostly Agree 7 – Entirely Agree

If you agree, please explain how much earlier (days, weeks, months) you would have benefited from receiving services.

- 12) What would you have changed about your Hospice experiences?

13) Do you have any suggestions on where Hospice could provide more awareness about their services?

14) How/who introduced you to the idea of Hospice support?

- Doctor
- Friend
- Family Member
- Community Care Access Centre Staff
- Other *Please specify* _____

Appendix E

Dear Sir or Madam,

Thank you for participation in the study “Understanding the Holistic Impacts of Hospice Care on Individuals Who Access its Services”. Your feedback is incredibly valuable and has helped us to further understand the effects of hospice care on individuals who access these services in the community. Your participation has allowed us to understand what support an individual would benefit having from St. Joseph’s Hospice of London and your experience of using this support. This research will add to the body of literature to show the impacts that hospice care has, and it will also help hospices to understand how to best support individuals in need of these services.

Sincerely,

Vanessa Eyre

Wendy Ellis