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## How to support caregivers and the bereaved: Psychoeducation and personal coping techniques

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A thesis submitted in partial fulfillment of the requirements for the Master of Arts degree in Education

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## **Abstract**

Canada has an increasing and ageing population and because of this it is experiencing an increase in its rate of deaths. Because of this the requirement for hospice and end-of-life support will likely increase. This creates the need for research on best practices regarding supporting individuals in the caregiving role, but also how they personally cope with the challenges they face. The first segment of this study looked at caregivers of individuals with life-limiting illnesses' experiences of receiving a psychoeducation grief resource package that contained a variety of educational materials that fall into the following categories of support: emotional, spiritual, psychological, and physical. The second segment of this study looked at the caregivers' personal coping skills in the following areas: emotional, spiritual, psychological, and physical. According to the results, hospices can help to provide a sense of connection to others and social support for their clientele. Additionally, hospices have exceptional employees and volunteers as well as a remarkable environment. Furthermore, psychoeducation about grief and bereavement can provide supportive information that can help to normalize the feelings and emotions of its users as well as give them effective education that they can implement into their lives. The quality and format of the content of psychoeducation is important and the educational information should be presented in an invitational and open manner. Finally, caregivers and the bereaved engage in holistic personal care and support themselves in these four domains: physical, spiritual, social, and emotional.

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## Chapter 1: Introduction

Hospices play a critical role in providing end-of-life support for individuals with life-limiting illnesses and the people in their lives. They provide holistic support based on clinical, social, and spiritual care. The goal of a hospice is to ease the suffering of individuals with life-limiting illnesses, increase their quality of life, and to holistically support their caregivers, loved ones and the bereaved (Canadian Institute for Health Information, 2007). The need for hospice support is likely to increase because Canada is experiencing an increase in its rate of deaths (Statistics Canada, 2017); this is happening because of the increasing population and ageing population (Statistics Canada, 2013). Furthermore, it is anticipated that Canada will experience a 40% increase in deaths from 2003 to 2020 and that 90% of these individuals will die from a prolonged illness (Ministry of Health, 2007). Because of this, the need for cost-effective and empirically developed hospice support will also increase.

Caregivers of individuals with life-limiting illnesses are an important group of people to whom hospices provide support and services. According to a report on the General Social Survey by Statistics Canada in 2013, eight million Canadians cared for an aging, chronically ill, or disabled loved one. This number is expected to rise because of our growing and increasing population and because the baby boomer generation is entering into their senior years. Caregivers provide a variety of helping activities, including transportation, household work, scheduling appointments, personal care, and finances. During this challenging time of being a caregiver, these individuals may also be working a paid job, raising children, and maintaining physical and psychological health. The majority of caregivers reported that they are able to cope well with the challenges they faced, but experienced stress, worries, and anxiety (Sinha, 2013).

This demonstrates the importance of having various types of support to help individuals during this time.

There is a body of research that explains the incredible emotional and physical burden that the caregiving role can have on an individual's life. Being in the caregiver role has been shown to negatively impact individuals' lives in various ways: significant emotional distress including symptoms of post-traumatic stress disorder (Bialon & Coke, 2012), spiritual issues like anger towards God, social concerns such as reluctance sharing thoughts and concerns with loved ones (Wittenberg-Lyles, Washington, Demiris, Oliver, & Shaunfield, 2014), and physical issues including issues sleeping and eating (Skalla, Lavoie, Smith, Li, & Gates, 2013). Overall, the literature has shown that this role holistically impacts the lives of individuals.

One of the ways that hospices provide support to caregivers is through education; hospices educate individuals on the dying process, grief, bereavement, and other important topics that pertain to their situation (Canadian Institute for Health Information, 2007). At this point in time, there is a growing body of literature showing the impact that psychoeducation can have on individuals with life-limiting illnesses, their caregivers, and the bereaved. Psychoeducation has been shown to elevate a caregiver's sense of being qualified and prepared for their role (Hudson et al., 2013), to create a variety of emotional and physical benefits in caregivers and their loved ones' lives (Northouse et al., 2014), to encourage bereaved individuals to reach out for social support and reduce distressing feelings (Bowden, 2011), to help reduce experience of grief (Knowles, Stelzer, Jovel, & Connor, 2017) and to improve quality of life for caregivers (Leow, Chan, & Chan, 2013). Additionally, research on psychoeducation has shown that caregivers valued the education because it helped to validate the way that they felt and to support them through their challenges (Steiner, 2006).

The first segment of this study looked at caregivers of individuals with life-limiting illnesses' experiences of receiving a psychoeducation grief resource package that contained a variety of educational materials that fall into the following categories of support: emotional, spiritual, psychological, and physical. Additionally, this package contained information about different grief and bereavement community resources such as support groups or counselling services, and it contained information about logistical concerns that have to be taken care of after someone dies, like funeral arrangements. At this point in time, there is only a small body of research on supporting caregivers of individuals with life-limiting illnesses using psychoeducation in a hospice setting, even though this is a common practice used throughout palliative care settings in Canada (Canadian Institute for Health Information, 2007). Considering only a small percent of bereaved caregivers utilize hospice support (Cherlin et al., 2007), this may be an impactful way to support those who do not.

The second segment of this study looked at the caregivers' personal coping skills in the following areas: emotional, spiritual, psychological, and physical. Research has shown that caregivers used religious and spiritual beliefs as a coping technique (Paiva, Carvalho, Lucchetti, Barroso, & Paiva, 2015), they received social support from their loved ones, physical support from health care staff (Leow & Chan, 2017), and emotional support from their loved one with an illness before the time of his or her death (Strang & Koop, 2003). This informed the researchers on how the caregivers and bereaved have met their needs in their own lives, whether they utilized personal or professional resources. Additionally, this helped to educate the researchers on the caregivers' needs and how to best support this group of individuals.

There are several research questions in this study. The first research question is: What is the experience of caregivers who receive a psychoeducation grief resource package? The first

prediction in this study is that providing psychoeducation support helps to educate caregivers on important topics that increase their resiliency and psychological well-being. The second research question is: How do individuals personally cope with their grief and bereavement? The second expectation is that caregivers utilize different resources throughout their lives to personally cope with the challenges they face, including social, physical, spiritual, and psychological coping. The objective of this study is to articulate the experience of caregivers when receiving this support and to understand how they personally cope. Additionally, this research will add to the body of literature on the use of psychoeducation to support caregivers of individuals with life-limiting illnesses and how caregivers are able to cope with the challenges they face in the role. Finally, it will further our understanding of the experience of individuals who utilize hospice care.

This area of research is relevant to the counselling psychology field, considering the increasing death rate in Canada (Statistics Canada, 2017). Because of this, the need for caregiver support is likely to increase, including professional support provided by psychotherapists. This stresses the importance of psychotherapists being educated on the demands of caregiving, best practices to support them, what caregivers' needs are, and how they meet their needs.

Research on the use of psychotherapy to support individuals who face grief and bereavement has shown that it can produce beneficial results in the lives of those who receive it. According to Shear and colleagues (2016), the use of psychotherapy to support individuals who face complicated grief has been shown to be significantly more effective than antidepressants at reducing symptoms such as suicidal thoughts, intense feelings of guilt, and inability to feel a sense of happiness. Furthermore, Vlasto (2010) found that both group therapy and individual therapy were both beneficial for individuals facing grief. The results of this study found that group sessions helped to facilitate social support, provided a supportive environment, helped to

normalize feelings of grief, and created an environment where individuals were able to share their feelings. Individual sessions created an environment where individuals felt a sense of safety, were provided healing relationships, were allowed to work on a deep emotional level, and were able to openly express distressing and intense emotions (Vlasto, 2010).

Another study on psychotherapy by Applebaum, Kulikowski and Breitbart (2015) has shown the positive benefits it can have on caregivers. In this case study, the researchers took a psychotherapy approach with the intention of reducing spiritual and existential distress as well as helping caregivers make meaning of why they are in a caregiving role, and this was shown to help an individual in a variety of dimensions in his or her life. Their research showed that psychotherapy helped to create personal growth, improved self-care techniques, promoted engagement in meaningful activities, and promoted a sense of connectedness to others (Applebaum et al., 2015). Overall, this research shows that psychotherapy can be used as an important coping technique for individuals facing grief and bereavement as well as caregivers of individuals with life-limiting illnesses.

## Chapter 2: Literature Review

### Caregiver Burden and Needs

Caregivers of individuals with life-limiting illnesses are individuals who support an individual by providing them with physical and emotional support. These caregivers are typically family members who have a variety of different responsibilities, including providing medical care and assistance with living to their loved one. Additionally, these individuals contribute to our health care system because of the unpaid care they provide (Brewer, Sannes, & Laudenslager, 2015).

Being a caregiver to an individual with a life-limiting illness has been shown to have more negative consequences than other caregiving roles (Williams, Wang, & Kitchen, 2014). Williams and colleagues (2014) compared caregivers of individuals with a life-limiting illness to caregivers providing long-term and short-term care to another in need. Caregivers of individuals with a life-limiting illness were shown to have significantly higher levels of health issues, more negative consequences towards their social groups and personal activities, greater negative financial impact, and more consequences in regard to their employment situation. Overall, the results of this study suggest that being a caregiver of an individual with a life-limiting illness is the most burdensome of all the caregiving roles.

A study by Bialon and Coke (2012) illustrated the burden of this role and how it impacts individuals in a variety of areas throughout their lives. The researchers interviewed caregivers who provided support to an individual with a life-limiting illness before and after the introduction of hospice support. Their final analysis found that the caregivers had a decline in their health, experienced issues maintaining a balance between taking care of themselves and the individual they cared for, and felt they lacked knowledge and training about their role.

Furthermore, the caregivers expressed feelings of guilt, frustration, or anger towards God, showed symptoms of post-traumatic stress disorder, experienced a lack of support from families, and desired more education on how to be a caregiver (Bialon & Coke, 2012). This study demonstrated that the caregiving role impacts individuals in a variety of different domains in their lives.

Caregivers are able to identify the areas of their lives in which being in the caregiving role has affected them. According to Hawranik and Strain (2007), caregivers experienced deterioration in their physical health and worsening health concerns, weight gain and issues sleeping, and encountered a psychological toll because of the emotional pain they experience. Caregivers also had additional stressors like issues with their employment, marital difficulties, and financial troubles. Furthermore, they reported a lack of knowledge about the caregiving role and the services that were available to them, and a sense of reluctance to receive support from community services. Even with these difficulties, caregivers report feeling a great sense of responsibility to be in their role (Hawranik & Strain, 2007). The lack of knowledge about support and services shows the importance of providing caregivers with this information.

The role of caregiving can burden individuals' social support because it negatively impacts their relationships outside of the caregiving role. Wittenberg-Lyles and colleagues (2014) conducted a study with caregivers and revealed that they struggled with feeling unsure about boundaries in friend and family relationships, and felt reluctant and uncomfortable about receiving and asking for assistance. Additionally, the caregivers restricted their time spent with friends in order to spend more time taking care of their dying loved one and were less emotionally available to others. Overall, they felt uncertainty and barriers in their ability to seek social support. In another study on social support by Albright and colleagues (2016), the size of

the caregivers' support network declined as their time spent caregiving time increased. This suggested that as burden increased, family members' and friends' support decreased. Hawranik and Strain (2007) also found that being in the caregiving role negatively impacts an individual's social support. In this study, caregivers experienced a loss of social relationships, perceived lack of support from family members, and even isolation. These studies illustrated the complex concerns that caregivers face regarding their need for social support, and their reluctance in seeking it.

Research has shown that caregivers have many different needs throughout their lives. A study by Waldrop (2017) demonstrated the wide range of caregivers' needs. The researcher found that the caregiving role impacted participants' social functioning; the participants desired social and emotional support from their friends and family, and perceived that their friends and family were uncomfortable or felt fatigued with their needs. Additionally, the caregivers were impacted in a physical way as they experienced sleep issues, feelings of exhaustion and fatigue, and exacerbation of illnesses. They were also affected in a psychological way. They experienced sadness, anger, and attempted to avoid their distressing feelings and emotions. Skalla and colleagues (2013) looked at the diverse needs of caregivers. This study found that the caregivers had multidimensional needs and discovered their top four concerns were: fatigue, anxiety, insomnia, and weight gain. Additionally, the researchers revealed that the caregivers experienced depression, eating issues, memory changes, forgetfulness, financial difficulties, and struggled to make meaning in life.

Other examples of caregivers' needs are given in a study by Beck, Ellington, Dingley, Aprn, Reblin, and Moffitt (2016). According to the researchers, caregivers have multidimensional needs, including physical issues such as issues sleeping and back strain,

psychological needs such as finding a sense of balance between caregiving for others and caring for oneself, and dealing with the sense of being overwhelmed with duties. Caregivers also face challenging spiritual or existential concerns, such as preparing for the death and loss of a loved one, witnessing the suffering of a loved one, and making meaning of being in the caregiving position (Beck et al., 2016). Once again, the research on this topic has shown that the caregiving role is burdensome and caregivers require multidimensional support.

Research has shown that caregivers have the ability to identify and express their needs. A qualitative exploration by Smith, Lauret, Peery, and Mueller (2017) asked caregivers what their needs were. The researchers found that these individuals required financial, legal, medical, and housing assistance, as well as emotional, and spiritual support. Additionally, several participants expressed that they found support groups very helpful, but experienced a lack of support from their families and religious communities. Kutner and colleagues (2009) used focus groups to understand the needs of caregivers who received counselling sessions over the telephone provided by a hospice. The caregivers consistently explained that they had specific areas of support needs: emotional, practical and logistical, coping and bereavement. Additionally, the caregivers expressed how difficult their roles were, how it strained their relationships with friends and family members, and their feelings of being reluctant to reach out for help. This research explained that caregivers have an understanding of where they would benefit from receiving support.

Angelo and Egan (2015) used photovoice to have caregivers of individuals with life-limiting illnesses visually explain their needs. The photos showed the issues and concerns the caregivers experienced. These issues included: physical needs such as the desire for more sleep and assistance with taking care of their loved one, psychological needs such as the need for

emotional support after witnessing the declining health and distress of their loved one, and spiritual needs such as the desire to make meaning from their struggles and prepare for a future where their loved one is no longer there. These caregivers were reluctant to accept help from others and felt guilty asking for assistance (Angelo & Egan, 2015). This was a novel way for the caregivers to express what their needs were.

Overall, there is evidence that suggests that being in the caregiver role can negatively impact individuals in various ways throughout their lives. The research has shown that caregivers' support needs exist in the following areas: spiritual, psychological, social, and physical. Spirituality is important to individuals during this time, considering the end-of-life care they are providing and the existential concerns that this role can bring (Beck et al., 2016). Caregivers have psychological needs, such as the need for support in dealing with distressing emotions (Waldrop, 2017). Social support is another important aspect of support for caregivers, considering the negative impact this role can have on caregivers' network of friends and family (Albright et al., 2016). Finally, physical support must be considered because of the physical burden this role can have on individuals' physical health (Skalla et al., 2013). Moreover, when caregivers are asked what their needs are, they explain that their needs exist in these areas. This knowledge stresses the importance of providing support to caregivers that helps to meet their needs in a variety of domains.

### **Caregiver Coping**

How caregivers personally cope with challenges before and after the death of their loved one is an important topic to consider when working with them. Lorraine, Allison, and Karen (2005) looked at hope as an aspect of caregiver coping. Using focus groups and a qualitative analysis on the data collected, the researchers found several important themes that influenced

caregivers' hope, including: doing what you have to do, living in the moment, staying positive, creating your own narrative, finding support, and connecting with others. "Doing what you have to do" was described as finding a sense of acceptance in the situation you have been provided with, staying motivated and determined, and using self-care to replenish one's self. Caregivers worked to live in the moment by living day to day and avoided being future oriented because it was overwhelming. They worked to stay positive by appreciating life and looking for positive aspects throughout their lives. Writing their own narrative was important because it helped them to maintain a sense of control in how they viewed their lives; caregivers made their own decisions about the future of themselves and their loved one, and explored different ideas and options. Finally, caregivers maintained a sense of hope by receiving support and connecting with loved ones and different community resources (Lorraine et al., 2005). This research showed that even though caregivers face incredible challenges, they are able to maintain a sense of hope.

Caregivers have been shown to be able to use a variety of coping skills. According to a study by Strang and Koop (2003), there are different facilitating factors that help caregivers to cope. The caregivers in this study used different personal strengths, including: a sense of inner strength, self-knowledge and self-awareness, problem solving skills, as well as personal values, attitudes, and beliefs. Additionally, the caregivers relied on religious and non-religious spirituality as a coping method. Another finding in this study was that individuals with life-limiting illnesses helped their caregivers to cope by providing moral support, accepting their own mortality, respecting and understanding the caregivers' personal needs, providing practical assistance like making their own funeral arrangements, and with their personal spiritual beliefs. Finally, the caregivers coped by receiving support from outside sources from their loved one,

palliative care nurses, and home care (Strang & Koop, 2003). This illustrates the resiliency of caregivers and their ability to cope using different methods.

Religious and non-religious spiritual beliefs are an important coping tool for caregivers. Paiva and colleagues (2015) found that caregivers used religious and non-religious spiritual beliefs to help them cope while taking care of a loved one with advanced cancer. The caregivers reported that their faith in God became stronger after their loved one became ill, they rethought life issues and worked to make meaning through their challenges, and they had an overall desire to use spiritual beliefs for support and strength. On the other hand, they reported that being in the caregiving role negatively interfered with their ability to attend religious ceremonies and events (Paiva et al., 2015). Considering that caregivers are facing the death of a loved one, religious and non-religious spiritual beliefs are an important coping tool at this time.

The personal characteristics of the caregiver and the relationship between the caregiver and the individual with a life-limiting illness have an important role in how the caregiver copes. Stajduhar, Martin, Barwich and Fyles (2008) found five factors that influenced a caregiver's ability to cope. The first factor was the caregiver's approach to life in terms of whether he or she was able to stay motivated, organized, and confident. The second factor was the caregiver's experience of the illness: the severity of the illness, the physical difficulties, and whether the individual with the illness was able to accept his or her mortality. The third factor was whether the individual with the illness was able to recognize, understand, and appreciate the caregiver's contributions as well as treat him or her respectfully. Next was the quality of the relationship between the caregiver and the individual who was ill; the stronger the relationship, the better the caregiver coped. Finally, the sense of the security the caregiver felt influenced his or her ability to cope. This area was influenced by the extent to which the caregiver felt supported by friends

and family, if he or she was able to access important information to help them be a caregiver, and if he or she felt supported by the health care system (Stajduhar et al., 2008). The results discussed above are an example of how caregivers cope with their own internal resources and with external support from others in their lives.

Caregivers rely on a variety of resources throughout their lives to cope. Leow and Chan (2017) looked at the challenges, emotions, and coping strategies of caregivers of individuals with advanced cancer. Several different themes were identified, which helped to explain how these caregivers were able to cope. Caregivers received social, emotional, and physical support from their loved ones and health care staff. They received spiritual support from prayer and having a relationship with God. Caregivers reported that they temporarily distracted themselves by doing different activities such as watching television or listening to music. Furthermore, the caregivers reported that they coped by finding a sense of balance in their lives by managing the time they spent caregiving and by spending time with their other loved ones. Finally, the caregivers reported having a sense of moral responsibility to maintain their role; this helped them to accept the role and the responsibilities that came along with it. According to Foxwell (2011), caregivers cope on their own and with the help of others. This study found three ways that caregivers coped: internally, with others, and with their loved one who had a life-limiting illness. Caregivers used internal resources such as finding a sense of acceptance in their situation, utilizing religious beliefs and a personal faith, personal strength, focusing on the present rather than the future, finding a sense of control in their lives, and avoiding their emotional suffering. They coped with others by relying on support from their friends, family members, and the health care system. Finally, they coped together with their loved one with a life-limiting illness by talking, looking

after him or her, focusing on the needs of one another, and working through challenges together. This research helps to show the dynamic way caregivers cope with this position.

It is also important to consider how caregivers cope with the grief and bereavement they face. Hudson (2006) asked: How well do family caregivers cope before and after the death of their loved one? After the death of their loved one almost half of the caregivers in this study reported that they were coping well, just less than a quarter reported that they were not coping well, and 2% indicated that they were unable to cope. Caregivers reported that they experienced feelings of loneliness, sadness, or exhaustion after their loss. When asked to reflect on the time they spent in the caregiver role, the caregivers indicated that they found meaning in being able to provide support to their loved one in their final days and to spend intimate time with them.

Another study looked at caregivers and how they cope during bereavement. Asai and colleagues (2012) looked at bereaved caregivers of individuals with advanced cancer and found three themes of how they coped with the loss. The caregivers were able to have a continued bond with their loved one and maintained a sense of having a relationship even after the loss, they worked to distract themselves from their emotional pain by performing tasks, and they sought out social support. Even so, they still experienced anxiety and depression, and a sense of yearning for their lost loved one. Caregivers are not only able to cope with the challenges they face when caring for their loved one, but they are also able to cope with the loss.

Research has also shown that caregivers personally grow and develop from being in the challenging role. According to Leow, Chan and Chan (2017) caregivers reported that they have received a sense of personal satisfaction and fulfillment from being able to care for their loved one during this time, it helped them to find a sense of meaning in life, it influenced character development because they became more patient and a stronger person, they learned important

skills and tools if they were ever presented with a similar situation, and it helped to make their family grow closer (Leow et al., 2017). This research supports the idea that caregivers are incredibly resilient individuals who are able to cope with the challenges and who personally grow because of them.

### **Psychoeducation**

Psychoeducation is one of the ways hospices and palliative care agencies support individuals with life-limiting illnesses, their caregivers, and the bereaved. A research study by Steiner (2006) suggested that caregivers want and need education. An analysis of data collected from focus groups found that the caregivers wanted to have their grief normalized and validated. Additionally, the analysis found that they wanted education regarding the challenges of being in a caregiving role. The results of this study support the idea that psychoeducation is helpful for individuals during the time they spend caregiving.

A study by Hudson and colleagues (2013) presented an example of the benefits of psychoeducation. This study compared two groups: one group received regular hospice support and the other group received regular hospice support as well as psychoeducation sessions about their caregiving role as a caregiver of an individual with advanced cancer. The intervention was shown to have increased their overall sense of being prepared and competent to begin their role. On the other hand, the intervention did not reduce their feelings of emotional distress, but it was hypothesized that it may have increased their psychological well-being. The results of this study show that one of the benefits of psychoeducation is to prepare caregivers for their challenging role (Hudson et al., 2013).

Another example of the impact of psychoeducation is a study by Northouse and colleagues (2014). In this study, the researchers had caregivers and individuals with life-limiting

illnesses use a web-based psychoeducation program that would tailor the information presented to them based on their needs. The program educated people in the following areas: communication skills, support skills, self-care, and meaning-making. The results of the study showed that this program helped to decrease emotional stress, anger, and fatigue. Additionally, it was shown to have increased physical functioning, meaning-making, and the physical health of caregivers. Furthermore, Knowles and colleagues (2017) also used an online format to provide psychoeducation to individuals. This study looked at the differences between participation in an eight-week virtual reality support group and a grief-education website. Both groups showed significant decreases in severity of grief, thoughts of grief, yearning for their deceased loved one, feelings of loneliness, perceived stress, and increases in quality of sleep. These studies demonstrated that psychoeducation in an online format can be helpful to caregivers, individuals with life-limiting illnesses, and individuals facing grief and bereavement.

Psychoeducation has also been shown to have a positive influence on individuals bereaved by suicide. A study by Bowden (2011) showed the tremendous benefits of an eight-week psychoeducation support program for individuals bereaved by suicide. According to an analysis of focus groups, the program helped the participants to understand suicide and why their loved one died. Additionally, being educated on the subject helped to encourage the participants to reach out to their friends and family members for support. Also, it reduced distressing feelings and feelings of isolation, and increased resiliency (Bowden, 2011). This study showed how psychoeducation is a powerful tool for empowering and supporting individuals during an incredibly difficult time.

Research has shown that psychoeducation can impact individuals in many different ways throughout their lives. According to Leow and colleagues (2013), a psychoeducation intervention

with the intention of improving caregivers' quality of life, increasing social support, reducing stress and distressing emotions, increasing self-care and self-efficacy, and increasing the caregivers' sense of reward from the caregiving role was shown to have an incredible impact on its participants. The participants in this study watched educational videos on managing stress and emotions that arise in the caregiving role, had two follow-up telephone calls, participated in an online forum, and received their regular routine care from the hospice. The final analysis by Leow and colleagues (2013) revealed that the participants had a higher quality of life, higher levels of social support, lower levels of stress and depression, higher amount of self-care and self-efficacy, and an increased sense of reward from the caregiving role. This study is another example of the incredible results of providing caregivers with education.

At this point in time, there is a growing body of literature showing that psychoeducation is a successful way to help meet the needs of individuals in the caregiving role and to support them through grief and bereavement (Bowden, 2011; Hudson et al., 2013; Knowles et al., 2017; Leow et al., 2013; Northouse et al., 2014). Psychoeducation can be used as an innovative and cost-effective technique to educate individuals who utilize hospice support. Additionally, it can help to normalize an individual's grief, which previous literature has shown to be important to caregivers (Steiner, 2006). Even though there is a growing body of literature on this subject, the present study is novel considering there is still limited knowledge of the use of psychoeducation in a hospice setting specifically.

Another indication of the need for psychoeducation is the fact that only a small number of caregivers utilize bereavement support services after the death of their loved on. According to Cherlin and colleagues (2007), in a study with 161 caregivers, only 30% used bereavement services after the death of their loved one. The participants who used bereavement services

typically used ones provided by a hospice, otherwise the services were provided by a religious organization or a crisis-intervention group. This research found that the main reasons people did not access support were because they perceived they were adjusting well to the loss, they had other forms of support, or they felt uncomfortable talking about their loss. Providing caregivers with a psychoeducation grief resource package may be one way to support this vulnerable population and meet the needs of the large percent who do not seek additional support. Furthermore, in a study by Hudson (2006), bereaved caregivers indicated that they would have benefited from receiving information about what to expect after the death of their loved one. The caregivers suggested that practical material on information like finances, wills, and funeral arrangements would have been beneficial. This supports an important aspect of this package where the caregivers are provided with relevant material, like information about contacting funeral homes and what logistical dealings will need to happen.

### **Present Study**

The present study used in-person and telephone interviews to understand individuals' experience of receiving a psychoeducation grief resource package provided by a hospice. The questions in the interview guide were developed specifically for this study and fall into the following categories of support: physical, social, psychological, and spiritual. The individuals who participated in the study were caregivers, bereaved caregivers, and bereaved family members who are involved with a hospice located in a medium-sized central Canadian city.

At this point in time, there is only a small body of research on supporting caregivers of individuals with life-limiting illnesses using psychoeducation in a hospice setting, even though this is a common practice used throughout palliative care settings in Canada (Canadian Institute for Health Information, 2007). The present study interviews individuals who were provided with

a psychoeducation grief resource package by a hospice. This is a common practice for this hospice, and the researchers looked at individuals' experiences of receiving this type of support. Considering only a small percent of bereaved caregivers utilize hospice support (Cherlin et al., 2007), this may be an impactful way to support those who do not.

Another aspect of this study is to understand how individuals have coped with both the current challenges they face and also the ones they have faced in the past. The existing research has shown that caregivers have many different ways used to cope with the challenges they faced while being a caregiver and after the loss of their loved one. The novel aspect of this study is that individuals were asked how they coped in the following dimensions: physical, social, psychological, and spiritual. Additionally, individuals were asked how they coped both in the past and present rather than only one or the other. This is important knowledge because it allowed the researchers to understand how these individuals cope on their own and how additional support would be helpful to them.

### **Chapter 3: Method**

I have worked and volunteered in this particular hospice for approximately five years and have had a variety of different roles. Some of the roles I have had include being a placement student and a volunteer visitor for the terminally ill, and I have conducted three research projects. My time spent at the hospice has taught me that a hospice is not a place for individuals to come and die, but instead a place for them to live their life to their fullest. The hospice provides a variety of services for individuals with a life-limiting illness, their caregivers, and the bereaved. They offer community support where individuals in the community can access their services as well as residential services where individuals with a life-limiting illness can come and spend their final days.

My journey at the hospice started as a practicum student where I worked under their spiritual care coordinator and assisted him with a variety of different activities. I quickly learned that the employees at the hospice were hardworking and driven individuals who were intrinsically motivated to be there and to support their clientele. Next, I worked as a volunteer visitor where I visited an individual with a life-limiting illness in the community for approximately a year and a half. This was one of the most rewarding volunteer positions I have had, and it was a very difficult decision for me to stop being in the role. These roles have given me a perspective on what it is like to be a volunteer and an employee at the hospice.

The first research project I conducted at the hospice was one where families of individuals with a life-limiting illness were sent a quantitative survey in the mail to measure their level of satisfaction with the support and services they received. The final analysis revealed that the participants were incredibly satisfied with their hospice experience. The second study I completed was a qualitative study where I interviewed individuals with a life-limiting illness and

their caregivers about their experience of receiving support from a hospice volunteer visit. I was touched by the stories I heard as the participants shared intimate details about their lives and the relationships they developed. The final analysis of the data indicated that the hospice volunteers played an influential and positive role in the lives of the individuals they supported and were able to support them in a variety of ways throughout their lives. Overall, the past studies I have completed at this hospice have taught me that the hospice has exceptional employees and volunteers and they support their clientele in a holistic manner that includes their emotional, social, physical, and spiritual lives.

Because of the time I have spent working at and researching hospices, I have researched the previous literature in this area. The literature has explained that hospices attract employees and volunteers who are incredibly motivated to do this work and who have exceptional personality traits that help them support and care for the individuals they encounter. Additionally, the literature has demonstrated that individuals who receive hospice support and services are typically incredibly satisfied with the support they have received.

Overall, my personal experiences and research influenced my expectations and lead me to suspect that the participants would praise the support they received from the hospice. I suspected that the participants would comment about their experiences there even though I never directly asked about it. Furthermore, I expected the participants to enjoy speaking to me and to openly express their feelings and thoughts. Finally, I expected that they would appreciate having the psychoeducation package, considering it contained helpful information that was not only educational, but also meaningful and useful.

## **Participants**

The participants in this study were individuals who were involved with a hospice in a medium-sized central Canadian city. Semi-structured interviews were conducted ( $n = 6$ ) either over the telephone or face-to-face over a period of several months by one researcher. Interviewees were two men and four women. The participants ranged in age from 30-79 ( $M = 63$ ), the length of time of hospice involvement ranged from four to 24 months ( $M = 15$ ), and length of time caregiving ranged from zero to 120 months ( $M = 23.5$ ). One individual was currently a caregiver, four of the individuals were bereaved caregivers, and one individual was a bereaved family member. The relationships to the individuals with a life-limiting illnesses included: mother, spouse, and sibling. All of the individuals received hospice services with the exception of one, who was a long-term hospice volunteer.

### **Materials**

The potential participants were provided with a psychoeducation grief and bereavement resource package that contained information that falls into the following categories: spiritual, social, physical, and psychological support. The contents of the package included education surrounding several topics, including: what is grief, the domains of grief, how to address the domains of grief, spending final moments with your loved one, self-care and compassion during grief, what we need during grief, and helping yourself heal when someone dies. Additionally, this package contained information about programs and services offered by the hospice such as complementary therapies. This package has been specially designed by the researcher and the hospice clinical team to meet the needs of their caregiver clientele in a variety of dimensions in their lives.

This package contained a questionnaire with three open-ended questions (Appendix A). An example of one of the questions is: Is there something in this package that you find helpful?

The purpose of this questionnaire was to encourage the potential participants to reflect on the package and consider what has been helpful or not helpful for them. Additionally, there was a flyer (Appendix B) that educated the potential participants about the study; the flyer presented the name of the study, a brief description of the purpose, the participation requirements, and gives the contact information of the researchers. The hospice's staff also handed out the flyer during support groups to educate potential participants about the study.

Before participation, the potential participants read, signed, and dated the consent form (Appendix C). The consent form contained the following information: invitation to participate, the purpose of the study, the length of the study, the study procedures, any risks and benefits from participating, the rights of participants, and who to contact with questions. It stated that the participant is able to withdraw from the study at any point in time. The consent form had the contact information of the hospice's grief and bereavement counsellor in case the participant faced any emotional distress and desired support. Additionally, there was a clear explanation that participating or not participating in the study would not impact any services from the hospice and that the information collected would be kept confidential. It explained that the study was completely voluntary and that the participant could decide whether or not he or she answered a question.

After the participants agreed to the consent form, then the interview started. The researcher conducted semi-structured interviews with the participants with questions that had been specifically designed for this study (Appendix D). Each interview took approximately 30 to 60 minutes to complete. The questionnaire first collected demographic information about the participants: gender, age, ethnicity, length of time caregiving, relationship to the individual, length of time receiving hospice services, whether he or she has received formal grieving

support, first language, and marital status. The interview was designed to ask questions regarding the participants' perceptions of the grief and bereavement resource package in the following areas of support: physical, spiritual, social, and psychological. An example of one of these questions is: Tell me about your impression of the grief resource package and information regarding physical support (e.g., the information about self-care as well as sleeping and eating habits). After the questions about the psychoeducation grief and bereavement resource package had been asked, the interview focused on how the participants met their needs in their lives in the following areas: physical, spiritual, social, and psychological. An example of a question in this area is: How do you meet the needs in your life regarding social support (e.g., attending community events or spending time with loved ones)? The interviews ended with the researcher asking an open-ended question: Is there anything else you would like to share?

After the interview had been completed, the participants were provided with a debriefing form (Appendix E). The debriefing form contained the contact information of the researchers, thanked the participant for participating, stated the hypothesis and procedure of the study, and provided information for individuals who work at the hospice who are able to provide emotional support if necessary.

### **Procedure**

A University Research Ethics Board approved this study, and it complied with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. This study was advertised at the hospice in a variety of different ways, including giving caregivers and families the psychoeducation package and handing out the package flyer at support groups. The package was designed by the researcher and the hospice clinical team, and it contains different valuable

educational materials to help support individuals facing grief or bereavement and those in the caregiving role.

When an interested individual contacted the researcher for further information about the study, the researchers began by educating them on the purpose of the study and the requirements; the individual was required to complete a 30-60 minute interview. The researchers informed the individual that participating or not participating in the study would not affect any support or services provided by the hospice. The researchers informed the caregiver that all information would be kept completely confidential. Once the potential participant agreed to participate, an in-person interview was scheduled.

The typical clientele of the hospice were elderly individuals with mobility concerns, and because of this, the location of the interview needed to take this into consideration. The interviews either took place over the telephone or on location at the hospice. The hospice was an ideal location because it was an accessible building, and there were volunteer drivers who were trained and capable of transporting individuals with mobility concerns.

Before an individual was able to participate, they were required to have read and agreed to the consent form. One interviewer conducted the interviews over several months. The interviews took approximately 30-60 minutes each. The interview could have been stopped or placed on hold at any time. After the interview was completed, the participants were provided with a debriefing form.

### **Data Analysis**

The research method used in this study is called a qualitative content analysis. According to Creswell (2007), the process of analyzing qualitative data involves understanding and interpreting your transcriptions in order to form answers to your research questions. Furthermore,

there are six steps in analyzing and interpreting this data, including: collecting the data, preparing the data, reading the data, coding the data, identifying themes, and describing the themes.

Overall, it is understood that the process of collecting and analyzing the data does not always happen in sequence. In this study, I used content analysis to develop an understanding of what the participants thought of the psychoeducation package and how they meet their self-care needs.

The first step of content analysis involves collecting the data. This is where I interviewed the current and bereaved caregivers as well as a bereaved family member. The interviews were either audio-recorded or recorded by hand and field notes were taken. The next step is preparing the data where I transcribed the recorded interviews and organized the notes I collected. After that, I read through the data to gain a greater sense of the information I collected. Additionally, I marked the data by making notes and coding by labeling text and establishing broader themes. After that, I developed categories from the codes that answered my research questions, and I described the categories. Finally, I created subcategories that fall under the categories to better describe and understand the phenomena found in the data.

## Chapter 4: Results

The results of this study detail the impact that psychoeducation support had on caregivers. Additionally, the results indicate the importance of hospice support and physical, emotional, spiritual, and social self-care. All names and any identifying information have been changed to protect the confidentiality of the participants.

### **Benefits of Hospice Support**

The interviewer did not ask the participants directly about their experience of being involved with the hospice or other hospice clientele, but throughout the interviews the participants continuously commented on them. Additionally, they were not asked about the support and services they received from the hospice's employees and volunteers, but each participant reflected on the quality of the care they received. The participants reported that the relationships they formed with employees, volunteers, and fellow hospice clientele, as well as the care they received from the hospice, formed an essential part of supporting themselves through the difficult circumstances they faced.

**Connection/social support.** The participants talked about the importance of the social support they received from the other clientele at the hospice. Judy described the emotional and social support that she received at the hospice using the metaphor of a butterfly's cocoon: "Just the fact that you get it here. You can come in and hug someone. You felt that you were in a cocoon here." When Elizabeth was asked about how she supports her social needs, she shared that the other clientele at the hospice were an essential part of her journey:

Here you are walking the journey with the same people from one program to another or because socially you have felt safe to have a coffee. You are on the same journey. When you are grieving you need to

walk that mile with people who are just like you. My family can be wonderful but they are not on the same journey at that time in their life.

They are really hurting the same way as you.

Overall, throughout the interviews the participants reported that the support they received from the hospice helped to fulfill their social needs and that they felt a strong sense of connection with the individuals there.

**Exceptional employees and volunteers.** Several of the participants explained that the volunteers and employees at the hospice provided exceptional support and care. According to Chris: “The people I met here, boy, are they good quality. They are extraordinarily high quality, and if anyone wants to meet high quality human beings, they should come here and meet staff.” Additionally, Chris shared: “You have trained counsellors here, you have people who are psychotherapists, and you have people with tremendous backgrounds.” These quotes help to illustrate the quality of the employees at the hospice and why the participants spoke highly of them.

Furthermore, Elizabeth talked about her experience with the employees and volunteers:

Words cannot express what I got out of every program I was involved with. It just floors me to think how can they pick their volunteers, their facilitators, and these are volunteers and they give their whole heart and soul and you have to be a part of it to understand.

This quote supports the concept that not only was the staff at the hospice providing exceptional support and services, but also the volunteers.

**Remarkable environment.** During the interviews all of the participants commented on the hospice being a remarkable environment where they felt safe and comfortable. Tim stated:

“The hospice has been a life saver for me.” Abby shared: “I mean, this place is wonderful and everyone says this is a place they can come to and a place they can relax.” According to Elizabeth: “The environment here has helped me to feel safe with other people... I feel more vibrant and I want to live.” And finally, Chris expressed: “Hospice is unbelievable and I hope that the day I die I will be in an environment like this here or at home.” These are just a few of the quotes from the participants that demonstrated the important role that this hospice played in their lives.

Furthermore, Elizabeth shared the way the hospice and its environment influenced her life after the loss of her husband:

I can honestly tell you there are so many times I did not want to go home.

I was so wrapped up in safety in this environment. It was a safe place to cry, a safe place to share, and everybody seemed to understand. So much compassion compared to a hospital setting.

Her statement supports the idea that the hospice provided a safe environment for individuals to heal after facing a tremendous loss.

### **Supportive Information**

When the participants were asked about their impression of the psychoeducation package, they reported that the information helped to support them in a variety of different ways throughout their lives. The participants were able to articulate several different reasons why they found the information helpful, including how the information helped to normalize their experiences, the content and format was accessible and readable, it was effective education that they were able to use in their daily lives, and it was presented in an inviting and open manner.

**Normalizes feelings/emotions.** One of the important features of the psychoeducation package is that the information in it helped to normalize the feelings that the participants had been experiencing. Christine reported that she felt confused about why she was not reacting like others and she explained:

There is a section that talked about feeling numb so I had a lot of times I felt numb so emotionally. It is hard for me to watch other people to feel sad and cry, and I think why am I not crying?... It was nice to read that is okay. So I felt validated.

This statement explains that the information helped to normalize her emotional response while also validating her experience.

Additionally, Abby shared that learning this information helped her to feel less alone: “It makes you realize you are not alone. This is normal during the grieving process and this is the emotions you are going through.” Abby further explained how this information helped to normalize her experience:

It really covers everything from start to the finish. I guess it covers everything. It makes you feel like you are not alone and you are not going crazy and what you are feeling is normal. Whatever your new normal is.

Overall these quotes demonstrate that psychoeducation can help to validate and normalize individuals’ experience of grief and bereavement and the wide range of emotional experiences that they have.

**Quality of format and content.** Throughout the interviews, the participants communicated that they found the psychoeducation package to be comprehensive and practical.

Elizabeth shared how she felt about the package: “It was all done very well. . . . I like the way you have little bits of information on various subjects. It’s not too long, it’s enticing.” Judy suggested that she felt it covered important information: “The whole thing is brief but it has got it covered. . . . It covers everything. Really. It really does.” Additionally, Tim shared his impression of the content: “The thing that struck me was that the coverage was thorough.” The feedback from the participants suggested that they found the content of the psychoeducation package to be extensive but presented in a manner that was enticing and engaging.

Furthermore, Abby shared how the information in the package affected her: “I found it very helpful reading it. It is well laid out. It is a good reference guide overall.” Finally, according to Chris: “I was really impressed with this thing, to be honest.” Overall, the data collected from the interviews determined that the participants’ impression was that the package was a comprehensive, accessible, readable guide full of useful knowledge and information.

**Effective education.** The analysis of the interviews demonstrated that the participants found the information in the psychoeducation package to be educational and that this knowledge was helpful to them. Christine described the impact the educational information had on her:

I was surprised to know that grief affects your life in different ways not only emotional, but I was interested in know the facets of grief: emotional, intellectual, and physical. So you hear that exercise is good but it reinforced the mind/body connection and what I already know. Whatever is going on with your emotions it translates into physical symptoms.

Additionally, Christine shared a personal story and explained that learning about disenfranchised grief helped her to understand an interpersonal situation in her life: “There was something about

disenfranchised grief that was really helpful for me. . . . Learning about that was really helpful.” Christine’s experience of the package promotes that psychoeducation is one of the ways to support caregivers of individuals with life-limiting illnesses.

Several of the participants commented specifically on their impression of the educational information. Elizabeth explained the effect the package had on her: “Knowledge support that sticks and you go home and use it.” Furthermore, Abby shared her impression of the educational information in the package: “It is a good resource. There is a lot of information in it. It is well laid out. Actually, it answers a lot of questions.” According to Chris: “There is some downright good advice. Like don’t make any major decisions for at least a year. And that is something that most people don’t know about.” These comments help to express the effectiveness of providing educational resources to individuals in a caretaking role and the important influence it can have on their lives.

**Invitational/open.** The participants in the study shared that they found the information in the psychoeducation package to be shared in a way that they interpreted as being open and invitational. According to Elizabeth: “Nothing is pushed on you, it is very invitational.” Furthermore, Chris explained his impression of the package:

I think what it says is that doors are open. . . . There is an openness to all of it so it will be respected in terms of the form that it is manifested in the person who is grieving. There is a simple message of this in the package and it’s there for those who pick it up. The big thing is respect and that is in here completely.

These comments suggest that the participant perceived the psychoeducation package to be presented in a way that is open and invitational and this helped to support their positive impression of it.

### **Holistic Personal Care**

The second half of the interview asked caregivers how they fulfill their self-care needs in these four domains: physical, spiritual, emotional, and social. The participants in this study shared that they did a variety of different activities in these four dimensions to ensure that they had the physical, mental, and emotional health in order to be in the caretaking role.

**Physical.** The participants shared that they engaged in physical therapies like having a massage. Christine talked about the importance of receiving physical therapy: “I try to get massages often, I think that really helps me, and when you are sitting all day at the hospital your posture becomes horrible, and stress, you get so tense.” Additionally, several of the participants expressed that walking and physical activity played an important part in their self-care. Tim talked about the importance of walking: “I always feel better when I walk.” Additionally, he expressed that he felt there was a connection between walking and his ability to sleep: “Exercise is dual: you feel better plus you sleep better.” Abby also explained the importance of being physically active: “I try to get out every day. It does not matter whether it is to go to the mall, you need to get out, you need to move. It is too easy to sit at home.” Overall, the participants in this study shared that taking care of themselves physically through exercise and physical therapies was an important part of their self-care.

**Spiritual.** Spirituality and existential concerns often play an important role in the lives of individuals who are faced with death, including caregivers of individuals with life-limiting

illnesses. The participants in this study discussed engaging in various spiritual activities. Judy shared the important role that faith played in her life and the losses that she had faced:

I think your faith does keep you solid. I think for me that has kept me solid. And I don't weep and mourn that much because it's okay, you are in a better place. We are all together and you are with me.

Elizabeth talked about how the church she belonged to and its community was part of her journey of healing: "I belong to a wonderful parish. And I'm actually currently in three different programs at the parish. Some are three months long and others are six weeks and I will continue to allow my spiritual life to grow." The comments shared by Judy and Elizabeth illustrate that religiosity and spirituality can be used as a tool to nurture us during difficult times.

Participants also shared engaging in other spiritual practices including meaning-making and meditation. Tim shared that religiosity did not play a role in his life, but instead meaning-making and feeling grateful did: "Meaning-making, I guess. A part of it is to do with focusing and trying to remind myself where I feel I am very fortunate. Also, I tend to think about the meaning of life and whatnot." Christine talked about the importance of meditation as a spiritual practice in her life:

I do meditation, so I consider that to be somewhat of a spiritual practice. I like guided meditation, so at some point a few years ago I bought a book and it came with a CD, so I have some guided meditations and there are so many podcasts.

According to the results of this study, spirituality played an important role in the lives of the participants in a variety of different ways including religiosity, meaning-making, and meditation.

**Emotional.** Emotional support was reported as an area that the participants focused on in order to take care of themselves throughout the challenges they faced. The participants conveyed that they received emotional support for individuals in their lives, including their friends and family members. Additionally, several participants shared that they received formal support from a counsellor. Abby described how she received emotional support from counselling and her son:

I do the individual counselling and I live with my son and his wife and I talk to my son a lot. He is so logical. He went through the death of a child so we can relate to it. He will tell me it is okay to feel sad.

Christine also shared that she attends individual counselling: “I have been seeing her for a while, four years, and she is just a really well-rounded therapist and she helps me move through this as well.” The experiences shared by Abby and Christine illustrate that emotional support can be acquired through professional services or by talking to loved ones.

Another form of emotional support that the participants communicated they received was from the hospice. Judy expressed that she received emotional support from the hospice: “Emotional support I found here.” Chris also shared his impression of receiving emotional support from the hospice:

You are never going to have anyone around here saying “get over it.” You will have people trained to respect feelings, whatever those feelings are.

You have people who are trained to respect emotions, respect feelings, and they will walk with people and that is in here.

Emotional support was an important consideration for the participants whether they met their needs by receiving support from friends and family members, individual counselling, or by their association with the hospice.

**Social.** Social support was another dimension that the participants discussed as being an important area of self-care. Judy talked about the role that her female friends played in her life: “My girlfriends, they are my social circle and they listened. They were on the phone and they were there at the door and they listened.” Tim shared that he attended programs at the hospice as a way to connect to other individuals: “I go to the meditation group, but it’s not for the meditation, I go for the people. Their walking is not fast enough for me, but the social part is useful for me.” Abby also expressed that the hospice was where she received her social support: “I think right now it’s going to the hospice.” The responses of the participants suggested that having social support was an essential aspect of their self-care, and that they received this support from individuals in their lives and from the hospice.

## Suggestions

Several suggestions were given in response to the psychoeducation package. Elizabeth made a suggestion on the content of the package: “Quotes could be put in there. Quotes from people who have been there done that, been through the program. Quotes under the pictures.” Additionally, Christine shared her thoughts about the format and when it would be a good time to receive the package:

Electronic version on the website. Also, to come to hospice you have to do a registration and I was thinking of opportunities when people might have their first interaction with hospice and whether or not their page can be provided. It might be helpful to have it earlier.

Furthermore, Elizabeth explained her impression of having a paper package: “Paper is good. Paper you can pick up at any time. This you can pick up at any time and read it over and over again.”

There was one comment about the addition of more content. Chris shared his thoughts about the importance of ritual:

What isn't said in here that I would also encourage is the rituals at home. I would add that. Rituals at home are very important. It can be as simple as lighting a candle every once in a while. Or people who pray, to say it in their prayers every once in a while. There are concrete ways of remembering, not forgetting but remembering.

Considering the existential and spiritual concerns individuals faced with death and dying can have, this is an important consideration when formulating a psychoeducation package for caregivers. Overall the suggestions included: the

addition of pictures, stories and quotes, receiving the package at an earlier date in the caregiving role, keeping the paper format, distributing an electronic version, and adding more information about rituals and having rituals at home.

The participants were asked if they found any of the information to not be helpful, and there was mostly positive feedback. Judy: “No, I don’t think I did. Not when I first read it. I didn’t think of anything that was not helpful.” Judy also shared: “I think it covers everything that you need to say without offending anybody. In some ways it should be neutral, I suppose.” Out of the five participants, only one discussed something that he did not find helpful. Tim shared that he did not like information about saying goodbye to your dying loved one:

The only thing that struck me negatively is the part on saying goodbye. Because I did not say goodbye to my wife and I don’t think that is appropriate. Even though you are expecting someone to die, it is still a shock that they do. I did not give up hope.

This comment explains the importance of presenting information in a sensitive way, considering the individual differences when interpreting information about grief, bereavement, and loss.

Finally, two of the participants reflected on suggestions they had regarding the hospice. Judy suggested that individuals should have more time to access hospice support and the addition of more programs: “More programs at night. Because of the people that I met it makes sense if you think about it in the broad sense. I met four people that were working and they had to rush to get here.” Elizabeth stressed the importance of having more services like the ones provided at the hospice: “We need more of this. It is very sad that there is not the healing touch in the world, nowadays we need more of this. We really do.” These quotes exhibit the importance of having

support and services provided by a hospice for caregivers of individuals with life-limiting illnesses and the bereaved.

## Results Summary

According to the results in this study, caregivers of individuals with life-limiting illnesses and the bereaved can receive support from hospices that help to improve their quality of life in various ways. The participants reported that attending the hospice gave them social support and a sense of connection to others. Additionally, the employees and volunteers at the hospice were spoken about with high regard, and the environment was described as remarkable. The participants were never directly asked about their experience of the hospice, but insisted on sharing their experiences anyway. This shows the incredible effect their involvement with the hospice had on their lives. The hospice employees, volunteers, clientele, and environment were able to provide the participants with a sense of social support and a place where they were able to cope with the difficult challenges they faced surrounding the loss of a loved one.

Another important finding in the study was that the participants found the psychoeducation package to be beneficial in a variety of ways. The participants reported that the educational information helped to normalize and validate the array of emotions they experienced. Furthermore, they commented on the quality of the format and content of the package; they explained that they found it to be comprehensive and practical. The educational information in the package was described as being effective and useful information that the participants were able to use in their lives. Finally, regarding the information in the package, the participants expressed that they found it to be presented in a way that was inviting and open, and this helped to create an overall positive impression of it.

The participants were also asked about how they personally coped with the challenges they faced. It was found that they engaged in a variety of self-care techniques to support themselves that fell into the following categories: physical, spiritual, emotional, and social.

Regarding physical support, the participants explained that they participated in exercise like walking and received physical therapies such as massage and chiropractic adjustments.

Additionally, the participants had spiritual practices, including having faith, attending religious ceremonies, being involved in religious communities, and practicing meaning-making and meditation. Next, the participants expressed that emotional support was another important area of self-care. The participants sought emotional support from friends, family members, the hospice, and individual counselling. Finally, social support was found to be another dimension where individuals cared for themselves. It was found that the participants received support from their friends and from their involvement with the hospice.

Participants were asked if they found anything not helpful in the package, or if something was missing, and several suggestions were given. The suggestions were: adding pictures and quotes, adding an electronic version on the hospice's website, continuing to supply it as a paper version, providing it to hospice clientele earlier in their journey, and adding information about the importance of rituals and having rituals at home. Additionally, there was one recommendation regarding the information in the package. One of the participants indicated that he did not find the information about saying goodbye to a loved one as helpful, but instead he perceived it negatively. This comment is a reminder of the importance of information being presented in a sensitive manner considering sensitive nature of this topic.



## Chapter 5: Discussion

The results of this study suggest that hospices provide essential care to their clientele that is an essential part of their healing journey while facing a loss or after a loss. Being affiliated with the hospice provided the participants with a sense of connection to others and with social support. The employees and volunteers were described as being exceptional individuals with positive personality traits. Finally, the hospice was explained as a remarkable environment where the participants felt safe. Overall, the hospice was described as an incredible place where the participants took refuge during the difficult times they faced.

Another finding in this study is that psychoeducation can be one of the ways to support caregivers and the bereaved. The psychoeducation package was described as providing supportive information that helped to normalize its users' feelings and emotions. Throughout the interviews, the participants commented on the quality and the format and explained that it was comprehensive and practical, which supported an overall positive impression of it. Furthermore, they explained it was an effective education tool that they were able to take home and use. It was also described as being presented in a way that was invitational and open. Individuals facing grief and bereavement in the caretaking role may have a lot of different questions, and providing psychoeducation is one of the ways that hospices can help to answer them. The experiences shared by the participants illustrate that receiving psychoeducational information can provide its users with useful information that they can apply into their personal lives.

Another topic the participants were asked about was their personal self-care. It was found that the participants engaged in holistic self-care. They described that they engaged in a variety of self-care techniques that fell into the following categories: physical, spiritual, emotional, and

social. All around, each participant explained many different ways they took care of themselves without valuing one dimension over another.

Finally, several suggestions were made for improvements on the package, whether they were regarding the format, the content, or the best time to receive the package. It was suggested that receiving the package early in one's grief journey might be helpful, a paper format is well received, more information about rituals would be beneficial, and that pictures and questions could make it more welcoming. Additionally, the package was found to be very well received, with the exception of one participant's suggestion that he did not find the information about saying goodbye to your loved one to be helpful.

### **Similarities to the Literature**

When comparing the existing literature to the current study, there were several similarities between the two. There were similarities regarding the evidence surrounding psychoeducation: it supports psychological well-being (Durepos, Kaasalainen, Carroll, & Papaioannou, 2016); Hudson et al., 2013), it helps its users to have a deeper understanding of their feelings and emotions (Alves-Costa, Hamilton-Giachritsis, Christie, & Halligan, 2018), and it normalized their experience of grief (Bowden, 2011). Furthermore, there were similarities surrounding the domains of self-care, including the importance of social support (Lorraine, Allison, & Karen, 2005; Strang, & Koop, 2003), the meaningful role that spirituality plays in the lives of caregivers and the bereaved (Lorraine, Allison, & Karen, 2005; Paiva et al., 2015), and how individual counselling can support individuals who are faced with grief and bereavement (Vlasto, 2010). Finally, another similarity was regarding the role that hospice support plays in the lives of individuals who utilize their services. The previous literature on this topic has suggested that hospice volunteers have exceptional personality traits (Claxton-Oldfield &

Banzen, 2010; Claxton-Oldfield & Blacklock, 2017) and that hospice clientele have typically been satisfied with the support they received (Bainbridge & Seow, 2018), especially when hospices provide emotional and spiritual care (Rhodes et al., 2008).

According to the previous literature on the subject, psychoeducation can be a helpful tool to support individuals facing grief and bereavement. A study by Hudson and colleagues (2013) found that a psychoeducation intervention supported overall psychological well-being in caregivers and had a protective quality against increasing distress. Another study by Durepos, Kaasalainen, Carroll, and Papaioannou (2016) demonstrated that psychoeducation for current and bereaved caregivers helped to improve their sense of emotional well-being and that they found the knowledge and information to be empowering. Once again it was found that psychoeducation increased individuals' sense of well-being. This suggests that the variety of benefits from receiving this information can positively affect psychological well-being. The results parallel the results in the current study. According to the results, psychoeducation can help to validate one's own feelings and emotions, can help to normalize the grieving experience, and provides useful information that an individual can implement into their life. These qualities helped to foster a sense of empowerment in the individuals who access psychoeducation. Additionally, the benefits may have contributed to their overall sense of psychological well-being and in turn reduced their perceived sense of distress.

Similarly, another study looking at the effects of psychoeducation found similar results as the present study. Alves-Costa and colleagues (2018) looked at the effects of psychoeducation on individuals bereaved by homicide. According to the researchers, providing these individuals with psychoeducation helped to give them a greater understanding of their personal, emotional, and psychological reactions and responses to what happens after you experience a loss. Additionally,

the individuals reported that it helped them with putting things into perspective and improved their adaptive coping resources. Bowden (2011) studied the impact of receiving psychoeducation for individuals bereaved by suicide. The researcher found that it helped to support the individuals in understanding why their loved one died and that receiving this education encouraged them to reach out to their loved ones for support which reduced their sense of isolation. The results in this study can be compared to the current study. It was found that psychoeducation helped to educate its users with knowledge that they actively used in their personal lives. Additionally, the participants explained that the information educated them on different aspects of the experience of grief and bereavement, and therefore they had a better ability to understand their own experiences.

Another similarity between previous research and the current study is the importance of having social support from friends and family. According to studies by Lorraine, Allison, and Karen (2005) and Strang and Koop (2003), receiving social support from family and friends is an adaptive coping technique for caregivers. Additionally, Lorraine, Allison, and Karen (2005) found that social support supported caregivers in having a sense of hope through the challenges they faced. The current study looked directly at coping skills and asked the participants how they coped. The participants explained that receiving social support from friends and family was an important way that they took care of themselves. Previous literature on caregivers coping supports the results in this study that indicate social support can be used as an adaptive coping technique for individuals during this time.

The essential role of spirituality and religiosity is another similarity found when comparing previous literature to the current study. In a study, Lorraine, Allison, and Karen (2005) found that a spiritual connection to someone bigger than oneself or a connection to God

was a positive influence on a caregiver's sense of hope. Furthermore, Paiva and colleagues (2015) looked at the role that spirituality and religiosity played in the lives of family caregivers. Their study revealed that the caregivers experienced an increased faith and sense of closeness to God during their time caregiving, meaning-making was an important coping technique for them, and that they used their sense of spirituality and religiosity for strength and support during this difficult time. Comparable results were discovered in the current study; the participants talked about the important role that their religious affiliation played in their lives, how their sense of faith supported them, and how the ability to make meaning was a coping technique they used. Both previous studies on this topic and the current study demonstrate that a sense of spirituality and religiosity are protective coping techniques for caregivers and the bereaved.

Several of the participants in the study indicated that they accessed individual counselling as a way to emotionally cope with what they had dealt with being in the caregiving role or with the loss of their loved one. A study by Vlasto (2010) looked at therapists' impressions of the effects of receiving bereavement counselling. The researcher found that individual counselling is a safe place for individuals to explore and express their emotions and feelings, the counsellor and client develop a relationship where there is a sense of trust, the client is able to access deeper material and can work through any blockages surrounding their grief. This supports the idea that individual counselling is beneficial for individuals facing grief and bereavement (Vlasto, 2010), and shows why the participants in the study in question sought counselling and benefited from receiving it.

Participants in the present study continuously commented on the quality of care they received from the hospice and its employees and volunteers. They shared stories that described experiences where they felt supported and cared for in this environment. Additionally, they

talked about the social support they received from the other clientele at the hospice. This is supported by the existing literature that has demonstrated the powerful impact of hospice support. Research by Claxton-Oldfield and Blacklock (2017) found that hospice volunteers viewed themselves as advocates for the individuals they support and the hospices they worked with. Furthermore, Claxton-Oldfield and Banzen (2010) looked at the personality characteristics of hospice volunteers and found that when compared to the typical population, they were higher than average in levels of agreeableness, extraversion, openness, and empathy. Additionally, they were found to be lower than average on neuroticism. Reflecting on the results in these studies it becomes easy to understand why the participants continuously shared experiences of interacting with the volunteers and the time they spent at the hospice. According to the literature on this subject, hospice volunteers have been exceptional individuals who have provided amazing support to others during a very difficult time in their lives.

The participants' perception of the hospice is also supported by a study conducted by Bainbridge and Seow (2018). In this study, the researchers looked at bereaved caregivers' impression of the support they received from a variety of palliative care settings. The majority of the participants in this study rated hospices as excellent or very good for providing physical, spiritual, and emotional support. Additionally, hospices were viewed as more favorable over other palliative care settings, including hospitals. Rhodes and colleagues (2008) found that bereaved family members were more likely to be satisfied with hospice services if they felt they received adequate emotional support and had contact with the hospice employees about their religious and spiritual beliefs. Overall, the participants in the present study reported that they received support in all of these domains and that as a result they were exceptionally satisfied with the services they received.

## **Differences From the Literature**

The findings of the present study have several differences from the existing literature on the use of psychoeducation for individuals facing grief, bereavement, and in the caregiving role. Reflecting on the differences regarding the use of psychoeducation, the literature has suggested that psychoeducation might reduce feelings of grief and physical issues like sleeplessness (Knowles et al., 2017), and that it can help to increase aspects of a caregiver's life, like their sense of self-efficacy and reward from being in the caregiving role (Leow, Chan, & Chan, 2013). Another difference is regarding caregiver coping. Previous studies have suggested that caregivers may cope using avoidance techniques and by developing a continued bond (Asai et al., 2012). Finally, to our knowledge, there is no previous research looking at how caregivers and the bereaved take care of themselves in the physical domain.

To begin, Knowles and colleagues (2017) found that a psychoeducation website on grief helped to reduce caregivers' feelings and thoughts of grief, yearning for a deceased loved one, loneliness, and overall sense of stress, and increased their quality of sleep. The current study did not find similar results, as the participants did not comment on reduction of symptoms or improved physical functioning. Furthermore, a study by Leow et al. (2013) on the use of psychoeducation to support caregivers revealed it can help to increase quality of life, lower stress and depression, increase self-efficacy about self-care, and increase sense of reward from being in the caregiving role. Once again, the current study found different results because the participants did not comment on reduction of symptoms or improvements regarding their perception of being in the role or how they felt about their lives.

Another difference in the literature was regarding how caregivers coped with the challenges they faced. Asai and colleagues (2012) found that caregivers' coping strategies fell

into three different categories: distraction, continued bond, and social support. The participants in the current study did not express that they used avoidance techniques or worked to develop a continued bond with their deceased loved one. On the other hand, they did suggest that social support was an important part of their self-care routine (Asai et al., 2012).

Finally, another difference in the literature is that to our knowledge, there is no prior research that looks at caregivers and the bereaved need for physical support. The participants in our study all indicated that taking care of their physical selves was an essential part of their self-care plan. They shared that they engaged in activities like walking, and saw physical therapists such as chiropractors. Considering the negative impact that physical effects like weight gain and issues sleeping can have on individuals in the caregiving role (Hawranik & Strain, 2007), it is important to engage in physical activities and therapies to support their physical bodies. Overall, a novel finding in our study was the importance that physical care had on the lives of our participants.

### **Implications**

There are several important implications for policy, research, and counselling practices based on the findings in this study. The first policy consideration is that government bodies can fund psychoeducation about grief, bereavement, and being in the caregiving role for organizations such as hospices. We have an aging and growing population (Statistics Canada, 2013) and there is going to be the need for more end-of-life support and care; psychoeducation is a cost-effective way to support this group of individuals. Additionally, the results of this study indicate the benefits that hospice support has on the lives of individuals. Hospices provide support for individuals at the end of their lives whether they are dying in the hospice residence or in the community. Additionally, they provide support to their caregivers, loved ones, and the

bereaved. Considering the growing and aging population, the need for hospice support is likely to increase. This will create a need for government bodies to allocate more funding for hospices. This research illustrates the positive effects that psychoeducation and hospice support have on the individuals who access these services. With the increase in need for end-of-life services, research like this can be used to understand how to best support individuals who require support during this time.

There are several implications for future research. First, future research can consider looking at the effects of psychoeducation about grief and bereavement and how it could help to support different groups of individuals, including but not limited to bereaved parents, caregivers of children with life-limiting illnesses, individuals who lost a loved one due to a traumatic situation, individuals who experienced prenatal and infant loss, as well as adolescents who lost a friend, parent or sibling. Another possibility for future research is to look at the ideal timing to provide an individual with psychoeducation about grief and bereavement. In addition, research can also look at the effects of receiving psychoeducation in different formats, including paper booklets, online, in-person groups, and one-on-one with a counsellor. Finally, another important area to be considered is how caregivers and the bereaved can best support themselves in the physical domain to cope with the challenges they face.

Counselling practice and psychoeducation about grief and bereavement is an important aspect to consider when reflecting on the findings in this study. Individual counselling and group counselling have been some of the ways that caregivers of individuals with life-limiting illnesses and the bereaved have accessed support. One of the ways that counsellors can support their clientele is by using psychoeducation about grief, bereavement, and the caregiving role. The results in this study demonstrated that psychoeducation in this area can help to support this group

of individuals in a variety of different ways, whether it helps to validate and normalize their experiences or educate them on topics that pertain to their lives. Counsellors can use psychoeducation to support their clientele and help them to understand what is happening in their lives. Furthermore, psychoeducation on this topic can be used in individual counselling or group counselling.

Another reason this study is relevant to the counselling practice is because counsellors need to be aware of different community services and how those services support individuals in need. Individuals in the caregiving role and facing grief and bereavement are likely to attend individual counselling. Counsellors can educate these clients on hospices and what supports they offer individuals. The results in this study found that hospices support individuals in a variety of ways, including social and emotional support. Counsellors can recommend their clients to receive additional support in their lives by receiving services from a hospice.

The final reason that the results in this study are important for the counselling practice is how caregivers and the bereaved support themselves in four areas: spiritual, social, emotional, and physical. Counsellors working with their clients can support them by working on developing their coping skills in these areas. Supporting clients in this way will help to ensure they are engaging in holistic self-care and therefore be able to be resilient and continue to work through the challenges they face.

### **Limitations**

There are two notable limitations in this study. The first limitation is the sample size of the study; six individuals participated. If the study had a larger sample size we may have been able to collect more data to support the study's findings. The second limitation is the lack of

diversity in the sample. To take into account the multicultural nature of Canada the sample could have included individuals with different ethnicities, sexual orientations, and disabilities.

### **Conclusion**

To conclude, the results of this study revealed the benefits of hospice support and the positive effects that psychoeducation can have on caregivers and the bereaved. According to the results, hospices can help to provide a sense of connection to others and social support for their clientele. Additionally, hospices have exceptional employees and volunteers as well as a remarkable environment. Furthermore, psychoeducation about grief and bereavement can provide supportive information that can help to normalize the feelings and emotions of its users as well as give them effective education that they can implement into their lives. The quality and format of the content of psychoeducation is important and the educational information should be presented in an invitational and open manner. Finally, caregivers and the bereaved engage in holistic personal care and support themselves in these four domains: physical, spiritual, social, and emotional.

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## Appendix A

1. Is there something in this package that you find helpful?
2. Is there something in this package that you do not find helpful?
3. Is there something in this package that you think is missing?
4. Do you have any comments or suggestions?

## Appendix B

# PARTICIPANTS NEEDED FOR RESEARCH LOOKING AT THE EXPERIENCE OF THE SUPPORTIVE CARE RESIDENTIAL RESOURCE PACKAGE

We are looking for volunteers to take part in a study that looks at the experience of The Supportive Care Residential Resource Package and individual coping.

Your feedback is incredibly valuable and will help to inform St. Joseph's Hospice and other institutions, of what resources are most beneficial. We sincerely appreciate you considering participation in this research project.

If you are interested in participation you will partake in an in-person or telephone interview at a location and time of your convenience. Your participation would involve one in-person interview. This interview will be kept completely confidential. The interview will take approximately 30-60 minutes.

If you would like to volunteer to participate or if you have any questions please contact Vanessa Eyre either by phone or email

**Principal Investigator**  
Dr. Jason Brown, PhD, Applied Psychology  
Western University

## Appendix C

# Letter of Information and Consent

## A Qualitative Exploration of Caregivers of Individuals with Life Limiting Illnesses: Their Experiences of Psychoeducation and Personal Coping Abilities

### Principal Investigator

Dr. Jason Brown, PhD, Applied Psychology

### Additional Research Staff

Vanessa Eyre

#### 1. Invitation to Participate

You are being invited to participate in this research study that looks at the impact of receiving The Supportive Care Residential Resource Package and how you personally cope with your loss. You are being invited because you were involved with St. Joseph's London and because you are considered a key informant.

#### 2. Why is this study being done?

The purpose of this study is to have a greater understanding of an individual's experience of receiving The Supportive Care Residential Resource Package provided by St. Joseph's Hospice of London and how individuals cope with grief and bereavement. This study is meaningful because of the important role that grief and bereavement support has on individuals who utilize hospice support and services and it will allow us to grow a greater understanding of the impact it can make in individuals' lives. Because of research like this evidence-based practices can be implemented into hospices that will lead to an improvement in support for grieving individuals, and ultimately effectively help to provide people with the best possible care.

#### 3. How long will you be in this study?

The study consists of participation in an interview with the researcher. You will be asked about your perceptions, opinions, and attitudes about the grief and bereavement support you were provided. The interview is anticipated to last between 30 and 60 minutes. You may stop the interview at any time, or ask for a break if you would like one. You have the right to decide if you want to participate.

#### 4. What are the study procedures?

If you agree to participate, you will be asked to take part in an interview about your perceptions of The Supportive Care Residential Resource Package you received and how you personally cope with grief and bereavement. The interview will include questions and open discussion about why grief support is important, strategies that currently facilitate or hinder

the development of grief coping skills within hospices, and what strategies could further aid in grief coping skills acquisition. The interviewer may rephrase your responses to confirm her perceptions of your attitudes and experiences are accurate. The interviewer may ask for your permission to audio record the interview that takes place so that she can have a clearer understanding of what has been said. If you do not agree you will still be able to participate in the study. Even though you agree to be audio recording you have the right to ask that recording be stopped at any time. The interviews will take place either within your home, on the telephone or within a private room at St. Joseph's Hospice London. You do not have to answer any questions/engage in discussions in which you do not wish to partake.

**5. What are the potential risks and harms of participating in this study?**

The possible risks of participating in the study include feelings of distress or discomfort when discussing personal experiences/perception/attitudes with regard to receiving grief support. However, since you will probably have talked about these experiences and attitudes to some extent before, specifically with other members of St. Joseph's Hospice London, there should be no more chance of becoming upset than during a typical discussion of this with others. If you do become upset or distressed during the interview please let me know and I will either stop the session or take a break, whichever you prefer.

**6. What are the benefits of participating in this study?**

It is hoped that this study will provide information that could lead to the formation of guidelines that represent best-practices for educational grief and bereavement support within the context of a hospice setting. Your personal experience might also offer insight to researchers by providing a first-hand perspective of challenges that are faced when providing care and/or supporting individuals who are grieving.

**7. Can participants choose to leave the study?**

You have the right to withdraw from the study at any time. You also have the right to request that any information you give in the interview be removed. Your decision to participate or to withdraw will have no effect on your membership or connection with the St. Joseph's Hospice London.

**8. How will participants' information be kept confidential?**

During the discussion we will only use your first name. Because the discussion might be audio recorded your first name may occur on the recording. If it is audio recorded the audio recording will be given a code number and put on a password protected and encrypted memory stick. Your full name will not be associated with the actual discussion. The consent form and notes of an interview will be given a code and the notes will be kept in a lock box in the researcher's home except when they are being analyzed. In all cases only the interviewer and the principal investigator will have access to the original discussions, consent form or field notes.

The results of this study may be published in scientific journals, or presented at professional meetings and conferences. However, your individual identity will not appear in any publication or presentation. While your individual identity will not be used, we may like to use direct quotes from our discussion. Sometimes the best way to express a point is to use your exact words. I will ask if you would allow me to use direct quotes in publications or presentations, but even in those cases I will not give your identification. Your information will be identified in a report or in the study records by given a pseudonym. This will be a first

name that is an alias used to represent you. It will have no relationship to your name and you will not be able to be identified by this pseudonym. It is entirely your decision whether you will allow me to use non-identifiable, direct quotes---it will have no effect on your participation in the actual interview.

I will keep the data in a secure location as all data should be kept in a secure location for a minimum of 7 years. After this time the information will be professionally destroyed.

If the results of the study are published, your name will not be used. In addition, St. Joseph's Hospice London will simply be described as "a hospice located in a medium sized central Canadian city".

Other members of St. Joseph's Hospice London Network may know that you have participated in the study. This may happen if the interview takes place at St. Joseph's Hospice of London and a member notices that you are participating. Other members will be aware of the study and may come to know of your involvement; however, your participation in the study will have no effect on your connection with St. Joseph's Hospice London, but I feel it appropriate to let you know that we cannot guarantee that no one will know that you have participated.

**9. Are participants compensated to be in this study?**

You will not be compensated for your participation in this research.

**10. What are the rights of participants?**

Your participation in this study is voluntary. You may decide not to participate. If you consent to participate, you have the right to withdraw from the study at any time. You also have the right to skip any of the questions/discussion points in the interview without answering/contributing. If you choose not to participate, or if you choose to withdraw from the study at any point, it will have no effect on your connection with St. Joseph's Hospice London. You do not waive any legal right by signing this consent form.

**11. Whom do participants contact for questions?**

If you have questions about this research study, please contact Dr. Jason Brown

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics

This letter is yours to keep for future reference.

## Written Consent Form

### A Qualitative Exploration of Caregivers of Individuals with Life Limiting Illnesses: Their Experiences of Psychoeducation and Personal Coping Abilities

#### Principal Investigator

Dr. Jason Brown, PhD, Applied Psychology  
Western University

#### Additional Research Staff

Vanessa Eyre  
Western University

I have read the Letter of Information, have had the nature of the study explained to me, and all questions have been answered to my satisfaction. I agree to participate by signing below.  
I agree to be audio-recorded in this research

**YES**      **NO**

I consent to the use of de-identified quotes obtained during the study in the dissemination of this research

**YES**      **NO**

Printed name of participant \_\_\_\_\_

Signature of participant \_\_\_\_\_

Date \_\_\_\_\_

Printed name of person obtaining consent \_\_\_\_\_

Signature of person obtaining consent \_\_\_\_\_

Date \_\_\_\_\_

**Appendix D**

## Demographic Questionnaire

1. Gender:           Female           Male

2. Age:

3. Ethnicity:   Caucasian       African American       Hispanic       Asian       Aboriginal

Other: *Please Specify* \_\_\_\_\_

4. Length of time caregiving:

5. Relationship to this individual:

6. Length of time receiving hospice services:

7. Formal grieving support (counselling or group therapy): *Please Specify* \_\_\_\_\_

8. First Language: *Please Specify* \_\_\_\_\_

9. Marital status:   Single           Married           Common law           Widowed

Semi-structured interview:

1. Tell me about your impression of the grief resource package and the information in following domains:
  - a. Physical support
    - i. Self-care – sleeping and eating habits
  - b. Spiritual support
    - i. Meaning making, or exploring one’s own spirituality
  - c. Emotional Support
    - i. How grief is expressed, understanding emotions
  - d. Social Support
    - i. Reaching out to loved ones, or attending support groups
  
2. Tell me about your impression of the grief resource package
  - a. The format
  - b. Was anything missing?
  - c. Did you find anything not helpful?
  - d. Community resources
  
3. How do you meet these needs in your life in the following areas:
  - a. Physical
    - i. Self-care, or attending appointments
  - b. Spiritual
    - i. Religious and non-religious spirituality, or attending religious events and ceremonies
  - c. Emotional
    - i. Talking to a supportive loved one
  - d. Social
    - i. Attending community events, or spending time with loved ones
  
4. Is there anything else you would like to share?

## Appendix E

# DEBRIEFING FORM

**Project Title: A Qualitative Exploration of Caregivers of Individuals with Life Limiting Illnesses: Their Experiences of Psychoeducation and Personal Coping Abilities**

**Principal Investigator:**

Dr. Jason Brown, PhD, Applied Psychology  
Western University

**Additional Research Staff**

Vanessa Eyre  
Western University

Thank you for your participation in this study. The purpose of this study is to understand how to best support caregivers with educational support in a hospice setting. We predicted that providing a grief and bereavement resource package will help to provide individuals with valuable resources and information that will help them during this difficult time. This research study is being carried out by conducting one-on-one interviews with caregivers who have received hospice support and analyzing the data received from the interviews to create themes that help to explain the impact of receiving this support.

Thank you,

Dr. Jason Brown and Vanessa Eyre

## Curriculum Vitae

**Name:** Vanessa Eyre

**Post-secondary  
Education and  
Degrees:** Masters in Counselling Psychology  
Faculty of Education, Western University  
London, Ontario  
2017 – 2019

Bachelor of Arts, Honours Specialization Psychology  
Kings University College, Western University  
London, Ontario  
2011 – 2016