Measuring Success:
Creating an Evaluation Tool for Children and Teen Bereavement Programming at The
Greystone Bereavement Centre

A Research Practicum Report Submitted to the Faculty of Social Work
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Abstract

The literature on children's grief recognizes the value of bereavement support programs as a method for facilitating children through their personal grief journeys. The long term impact and outcomes of such support programs for children's grief have not been identified. Evaluative measures, specific to children's grief, are complex, developing and limited. To further inform the development of an evaluative tool for children and teen grief and bereavement programming, this report focuses on the experiences of caregivers whose children have attended grief and bereavement programming at Greystone Bereavement Centre in Regina, Saskatchewan. Eight interviews were conducted with caregivers whose children attended Caring Hearts Camp. The eight participants shared the benefits and challenges to their children, themselves and their family units. Through a phenomenological approach to qualitative research, these experiences are highlighted within the findings. From these findings, recommendations are provided for the development of an evaluative tool for consideration by Greystone Bereavement Centre. A pilot evaluation has also been constructed and is attached in the Appendices. Further, the recommendations within this report contribute to the knowledge of death, dying and bereavement. Within the field of social work, this knowledge will continue to enhance the care provided to the individuals and families who have encountered a death loss.
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Table of Contents

Abstract                                          i
Acknowledgements            ii
Table of Contents            iii

Chapter One: Introduction           1
  1.1 Context             1
  1.2 Purpose            3
  1.3 Objectives of Project          4

Chapter Two: Literature Review          5
  2.1 Children's Grief           5
  2.2 Children's Grief Programming        9
  2.3 Evaluating Children's Grief Programming      11

Chapter Three: Research Methods          14
  3.1 Research Methods          15
    3.1.1. Qualitative research          15
    3.1.2. Phenomenological research         17
  3.2 Data Gathering Methods         18
  3.3 Population Sampled          20
    3.3.1. Participant Profile         21
    3.3.2. Camper Profile          22
  3.4 Ethical Considerations          22
  3.5 Data Analysis Procedures         24
  3.6 Limitations          25

Chapter Four: Findings/ Outcomes          27
  4.1 Introduction           27
  4.2 'W5' Demographics          28
  4.3 The Experience           28
    4.3.1. Surrogate support          29
    4.3.2. Normalizing grief          31
    4.3.3. Continuing bonds          33
    4.3.4. Bittersweet          34
  4.4 The Evaluation           35
    4.4.1. The grief haze          36
    4.4.2. Convenience          37
    4.4.3. Feedback          38
    4.4.4. Triangulation          40
  4.5 Essence of Findings          40

Page

Abstract                                          i
Acknowledgements            ii
Table of Contents            iii

Chapter One: Introduction           1
  1.1 Context             1
  1.2 Purpose            3
  1.3 Objectives of Project          4

Chapter Two: Literature Review          5
  2.1 Children's Grief           5
  2.2 Children's Grief Programming        9
  2.3 Evaluating Children's Grief Programming      11

Chapter Three: Research Methods          14
  3.1 Research Methods          15
    3.1.1. Qualitative research          15
    3.1.2. Phenomenological research         17
  3.2 Data Gathering Methods         18
  3.3 Population Sampled          20
    3.3.1. Participant Profile         21
    3.3.2. Camper Profile          22
  3.4 Ethical Considerations          22
  3.5 Data Analysis Procedures         24
  3.6 Limitations          25

Chapter Four: Findings/ Outcomes          27
  4.1 Introduction           27
  4.2 'W5' Demographics          28
  4.3 The Experience           28
    4.3.1. Surrogate support          29
    4.3.2. Normalizing grief          31
    4.3.3. Continuing bonds          33
    4.3.4. Bittersweet          34
  4.4 The Evaluation           35
    4.4.1. The grief haze          36
    4.4.2. Convenience          37
    4.4.3. Feedback          38
    4.4.4. Triangulation          40
  4.5 Essence of Findings          40
4.6 Outcomes

Chapter Five: Discussion

Chapter Six: Recommendations
   6.1 Recommendations
   6.2 Pilot Evaluation

Conclusion

References

Appendices
   Appendix A: Ethics Approval
   Appendix B: Letters of Contact
   Appendix C: Informed Consent
   Appendix D: Interview Guide
   Appendix E: Pilot Evaluation - Child Pre-test
   Appendix F: Pilot Evaluation - Caregiver Pre-test
   Appendix G: Pilot Evaluation - Child Initial Post-test
   Appendix H: Pilot Evaluation - Child Second Post-test
   Appendix I: Pilot Evaluation - Caregiver Post-test
Chapter One: Introduction

Professionally, very few encounters have impacted me in the way that working with bereaved children has. While completing my undergraduate degree in social work, I had the opportunity to work for Regina Palliative Care Inc. for a summer job. As excited as I was to ‘land a good job’, I had no idea about the experiences that I would have, the colleagues I would come in contact with, and the impact that this position would have on shaping how I currently practice social work. During this time period I had the privilege of assisting with the planning of Caring Hearts Camp as well as the opportunity to volunteer at Caring Hearts Camp. This was a life changing experience. I was not prepared for the lessons in living that I was about to learn from sixty grieving hearts of children between the ages of four and seventeen. The raw emotion, the honesty, and the courage taught me about a population that has, until recently, been overlooked in the area of death, dying and bereavement. I knew this was something magical, and I knew that I wanted to be a part of it.

1.1 Context

Six years after first volunteering with Caring Hearts Camp, and having completed another university degree, I am now employed as a Bereavement Counsellor with Greystone Bereavement Centre (GBC). Within my professional role, I continue to work with children and provide them with assistance as they navigate through the complex nature of their grief. I have had the opportunity to work with GBC’s children’s programming; specifically Caring Hearts Camp. Please note that within this report, the term Camp will be used to refer to Caring Hearts Camp.

For the purpose of this research practicum, it is necessary for the reader to understand the context of the Camp experience. Below, I have included a brief explanation of what Caring Hearts Camp is, and the activities that are completed throughout the retreat. Understanding the
context of Camp will assist with understanding the goals and findings of this research practicum. Further, I have also included a camper profile in Chapter Three. This profile provides an explanation on the general demographics of the children who have attended Camp.

*Caring Hearts Camp* is offered by GBC twice a year. A three day retreat is offered in the spring (May) and a two day retreat is offered in the fall (October). Both retreats are for bereaved children between the ages of four and seventeen within Saskatchewan who have experienced the death loss of a family member. In order for Camp to provide support to as many children as possible, a limit is placed on the numbers of children attending each Camp. Campers attend based on a referral, or on an application. From the initial referral, an intake assessment is completed over the telephone. The GBC Coordinator then reviews all applications prior to offering registration to each child. The camp is free for all in attendance.

Campers stay overnight and are assigned to a cabin group and to a corresponding grief group. The cabin groups are gender specific and the grief groups are co-ed. Therefore, each child will sleep in the same cabin as members of their group as well as with the adult volunteers who have been in their group. This creates a safe environment for the children. Each group includes: a facilitator, a co-facilitator, support workers and the campers. The children and staff participate in scheduled activities during camp which alternate between art activities, grief activities, games, sports and music therapy.

The Camp volunteers are professionals that vary from, but are not limited to: teachers, university students, social workers, nurses and employees within the Regina Qu'Appelle Health Region. Each volunteer is required to attend the volunteer training session specific to Camp. A manual, as developed by the GBC, is provided to each volunteer. The training assists with facilitating the grief activities that are incorporated into the scheduled activities at camp. Some of these activities include: painting a feelings mask, playing board games that explore questions
about grief, burden burning at the evening fire, butterfly releases, a balloon release and a memorial ceremony.

Personally and professionally, this continues to generate my most profound experiences. As a volunteer, I was required to fill out numerous evaluations on the programs offered by GBC, and each time I commented I hoped that the children learned as much from myself and the program as I did from them. As a professional, I have become involved with the 'behind the scenes’ work to implement and facilitate the various groups. In my new role as one of the professionals within the various programs, my curiosity and interest in the children and teen programming, as it pertains to evaluation, has ignited. In terms of children and teen programming, I want to know what works, what does not work, and why it does not work. I want to know if the programming at GBC has helped the children in their grief journeys and if not, why that is. This curiosity has shaped this research practicum.

1.2 Purpose

When making the decision further my education, I knew that I wanted to continue within the field of social work and that I wanted my focus to be in an area that would contribute to the field of social work. With front line professional experiences that have taken me through the many facets of death, specifically traumatic death on the Critical Care units in the hospital, perinatal deaths in the Labour and Delivery Unit, and the stigmatized deaths of chronic diseases with Aboriginal Health Home Care; I became aware of the discomfort many people feel when facing another's imminent death. As a social worker, I have had colleagues and classmates that have felt ill prepared or uncertain as they worked with both individuals who were dying, and with the family members of the deceased. As I continued to dig deeper, the research supported the discomfort that many professionals face when working with death in our death denying society. From these experiences, I knew that death, dying and bereavement was an area that I
wanted to know more about, and an area that needs more attention in the field of social work.

As a graduate student, I have had the opportunity to shape course selections and course assignments to further enhance my knowledge in the area of children's grief, specifically in the area of evaluation. This research practicum was initiated because the children's programming at GBC had never undergone a formal evaluation. From this, multiple questions and conversations erupted. Why? Where does one start? What needs to be evaluated? How can these programs be evaluated? From these questions, I began where any researcher should begin, with the literature. By delving into the literature and navigating my way through hundreds of pages of inquiry, the issue under consideration was constructed. As the literature review in the next chapter will reflect; the area of evaluating children's grief and bereavement programming is complex, developing and limited. This research practicum was completed with the intention of providing recommendations to develop an evaluative tool for children and teen grief and bereavement programming at Greystone Bereavement Centre.

1.3 Objectives of Project

Research from this practicum will provide recommendations to inform the development of an evaluative tool for children and teen programming at GBC. This was accomplished through the following research objectives: 1) The completion of a comprehensive literature review pertaining to teen/children’s grief, teen/children's grief and bereavement programming and current evaluations of teen/children's grief and bereavement programming; 2) The facilitation of interviews with the primary caregivers of children and teens who have attended various programming at GBC; 3) A review of past evaluations as they pertain to programming at GBC, along with an analysis of the suggestions and recommendations that were offered in those evaluations; and 4) A provision of recommendations for the development of a tool for evaluating the teen and children’s programming at GBC. Further, this research practicum was completed
with the intention of contributing to the knowledge and education within the area of children and teen grief and bereavement.

Learning objectives for this project were identified as follows: 1) To gain knowledge and understanding of the complex nature of grief and bereavement for teens/children; 2) To gain knowledge and understanding of the current programming offered for children and teens in the context of grief and bereavement work; 3) To gain knowledge and understanding of the impact of grief and bereavement programming on teens/children long term; and 4) To gain knowledge and understanding of how grief and bereavement programming for teens/children is evaluated. By immersing myself in the literature, by engaging in the interviews and reviewing past evaluations, the above learning objectives were accomplished.

**Chapter Two: Literature Review**

A literature search was conducted using such terms as: “bereavement”, “children”, “teens”, “grief”, “camp”, “programming”, “support” and “retreat”. I searched for a combination of documents that included program evaluations, research papers, and program reviews relevant to children and teen grief and bereavement programming. Within this literature review I have provided sub-headings based on common themes found in the majority of the articles that were of relevance to this project. Please note that, for the purpose of the literature review, the term ‘children’ will also be inclusive of the ‘teen’ population. All relevant articles, in reference to programming, included children and teenagers under the heading ‘children’. Therefore, the three headings of this section are: *Children’s Grief, Children’s Grief Programming* and *Evaluating Children’s Grief Programming*.

2.1 Children’s Grief

“Anyone old enough to love is old enough to mourn” - Alan Wolfelt
Due to the complex and complicated nature of children’s grief, it is important that one understand children’s grief before trying to evaluate it. As Canadians, we currently live in a death-defying society; medical and technological advances have generated a focus on finding a cure and preserving life (Potts, Farrell & O’Toole, 1999). Death, in all of its complexities, can be further complicated by how it is experienced by the individual. For children, they are often excluded from the death proceedings which results in a lack of knowledge about what is happening and why (Stokes, Wyer & Crossley, 1997). Further, if children have gaps in their knowledge, they often make things up to fill in these gaps, which can be far worse than the reality (Stokes et al., 1997). For this reason, it is important for any grief and bereavement programming to increase the child’s understanding of death.

Children are at the mercy of their caregivers. In the context of grief and bereavement, this has significant impact on their own grief process. Their caregiver controls what is discussed, how it is discussed, as well as access to different support programming. Caregivers have the control to shape the grief process for a child and this can be complicated when adults try to shield children from the realities of death (Charkow, 1998). Further, Kramer and Sodickson (2002) found that the manner in which the surviving parent coped with the death loss affected how the children worked through their tasks of grieving. Davies (2002) found that open communication and parental support are crucial in supporting children as they adjust to the loss. When children are denied the opportunity to talk about death and their reactions, they may suffer needlessly (Davies, 2002).

Children's grief and fear may be compounded by witnessing parents' distress and vulnerability along with the explosive nature of their parents' feelings; children often attribute their parents' behaviour to some fault or failing of their own (Packman, Horsley, Davies & Kramer, 2006). Further, because a child usually has had little to no previous experience with
grief, they do not understand the depth of their parents' grief and the duration of this grief. This may cause them to become both overwhelmed and impatient with their parents' grief reactions (Packman et al., 2006).

The family unit has a significant role and impact on children's grief and therefore, must be taken into account. Walsh and McGoldrick (1991) stated that “of all life experiences, death poses the most painful adaptational challenges for the family as a system and for every surviving member, with reverberations for all other relationships” (p. 3). The family’s ability to restructure and readjust after the death can affect how each of the members adapts to the loss. Open communication and family cohesiveness are of paramount importance to this process.

Understanding how a child grieves, and the factors that influence grief, are imperative for program development in this area. There are a multitude of variables that can affect the grieving process. Charkow (1998) suggests that the following variables can have an impact: the relationship the child had with the deceased and the significance of that relationship; the way in which the death occurred; the child’s personality and previous death experiences; the child’s chronological age and developmental level; and the availability of support. Providing children with a safe environment from which they can openly express grief creates positive coping strategies. Kirwin and Hamrin (2005) found that children who were not supported in the early phases of grieving were at high risk for complicated grief. Creed, Ruffin, and Ward (2001) explained that, along with complicated grief, can come elevated symptoms of distress including pain, sadness, anger, bewilderment, confusion, sleep disturbances, and an inability to focus on schoolwork.

For children, grief typically manifests itself in behaviour problems, depression and fear. For a child, this is complicated by their limited understanding of the grief process. Creed et al. (2001) compiled an extensive list of symptoms of children experiencing grief that includes
loneliness, low self esteem, the inability to concentrate in school, reduced peer interaction, and trouble sleeping. For a child who does not understand that what they are experiencing is related to grief, this can be extremely confusing and troublesome.

To further complicate the grieving process for children, Nabors et al. (2004) found that, not only do children experiencing grief display a wide variety of problems, but these problems may endure for extended periods of time. Some grief symptoms may be manifested for up to five years or longer (Nabors et al., 2004). But, despite the multiple problems and intensity of experience, the consensus within the literature is that children are capable of resolving their grief (Schachter, 2007). Steen (1998) found that children who receive compassionate care and emotional support after the death of a loved one can be helped to grow emotionally without becoming maladjusted. Further, Potts et al. (1999) found that a child who is validated as a griever can begin to “rebuild and renew self esteem, can grow in understanding of self and others, and can process and accommodate, in a positive way, his/her own grief if given the opportunity to do so” (p. 52). Attendance at bereavement support groups and bereavement camps can provide professional and peer support for the child and are seen as helpful for bereaved children (Creed et al., 2001).

As professionals, whether it is in front line work or behind the scenes conducting research, the area of children’s grief and bereavement requires continued exploration and development. As I engage in the process of recommending an evaluative tool, understanding how a child grieves provides insight into how their needs can be better addressed. Potts et al. (1999) concluded their study with the following statement:

The acquired wisdom, humanity and compassion of these young people will become their gift to society, provided we take courage and give them the gift of acceptance and permission to grieve, to remember and to move on (p. 55).
While it is impossible to shield and protect children from the hardships of death and grief, it is possible to create an environment that is both inviting and safe for children to express their feelings and ask questions about death and loss (Charkow, 1998).

2.2 Children’s Grief Programming

Bereavement programs, specifically for children, are a recent development in the area of grief and bereavement. Kramer and Sodickson (2002) found that the lack of services is related to the myths about grieving children and the longstanding debate about children’s capacity to grieve. Creed et al. (2001) found that this perpetuated the problem as children’s feelings were being misunderstood or neglected resulting in a lack of appropriate outlets for the expression of their feelings. As research in the field of bereavement programming has increased, community-based programs for bereaved children are becoming more common and popular. But, research on the effectiveness of community based programs for children coping with the loss of a loved one is needed (Nabors et al., 2004).

Bereavement camps provide a safe environment for children to learn about grief and to express their own feelings. Christ, Siegel and Christ (2002) suggest that the opportunity to share feelings of grief, in a supportive environment among peers who have endured the death of a loved one, is one of the most powerful aspects of camp. These opportunities allow the children to interact with other bereaved peers, helping them realize that they are not alone (Schachter, 2007). Kramer and Sodickson (2002) state that one of the major goals of support programs for children is to promote a normal grieving process and adjustment to the loss of a loved one.

The various camps and programs cited in the research shared common activities that were used to facilitate the children’s grief. These activities included sharing circles, creating memory books and boxes, music therapy, art sessions, and a ritual of remembrance/memorial observance (Schachter, 2007; Nabors et al., 2004; Creed et al., 2001). Schachter (2007) found that children
enjoyed the camp experience and learned that it was acceptable to express one’s feelings. Spirito, Foreman, Ladd and Wold (1992) found that participating in the summer camp improved support for children and helped them to express, remember, and actualize their feelings regarding their sibling’s terminal illness.

Children’s bereavement programs are also valuable for the entire family dynamic. As death puts continuous strain on the family’s existing coping system, child support groups can be a useful surrogate support system (Kirwin & Hamrin, 2005). Further, this type of experience offers an important outlet for children who may not discuss their feelings with family members in order to protect them from experiencing additional emotional distress (Reynolds, Miller, Jelalian, & Spirito, 1995). Through the continued education surrounding children’s grief and the development of bereavement programming, an environment has been created that will continue to facilitate the grief process of children. This was emphasized by Potts et al. (1999) in the statement: “permission and honesty are the cornerstones in supporting bereaved children” (p. 55).

Creed et al. (2001) utilized staff evaluations and a comprehensive literature review to construct goals for children's grief and bereavement programming. The following four goals provide a strong framework for what children’s grief and bereavement programming should strive to achieve: “1) Reduce feelings of isolation 2) Assist children with the appropriate expression of their grief 3) Educate children about the grief process 4) Facilitate children in moving forward in their grief process” (Creed et al., 2001, p. 181). Ruffin and Zimmerman (2010) have also developed a model of children's bereavement therapy that includes the following seven objectives:

1) To help children “normalize” their grief,

2) To aid the development of coping mechanisms and to model self soothing techniques,
3) To aid children in acquiring the language necessary to express emotions and grief,
4) To aid the process of individuation as children acquire the skills to manage new and complex emotions independent of parent and guardian,
5) To acquire an appreciation of remembering and honouring the past,
6) To begin the lengthy process of reintegration of the memory of the lost person into children's everyday experience, and
7) To provide education to adults about the importance of helping children with grief work (p. 298).

This model focuses on assisting children to acquire the language necessary to express their emotions within their grief (Ruffin & Zimmerman, 2010). Without the proper language, children are unable to share what they are thinking and feeling with the adults in their lives; thus limiting the ability of the adults to provide necessary support. With these objectives comes the need for evaluative measures that provide evidence to support the impact of the interventions.

2.3 Evaluating Children’s Grief Programming

Although there has been increasing interest in the evaluation of adult bereavement interventions, there have been limited evaluations of interventions with bereaved children. An evaluation should attempt to answer the question: ‘is the intervention achieving its objectives?’ (Stokes et al., 1997). While compiling this literature review, it became evident that evaluative measures and empirical evidence are lacking in the area of children’s grief and bereavement programming. The need to evaluate children’s bereavement programming is paramount, but there is no consensus as to the most appropriate way to do this.

This literature review has highlighted that current evaluations are focused around post-camp evaluations as completed by the children, parents and staff. Creed et al. (2001) and Potts et al. (1999) used evaluations that combined a Likert-type scale combined with open ended
questions. These evaluations supported a positive experience at camp and indicated that the children and caregivers are open to, and responsive to, questions about their experience. However, this approach to evaluation lacks comparative data. Nabors et al. (2004) conducted a similar evaluation, but had the parents complete an evaluation prior to their child going to camp and then once again after their child returned. Although this study provided comparative data, both studies lacked a control group.

Curtis and Newman (2001) completed an empirical literature review and found numerous qualitative reports on the benefits of intervention but found little empirical evidence on the effectiveness of community based interventions for support services for bereaved children. Commonalities in limitations within the studies reviewed included high attrition rates, short pre/post intervention time scales, and problems with representation (Curtis & Newman, 2001).

Schillings, Koh, Abramovitx and Gilbert (1992) evaluated a group intervention for bereaved children using a pre and post intervention test to measure children’s depression and concept of death. The evaluation found that the children’s concept was more mature after the intervention, but identified no discernible change in depression levels. Because no control group was used, it remains questionable if the intervention itself caused the changes, or if the changes were merely related to the passage of time. An uncontrolled design for evaluation is argued as acceptable by Schillings et al. (1992) due to the lack of sophisticated intervention studies with bereaved children, and due to the belief that randomization for this population would be unethical. Stokes et al. (1997) state that this is a problem when not using an experimental approach to evaluation; although the data can be observed and described, any changes or causes are not able to be explained.

Several key issues have emerged when considering the evaluation of children’s bereavement programming. Stokes et al. (1997) found that, if the evaluation does not have a
control group, it is not possible to conclude that the changes were due to the intervention itself. Experimental and longitudinal studies have been suggested within the research to address limitations due to the lack of a control group when evaluating children and teen grief and bereavement programming. Experimental studies pose challenges in the area of children’s bereavement programming because of ethical considerations. It is unethical to refuse a needed service to a child based on the premise of evaluation. Stokes et al. (1997) suggest a quasi-experimental approach with possible multi-centred research protocols.

Curtis and Newman (2001), in their comprehensive review, suggested the inclusion of both qualitative techniques (pre and post intervention interviews) in conjunction with standardized instruments that measure specific program objectives. Stokes et al. (1997) identified a similar approach in the Harvard Bereavement Study. In this study, qualitative methodology was combined with standardized assessments of locus of control, self esteem, children’s understanding of death, and a child behaviour checklist.

Silverman and Worden (1993) are also committed to the use of qualitative methodology alongside standardized assessments. But, due to the multitude of interacting variables that impact a child’s grief process, they felt there is a need to shift from traditional forms of measurement which emphasize the presence and absence of symptoms or signs of psychological disturbances, to more dynamic terms that emphasize change and adaptation (Silverman & Worden, 1993). Because children are at the mercy of their caregivers, Stokes et al. (1997) suggest incorporating a measure of family functioning as well. A child is a part of a dynamic family system, with grief affecting different family members. Individual reactions are strongly influenced by those of the family.

In a process of evaluating children’s grief, Stokes et al. (1997) suggest the implementation of The Dual Process Model as developed by Stroebe and Schut (1999). This is a model of grief
that recognizes that both expressing and controlling feelings is important. Grief is a dynamic process where one alternates between focusing on the loss of the person who has died (loss-oriented) and avoiding that focus (restoration-oriented). Oscillation is the term used to describe the movement between loss-orientated and restoration-orientated coping behaviours (Stroebe & Schut, 1999). Within children and teen programming, grief activities would be labelled as loss-orientation, and fun activities would be labelled as restoration-orientation. Research has suggested that a balance between the two is suggestive of a typical grief process (Stroebe & Schut, 1999). Therefore, a process that measures the balance between loss-orientation and restoration-orientation may provide an effective method for evaluation.

There are few life events that have a greater impact on a child’s life than that of the death of a family member. As bereavement services and programming continue to develop for children, there is a need to evaluate and measure both the outcomes and impacts of these services. The development of an evaluative tool for children’s bereavement programming has been reiterated by the literature as complex, but necessary. The challenges of evaluating such services cannot deter the process from occurring. However, by combining previous research whilst integrating current findings, it is possible.

The compilation of the above literature review has set the framework from which the developmental project was constructed. What follows is a summary and discussion of the project that I have chosen to develop based on suggestions from the literature and the needs of Greystone Bereavement Centre.

Chapter Three: Research Methods

There is no burden of proof. There is only the world to experience and understand. Shed the burden of proof to lighten the load for the journey of experience.
3.1 Research Methods

A review of the literature pertaining to children’s grief, grief counselling, and evaluating programming for children as it pertains to grief and bereavement, was conducted. The findings of this literature review are discussed in detail in Chapter Two. By using the knowledge from the literature, the framework for this research practicum was developed.

Because the programs at GBC have never undergone a formal evaluation, this process posed to be both beneficial and challenging. As the sole investigator, it enabled a platform from which I could delve into the research, start from scratch, and develop recommendations for a framework of an evaluative tool without having a formal set of policies, rules and/or guidelines used from previous evaluations. This was challenging because I was starting with the research and only the research. Evaluating grief and bereavement is truly complex, and many days I felt that I was attempting to inform what was impossible. By starting with, and trusting, the research, I formulated the methodology for this practicum and carried it through.

This section examines the chosen methods that were utilized to inform this research project entitled, *Measuring Success: Creating an Evaluation Tool for Children and Teen Bereavement Programming at the Greystone Bereavement Centre*. This section addresses methodological procedures for this research project and includes a discussion of qualitative research, phenomenological research, data gathering methods including purposive sampling and qualitative interviewing, population sampled, ethical considerations, data analysis and study limitations. A discussion of the above topics will provide the reader with a framework from which this practicum was constructed.

3.1.1 Qualitative research

For the purpose of this practicum, qualitative research was the selected method of research.
Cresswell (2007) defines qualitative research as:

Beginning with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem... The final written report or presentation includes the voice of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call for action (p. 37).

Qualitative methods typically produce a wealth of detailed data about a smaller number of people and cases. Kibel (1999) provides the following summary reflective of qualitative inquiry:

For programs engaged in healing, transformation, and prevention, the best source and form of information are client stories that we discover how program staff interact with clients, with other service providers, and with family and friends of their clients to contribute to outcomes, and how the clients, themselves, grow and change in response to program inputs and other forces and factors in their lives. There is a richness here that numbers alone cannot capture. It is only for a story not worth telling, due to its inherent simplicity, that numbers will suffice (as cited in Patton, 2002, p. 13).

By interviewing caregivers of children and teens who have attended programming at GBC, I committed to using the method that was the best fit for the topic under research and for the individuals who volunteered to participate. Cresswell (2007) stated that “qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive material practices that make the work visible” (p. 37). Within qualitative research, the researcher is the instrument. The credibility of qualitative methods, therefore, hinges to a great extent on the skill, competence, and the rigour of the person doing the field work (Patton, 2002). Guba and Lincoln (1981) as cited in Patton (2002) comment on this aspect of qualitative research:

Fatigue, shift in knowledge, and cooptation, as well as variations resulting from differences
in training, skill, and experience among different “instruments”, easily occur. But this loss in rigor is more than offset by the flexibility, insight, and ability to build on tacit knowledge that is the peculiar province of the human instrument. (p. 14)

Researchers must recognize the importance of the subjectivity of their own lens and acknowledge the powerful position they have in the research (Cresswell, 2007). Further, it is imperative that the participants are recognized as the true owners of the information collected (Cresswell, 2007). Through the acknowledgement of the participants as the true owners of the information collected, the researcher has also engaged in ethical practice with the participants.

3.1.2 Phenomenological research

The phenomenological approach to research was chosen as the qualitative research method for this research practicum. The previous section discussed participants as the true owners of the information collected. Within phenomenological research, the participant is also the expert. Because grief is a unique and individual experience, phenomenology provided the most appropriate avenue in understanding the experience and opinions of caregivers whose children attended grief programming at GBC as it pertains to participating in, and completing, an evaluation. In phenomenology, the researcher transcends or suspends past knowledge and experience to understand a phenomenon at a deeper level (Cresswell, 2007).

Within research, phenomenology is utilized to gain a deeper understanding of the nature or meaning of one's experiences; how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others (Patton, 2002). For the purpose of this research practicum, the phenomenological approach was essential in formulating the interview questions and completing the data analysis. This practicum was not completed with the intent to describe a new phenomenon, but rather, to better understand the experience of Camp through the eyes of the caregivers and how that can impact the development of an evaluative tool for children’s
grief. As a researcher, it is required that one bracket out their own experiences and personal biases. Bracketing is a process of setting aside one's beliefs, feelings, and perceptions to be more open or faithful to the phenomenon (Patton, 2002). As explained by Cresswell (2007), “although studying in one’s own ‘backyard’ is often convenient and eliminates many obstacles to collecting data, researchers can jeopardize their jobs if they report unfavourable data or if participants disclose private information that might negatively influence the organization or workplace” (p. 122). As an employee of GBC conducting research at GBC, it was necessary to acknowledge and attempt to bracket out those experiences. This posed as a limitation as it is not known what, if any, sharing was withheld by the participants because I was an employee of GBC. Although the use of multiple researchers would address this limitation, it was not possible for this particular study.

3.2 Data Gathering Methods

Two methods of data collection were used for this research practicum; interviews, and the review of secondary data in the form of past evaluations of children and teen programming at GBC. The use of multiple methods of data, as opposed to a single method, served to increase the authenticity and trustworthiness of the research (Patton, 2002). The interviews were conducted between March 8th, 2011 and March 29th, 2011 with primary caregivers of children who had attended programming at GBC. A total of eight interviews were completed, seven of which were conducted by telephone, and one which was conducted face to face. Each interview averaged one hour in length. Although in-person interviews were the preferred method by the researcher, telephone interviews were the preferred method by the participants as it was more convenient and manageable within the schedules of their daily lives. As Patton (2002) states: “the quality of the information obtained during an interview is largely dependent on the interviewer” (p. 341).
Because the majority of interviews were completed over the phone, data triangulation was limited due to the lack of opportunity for observation.

An interview guide was developed to ensure that the same basic lines of inquiry were pursued with each person interviewed (Patton, 2002). The interview questions, which can be located in Appendix D, are open ended questions with no forced choice answers. This format provided participants with the opportunity to elaborate or expand as they thought necessary and to respond in any way they felt appropriate. This allows freedom for the interviewer to build a conversation within a particular subject area, to work questions spontaneously, and to establish a conversational style all the while focusing on a particular subject that has been predetermined (Patton, 2002). For many of the questions, with the majority of participants, this format encouraged additional comments and elicited further questions.

The interview questions were developed by the researcher in conjunction with input from the Academic Supervisor and Field Supervisor of this practicum. The literature also shaped the format of the questions; literature on children's grief, literature on children's bereavement programming, literature on evaluating children's bereavement programming and literature on developing evaluative tools for bereavement were utilized to inform the interview questions. The questions and format for the questionnaire were developed based on the following literature recommendations: the use of qualitative research and data collection (Curtis & Newman, 2001; Silverman & Worden, 1993), the use of open ended questionnaires (Stokes et al., 1997) and the need for a pre and post test from both the children and the caregivers (Schillings et al., 1992; Silverman & Worden, 1993). Further, from an examination of the literature, I became aware of the Dougy Centre in the United States. Through email contact with Dr. Daniel Coleman of the Dougy Centre, I was able to access samples of evaluations he had conducted for the Centre as well as his rationale behind the questions. Dr. Coleman, by sharing his documents, was essential
in providing a visual to what a completed evaluative tool for GBC may encompass. This
provided understanding, depth, and a vision for how the data from the interviews could and
would be used.

Previously collected evaluation forms were also accessed as secondary data from GBC.
These evaluations were accessed once ethics approval was received on January 20th, 2011
(Regina Qu’Appelle Health Region and the University of Regina). These evaluations are
anonymous and provided information to better assist the researcher in developing the evaluative
questionnaire. Because some of the participants had completed evaluations in the past,
understanding what questions they had been asked helped me to explore that data with the
current participants in greater depth.

3.3 Population Sampled

Caregivers of children and teens who have attended GBC programming were selected as
the population to be sampled as they would be the population required to be a part of the
evaluation once implemented by the Agency. Demographic information was not required or
requested. However, due to the format of the questions, various demographics were shared: the
gender of the interviewees, the community of residence of each participant, the nature of the
death loss experienced, and the ages and gender of the children who attended the various
programming opportunities at GBC.

Purposeful sampling was the strategy that was utilized to develop a population sample size.
Purposeful sampling focuses on “selecting information- rich cases whose study will illuminate
the questions under study” (Patton, 2002, p. 230). Because GBC has a record of the children
who have attended programming since 2008, and the contact information of their caregivers, this
was used to develop the master contact list. Permission was granted by both the Regina
Qu'Appelle Health Region and the University of Regina's Ethics Committee to access the
mailing addresses of the caregivers for the purpose of this study. In order to develop the largest sample size, the years 2009 and 2010 were selected. The Operations Assistant at GBC then developed a master list of caregivers whose children attended children and teen programming at GBC during the selected years. A total of one hundred and sixteen caregivers and their corresponding addresses were generated from the database. It was identified that, of that 116, one caregiver had since been deceased which left the final list serve at 115 caregivers. Letters were then mailed out to the corresponding addresses in the database. Of the 115 letters mailed, 7 letters were returned as undeliverable. As indicated in the initial letter of contact (Appendix B), potential participants were given a ten day period to opt out of the study. This provided participants an opportunity to have their names removed from the master contact list prior to the list being released to the principal investigator.

Eight participants contacted the principal investigator expressing interest to participate in the research practicum. This constitutes a response rate of 7.4%. Due to an initial response of eight participants, which was within the parameters of the practicum’s required sample size, no further contact from the list serve was required by the principal investigator. There were no participant requirements based on their type or level of education, occupation, gender, age, religious affiliation or social status. All participants gave permission to the researcher to be contacted with further questions as needed. Below, I have included a brief profile of the participants within this practicum as well as a profile of the children and teens who attend Camp.

3.3.1 Participant profile

All eight interviewed participants were the female caregivers of the children who attended Camp. The length of time since their child experienced the death ranged from six months to two years. Upon reflection, further research could be completed that focuses on a gender analysis and the high response rate of female caregivers versus male caregivers. On speculation alone, this
could impact the response rate for the evaluation based on if the primary caregiver is male or female. Participants also varied within their current residences; there was a variety between those in urban setting and those in rural settings. This was extremely helpful when determining the best method to contact the greatest variety of potential participants.

3.3.2 Camper Profile

As briefly discussed in Chapter One, children and teens who attend Camp range between the ages of four years old and seventeen years old. Gender differs for each camp, but typically the ratio is 50 percent male campers and 50 percent female campers. Each child has experienced a death loss, the death loss typically occurs within three months to one year of the child attending camp. The deceased range from a caregiver, sibling, grandparent, extended family, close friends and multiple losses. The cause of death typically ranges within the following ten categories: Cancer, Suicide, Homicide, Motor Vehicle Accident, Accidental, Heart conditions, other illness, Sudden death, Neonatal death, and Drug and/or Alcohol overdose.

3.4 Ethical Considerations

Ethics approval for this research project was granted by both the Regina Qu'Appelle Health Region's Ethics Committee and the University of Regina's Ethics Committee (Appendix A). As the principal investigator, I completed a joint application that required information as it pertains to the following sections: Identification, Department Approvals, Summary of Research Proposal, Studies Involving Human Subjects, Project Details, Informed Consent, Privacy Protection, Investigator Profile and Attachments. Approval for this application was received January 20th, 2011.

Ethical considerations extend beyond gaining approval from necessary committees, it is required that sensitivity to vulnerable populations, imbalanced power relations and the potential for placing participants at risk is acknowledged and respected (Hatch, 2002). Although the
population that I was collecting data from were not deemed to be vulnerable, and the risk of the study was considered to be minimal, I was mindful of the sensitive nature of grief and bereavement. As the researcher, I needed to create a platform that honoured the experiences of each individual and was a safe place within which participants could share their stories and experiences. As the sole researcher, I was committed to fulfilling all ethical obligations to this research practicum.

Ethically, seeking consent, maintaining confidentiality, and protecting the anonymity of the individuals who were interviewed, is of extreme importance. Within this research practicum, each participant provided a verbal informed consent which was audio recorded. The consent form is attached in Appendix C. The consent form informed participants of the purpose of the project, which was to gather information to be used in developing an tool that could be used to evaluate children and teen programming offered at Greystone Bereavement Centre. They were also informed of procedures, potential risk and benefits of participation, their right to withdraw, and contact information for any questions, concerns or follow-up. Confidentiality was also explained on the consent form. Further, participant interviews were also de-identified as a method to assure confidentiality. I was unable to promise anonymity due to the small size of both Greystone Bereavement Centre and the population that it serves. Although data would be de-identified, I could not guarantee that any quotations used could not be linked to an individual from another member of the community or the organization. I explained this to each participant and no concerns were brought forth.

Informed consent was received from participants prior to initiating each interview. Once the researcher was contacted by the participant, the researcher then mailed (either electronically or via ground mail) a copy of the consent form to be reviewed by the participant prior to the interview date. At this time, participants were also encouraged to contact the researcher should
any questions or concerns arise. At the time of interview, the researcher provided an introduction and reviewed the purpose of the interview. The researcher then confirmed that the participant had the opportunity to review the consent form. Once the participant stated that they had reviewed the consent form and they had no questions, the researcher then read the last paragraph aloud and the participant would state “I consent”.

3.5 Data Analysis Procedures

All interviews were conducted and transcribed verbatim solely by the researcher. Patton (2002) and Cresswell (2007) both provide suggestions for phenomenological data analysis based on the work of Moustakas (1994). The work of Moustakas (1994) has been used to inform the analysis of the data in this study. The following seven steps were taken in the data analysis: epoche; phenomenological reduction; horizontalization; meaning unit organization; textural description; structural description; and composite description. Each of these steps will be discussed in some detail.

The first step in the data analysis, ‘epoche,’ is essentially the process of setting aside one’s own everyday way of knowing, as was discussed previously by Patton (2002). Phenomenological reduction is the first step in reviewing the transcripts. During this stage all written transcripts are read several times to develop an overall feeling and understanding for them (Cresswell, 2007). By paying attention to the language used by the participants during this stage of the data analysis I was able to gain greater insight into the essence of their perceived experience. I then proceeded to dissect the data, work to understand what the respondents were revealing about the phenomenon, and confront the terms and meaning of what the respondents shared (Patton, 2002). After having reviewed the transcripts several times in detail, I was able to begin the process of data horizontalization. Data horizontalization, as defined by Moustakas (1994), is the process of “laying out all data for examination and treating the data as having equal
weight; that is, all pieces of data have equal value at the initial data analysis stage” (p. 96).

Through the process of horizontalization, I extracted a list of equally weighted, non-repetitive statements from all of the participants (Cresswell, 2007).

The interview transcripts were the source for content/theme analysis. “Content analysis is used to refer to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meaning” (Patton, 2002, p. 453). The following ‘themes’ were derived from the content analysis: *Surrogate Support, Normalizing Grief, Continuing Bonds, Bittersweet, the Grief Haze, Convenience, Triangulation and Feedback.*

The next step in the data analysis process was the textural description, which is a description of ‘what’ was experienced, including verbatim examples (Cresswell, 2007). Following the textural description was the development of the structural description, which describes the ‘how’ of the experience. These descriptions are constructed through the use of direct quotations from the participants. In concluding the data analysis, I wrote a composite description of the phenomenon which incorporated both the structural and textural descriptions. The composite description provides “a synthesis of the meanings and essences of the experience” (Patton, 2002, p.486). It should also be noted that my own personal interpretation was unavoidable in the analysis and interpretation of the data. To address this limitation, verbatim statements from the participants have been integrated throughout the next chapter. The statements shared from the participants are used to reflect the various themes that emerged within the data analysis process. These statements are shared with the intent that the true voices of the participants are properly conveyed, and the experience that each person shared is captured.

### 3.6 Limitations

Although limitations have been discussed throughout this paper, it is important to readdress
those that posed particular challenges to this study. Response rate, validity, ability to generalize data, and data triangulation are limitations that will be briefly discussed in this section.

Although there are no rules for sample size in a qualitative study, I was initially concerned with the low response rate and the potential that such low numbers of participants might impact the ability to generalize the data as well as the validity of the data. As the interviews progressed, it became apparent that the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selection and the observational/analytical capabilities of the researcher than with the sample size. (Patton, 2002, p. 245)

Within the first two interviews, redundancy became evident and common themes were already beginning to emerge. This validated and supported what was outlined in much of the literature.

As the sole researcher, triangulation was integrated into the study design to increase credibility and decrease vulnerability to errors. Because only one participant was able to be interviewed in person, this limited the ability for observation. Time constraints for both the participants and the researcher limited the opportunity to schedule face to face interviews. Although the information gathered in the telephone interviews were rich with data, the recommendations for the evaluative tool suggest the use of face to face interviews and the possibility of utilizing focus groups.

As discussed within this chapter, a qualitative approach to research has both its benefits as well as its limitations. The methodologies employed by this research practicum have shaped the following chapter. In Chapter Four, the lived experiences of the eight participants are discussed.
Chapter Four: Findings/Outcomes

Qualitative findings in evaluation illuminate the people behind the numbers and put faces on the statistic, not to make hearts bleed, though that may occur, but to deepen understanding

- Cresswell, 2007

4.1 Introduction

The hours I spent analyzing data proved to be a rewarding experience. Although it is difficult to integrate tone, pauses, tears and smiles from an interview into a written document, it is my intention to convey the experiences that the eight participants shared with me while their children were napping in the afternoon, still at school, or late at night when the rest of the family had gone to sleep. For this, I am eternally grateful. I share the same intention as stated by Cresswell (2007):

... to produce a research report that gives an accurate, clear, and articulate description of an experience. The reader of the report should come away with the feeling that ‘I understand better what it is like for someone to experience that’. (p. 62)

After the interviews were completed, I would spend time in my office to reflect on everything that was shared with me before I headed home for the night. Within my field notes one evening, this is what I wrote:

I have been humbled by the honesty and openness that eight different individuals have shared with me. I was a complete stranger for each of these individuals, and each person provided me with stories, both personal and powerful, of their grief journeys. Their generosity is not taken for granted as I know for most; it required them re-visitting a place that time has allowed them to have more control over. Whether it was the silent pause over the phone to gather themselves or the single tear that escaped their eye, I know they re-visited their grief and they allowed me to go back with them.
Through the interview process, themes emerged that would assist in informing the development of a framework for an evaluative tool for children and teen programming at GBC.

The interview guide was developed to gather data within three different sub headings; ‘W5’ Demographics, The Experience, and The Evaluation. The findings will be discussed further within these three sub headings.

4.2 ‘W5’ Demographics

When developing the interview guide, the first two questions were designed to gather information on the “W5” demographics of the participants: who utilized the service, what services were accessed, where they found out about GBC services, when they accessed GBC, why they accessed the service, and how they were initially connected to GBC. Although not all of the information was pertinent or required, the questions were framed to gather as much of the information as each participant was comfortable to share and expand upon. Further, this created an opportunity to develop rapport and for the participants to feel comfortable with the interview and the interviewer. For the reasons previously discussed, this demographic data has not been themed.

4.3 The Experience

This portion of the interview, and the questions asked within, were centred on the experience – both the caregivers' experience and the interpretation of their child's experience with the programming at GBC. This was addressed by asking for the participant to identify challenges and benefits to the child, the caregiver, and the family unit from the child attending children and teen programming at GBC. By asking these questions, it was with the intention to gather feedback for GBC based on participants’ experiences with the programming. In reviewing previous GBC evaluation forms, it was evident that parents and caregivers are very generous with positive feedback and provided very little, if any, criticisms. Through dialogue,
and by sharing experiences, a better understanding was developed as to what caregivers and/or families struggled with and the best way to ask the question to get that information. The following sub themes emerged from these discussions: *Surrogate Support, Normalizing Grief, Continuing Bonds* and *Bittersweet*. Each of these sub themes will be discussed in further detail below. Within quotes, participants will be identified by pseudonyms.

4.3.1 *Surrogate support*

The experience of a death within a family system can shatter the family unit as a whole. It is not uncommon for a parent to become so engulfed in their own grief, especially over the loss of a child, that they are not able to 'parent' their surviving children (Schachter & Georgopoulous, 2010). Further, Schachter and Georgopoulous (2010) found that, with death, a child's need for parental attention is never greater, but a parent who is lost in the grief has little energy to recognize and attend to the needs of a grieving child. As participant ML stated:

I sent the kids there because I was dealing with my own grief and I didn't feel that I was there the way I should have been there for them because I was still dealing with my own [grief]... I knew that they needed more than what I was able to provide them with at that point.

At a time when families are under significant stress, and parents and caregivers are sometimes unable to respond to their children's need for reassurance and comfort, Schachter & Georgopoulous (2010) found that bereavement groups, and the facilitators of these groups, act as a surrogate support system for the children.

Professional facilitators involved in bereavement support for children are impartial; because they do not emotionally respond in the same way as a parent when a child expresses feelings of pain and sadness. Therefore, the child is freed to disclose feeling without fear of causing distress (Schachter & Georgopoulous, 2010). Participant BR found:
She knew that I was troubled by my sister's passing as well as my mom's. She didn't feel comfortable talking to me for the fear that I would get upset and I didn't know how to handle the subject with her because it was such a deep issue. So I didn't want to press the issue, and I didn't want to ignore it and I didn't know how to address our concerns of the family regarding our family's passing. By sending her there [to Camp], it dealt with all the things I wanted to say to her but couldn't.

Participant GY shared:

It [Camp] was fabulous for him. It's just another outlet for him, someone else for him to talk to or you know, that has nothing to do with what the problem is; a total outsider that has an unbiased opinion.

Children are aware of signs of distress in a caregiver; for this reason, they may pretend that all is well in fear of adding to a caregiver's burden of sadness (Schachter & Georgopoulous, 2010).

All eight participants voiced an appreciation for the support provided to their children. At the very least, it was recognized that the participation with the bereavement programming provided their children with a safe environment to express their feelings. As participant XU stated:

Since kids sometimes don't tell you everything, it was nice to know that he was with a bunch of kids and well taken care of and he was able to visit with other children who had gone through this and maybe talk to them about how they were dealing with it and all that kind of stuff.

This statement supports the need for a safe environment where children are able to express themselves and work through their grief. Wolfelt (1983) expressed that, for a child to work through his or her grief, it is necessary that the child has access to supportive adults.

Surrogate support, as offered by various children and teen grief programming, facilitates
healthy grief for the family as a unit (Schachter & Georgopoulous, 2010). Participant QV expressed the challenges as a crisis;

   If you found no way to balance the chaos, it's crisis. When a death happens it is a crisis, and if you were just balancing everything before the death, that just throws your entire life off kilter completely. So that would be hard.

This same participant continued to share that, because she did not have debts to worry about, paying rent or poor relationships with her children prior to the death; her family was able to focus on working through their grief rather than struggling for survival. For some families, where a basic struggle for food, water and shelter is a daily task, seeking support for grief may not take precedence.

4.3.2 Normalizing grief

Participant LP shared the following statement from her child who attended Caring Hearts Camp: “you know what mom, people grieve, no matter if its parents, grandparents, nieces, nephews or whatever”. The opportunity for grief to be normalized for the children was shared by all eight of the participants and within the past GBC evaluation forms that were reviewed for this project. While expressing why Camp was beneficial to her child, participant JY stated: “... He discovered that there are other kids who had lost a close family member like him because he didn't know anybody else who had been through kind of situation. He wasn't alone”. While discussing the benefits of attending Camp at GBC, participant QV explained:

   I am sure some of it was time but I am sure some of it was just going and seeing other people that this happens to, there was this feeling... you are not alone... you are not alone.

In discussing feelings of not being alone, participant LP stated “she just clicked with these people because they were feeling the same way she did in a lot of ways- lost”.

   A caregiver who completed a past evaluation form when asked if Caring Hearts Camp was
a positive experience for the child wrote “Absolutely, they were able to connect with kids their age going through the same thing. Having that opportunity was critical to helping them become whole again”. Another evaluation stated:

He had the opportunity to talk to many different people who are going through the same experience as he is and he was even able to helps some of the boys his age through some things. This was very important to him.

Another comment:

This is the second year that both of my children have attended the camp and they both met so many peers that were going through the same experiences, many of which they continue to keep in touch with and act as a support system for each other.

These statements are congruent with the findings of the Nabors et al. (2004) study that found peer support and friendships as a strong source of support, comfort and positive experience. A participant whose children had attended *Caring Hearts Camp* expressed:

I think for us it was that we were not the only ones going through this. I mean, this just doesn't happen right? So, to come here and see other families going through the same thing, you just, you just, to me it felt like such a huge mistake, such a bad thing- we must be bad people to have let this happen. And then you go here and you see that these are just ordinary people that this happens to (QV).

Schachter (2007) found that, by creating a safe environment, it enables opportunities for children to interact with other peers, helping them realize they are not alone. In turn, this process normalizes each of the unique, grief experiences. To summarize, the following statement from Ruffin and Zimmerman (2010) reinforces this sentiment:

At camp, we see and feel the children's relief on the very first day as they realize that here they are not different, that everyone at camp has had someone they are care about die, and
it is OK to talk about it (p. 306).

4.3.3 Continuing bonds

Robert Anderson stated “…death ends a life, but it does not end a relationship” (as cited in Klass, Silverman & Nickman, 1996, p. 17). This statement is indicative of what Klass et al. (1996) contributed to this particular area of research with the statement “… the resolution of grief involves continuing bonds that survivors maintain with the deceased and that these continuing bonds can be a healthy part of the survivor’s ongoing life (p. 22). Through the children and teen programming at GBC, therapeutic art activities are used to promote such continuing bonds. For example, children are provided with clay and asked to sculpt a favourite memory or a favourite ‘thing’ of their deceased loved one. These activities generate discussion at the Camp but also facilitate further discussion within the family unit once the child goes home.

Participant ML expressed:

He didn't want to go but when he came back, he was, he still looks at the stuff. He's got his Guido box, and he looks at the pictures and he goes through the stuff that he went through at camp

A past evaluation shared:

The kids have started to share more memories of our Dad. They are more open to expressing themselves. My youngest child was very proud to show me her journal and the crafts she made with the picture of our dad.

Participant ML, while sharing about the experiences of her child at Camp, closed by saying “we went through that stuff and we talked a bit more- it gave us an opportunity to talk to one another”. The therapeutic activities at Camp teach the children about rituals. Rituals, within bereavement, are activities that are done in memory of the deceased person. By providing children with this tool, the therapeutic activities help to facilitate continuing bonds by providing
a foundation for the child and the family unit to share and continue the relationship with their
deceased loved one in their new roles.

4.3.4 Bittersweet

The final theme that emerged with all of the participants was this notion of the experience
being bittersweet. Defined, the term bittersweet refers to contrasting emotions; both pleasureful
and painful (Oxford Dictionary, 2000). For families and the children who attended grief and
bereavement programming, the experience emerged as being both pleasureful and painful.
Participant WY, when discussing the challenges of attending grief and bereavement
programming at GBC expressed:

... the trouble sleeping and trouble going to sleep, all of those things were brought back up
again and I mean that is two fold. It is the benefit that she is talking about things and
letting things out but it's harder to go through again and it just kinds of brings everything
out, so that is always a challenge.

Participant JY noticed changes in her child:

From outward appearances, he didn't seem to have anything bothering him before he went
to camp but I think it really affected him while he was there because when he came back,
he didn't really want to tell me anything and this was different behaviour for him. I don't
know if that was just him or if something happened there that he didn't want to talk about if
some feeling came up, but yeah, he was very closed about it.

Participant QV expressed

My boys are not really talkative and I think they found it, painful. I would only say they
never balked at coming, they never balked at coming. I think somehow they knew it was
good for them

Participant BR, when discussing the benefit of her child attending the programming, found that
“I mean she struggled more after she came home but I guess the benefit to that is she was expressing things and she wasn't keeping things bottled inside”. Although the participants expressed notable challenges with their child(ren) after completing the grief and bereavement programming, as a whole, they also noticed improved communication between them and their child(ren).

Participant QV noticed improved communication between her and her children after they attended *Caring Hearts Camp* “It really makes you question, or answer the questions that need to be answered, there is no skirting around it, and they can't sweep it under the rug and pretend it is not there”. Grief and bereavement programming facilitates open communication for the child with peers as well as for the family unit once they return home; this provides children with the opportunity to acquire the appropriate language to express their grief (Ruffin & Zimmerman, 2010). Further, Ruffin and Zimmerman (2010) found that:

> Without language to express feeling and fears, children are unable to tell the adults in their lives what they are thinking and feeling, which often leads parents, teacher, and caretakers to misjudge the depth of children's emotional pain and need for nurturance and support (p. 298).

The overall 'feeling' expressed by the interviewed participants was the willingness to take the negative with the positive. All eight participants were grateful for the opportunity for their child to attend GBC's grief and bereavement programming.

### 4.4 The Evaluations

The final portion of the interview was essentially the 'meat' of the interview; this portion focused on seeking feedback about the evaluation process. The intention was to have participants recall what they remember of the evaluations they had completed previously, why that was the case, how to best access their feedback, and to ask for any suggestions they had in
developing an evaluative tool. Parent and caregivers' participation is required when accessing any child's information. Therefore, I felt it necessary to go right to the source, the caregivers.

The sub themes that emerged and that are discussed below are: The grief haze, Convenience, Feedback and Triangulation.

4.4.1 The grief haze

In speaking with the eight participants, it became clear that, at the peak of their grief, their memory was not sharp. Consequently, from this the sub theme, 'The grief haze' emerged. In order to access data that is rich with information, it is necessary to determine the best time frame for an evaluation. This requires further research. Due to the unique nature of one's grief, a process of trial and error will most likely be required in the process of developing the best time frame to access feedback. Within the interviews, it was evident that the participants were uncertain as to what the best time frame would be. Further, this time frame can vary for each person and situation. Participant WY reiterated this:

Your brain feels so foggy that umm, just because I mean obviously it affects everyone in our family, so yeah, I feel so, I feel very foggy with my brain about things that have happened in the last, well since September. It's like, did I fill out an evaluation? I was in shock for 3 months or something. It is so hard to know where everyone is at because you are not; I am not in my right mind so I don't know if my thoughts on where my kids are at or where my husband is at in the grieving process are accurate.

Participant XU expressed “the last couple of months are sort of blurry”. This theme and the feedback from the participants are pertinent to providing recommendations for an evaluative tool. Participant WY suggested:

... maybe for a person to fill out their evaluation within 2 weeks after the camp but then revisit it after. Like, if someone could bring back an evaluation to me now that I filled it
out 2 weeks after she had gone, you know, I might have different thoughts or want to add something different. You just aren't in your right frame of mind, I mean, I don't even know that I am now.

Participant QV shared similar thoughts in regards to revisiting the evaluation form more than once,

I still think that there is a lot to be said about doing an evaluation when it is still pretty fresh and when they are still so raw. When you have some of those bad experiences when you are raw, you will remember that forever, so I think that you do want to capture that. But I think another evaluation like a year later or something, that wouldn't be a bad idea... I don't think I had perspective on it for a year or so. And that, although right away at the beginning, when the sessions ended, I remember saying to people ‘I don't know what happened or what those sessions did, all I know is that we were better in then end then we were in the beginning’.

An evaluative tool needs to be developed that addresses the dynamic nature of grief and bereavement; emphasizing change and adaptation rather than the presence and absence of symptoms (Stokes et al., 1997). The statements above are suggestive of an evaluative tool that is process orientated rather than one based solely on symptomology.

4.4.2 Convenience

The ‘Paper Jungle’ was a term one of the participants shared when discussing the best method for her feedback:

We just get so much paper coming in the door and things so if I actually had to fill in a form and remember to put it in an envelope and put a stamp on it, that probably wouldn't happen. I am bad for those kinds of things if they come home sometimes, paper, the paper jungle (QV).
This statement was representative of the shared consensus and suggestions of all participants in reference to the best way to access their feedback.

In an era that is dominated by convenience and electronic communication, the mailed copies used in this research project were not the ideal method of communication. One participant shared:

I am not the greatest at opening my mail. I have to say; sometimes I am really late at opening mail so if it doesn't look like a bill or something I have to deal with right away, it might not get opened (LP).

Electronic mail proved to be the most convenient and accessible method to access feedback. Participant LP stated that “I think people are better at opening their emails. And, it makes it easier for them to send back”. Two participants also shared that an email would be best and they also suggested an external website to fill out the evaluation forms. They felt that, because the email was in front of them, they would more than likely take the time to complete what was asked rather than putting it to the side for another time. However, because not everyone is comfortable with technology, Participant QV suggested providing participants the option of choosing their preferred method - electronic or paper copies.

In reviewing past GBC evaluations, it was discovered that the majority of the evaluations were mailed out electronically and returned in the same format. Convenience proves to be an important factor for developing an evaluative tool.

4.4.3 Feedback

As a researcher, it was important to gather data, not only on the best method to contact the participants, but also the best method to gather data that was rich with information. Personal contact was equally weighted with convenience. Three of the participants shared similar ideas in the following statements:
Participant WY:

Like email is good for reaching lots of people and it is a great way to get it out there but phone is also good. I feel that I can express a lot more and I, you can probably, well dig for a little bit more you know? Try and clarify because sometimes meaning is lost in things, through email... it would give you a little bit of a better idea of what someone is thinking if it is in person or on the phone.

Participant ML:

How about a personal contact like you did? How long did it take. I never replied back, actually I did send a reply back saying I was willing to do it, you sent a reply back in email saying when was a good time, and I never got back to you until you picked up the phone. Right? When you picked up the phone, I then made the commitment to the time and changed it a couple of times but we are doing it... I am probably more honest with you talking to you this way in an interview then I probably would be on a... cause you can hear it in my tone, and the thoughts come out easier. Sometimes when you go to write things down on paper... I got teary eyed. I probably would have stopped, Right? And I wouldn’t have continued on. But because I am talking to you, I continued on. I took a moment to catch myself but I did continue on with my thoughts that I had. I just think that the personal contact probably, for myself, would be the best way of doing an evaluation.

Patton (2002), in discussing the purpose of interviewing, shares that it “allows us to enter the other person's perspective” (p. 340). Interviews facilitate the participant as the expert of their own grief and follow the assumption that the perspectives of others are meaningful, knowable and able to be made explicit (Patton, 2002). Interviews would require an expenditure of extensive resources from the Agency but, they have the potential to generate the highest quality of feedback.
4.4.4 Triangulation

Triangulation is the method of data collection that strengthens a study by combining several kinds of data or methods, including both qualitative and quantitative methods (Patton, 2002). Participants, when providing suggestions for how to best conduct an evaluation of children and teen programming at GBC, suggested the use of multiple data sources. When expanding on the best method to access feedback, Participant ML suggested:

Maybe a study where more of the child was involved. I can see what the kids got out of it but maybe the idea of what the kids actually got out of it... I think the kids could probably give you some valid feedback. And they are candid right? They will tell you!

Participant JY suggested the volunteers as a source for data:

I think that it’s important to get their [Volunteers] feedback because I think that they are really right there in the moment with the people and they can tell what works, what didn’t work, umm, that kind of thing.

The suggestion to utilize more than just the caregivers is congruent with that of triangulation and would provide more depth to the evaluation. Although the interview schedule did not include the question that asked caregivers if they would permit their child to participate in responding to an evaluation; this question was asked during the interviews, and all participants stated they would support the participation of their child(ren) in such evaluations.

The Stroebe, Stroebe, Hansson & Schut (2001) study brought attention to children as a part of a dynamic family system which influenced their grief reactions. For this reason, it is important for the family system to be a part of the evaluation.

4.5 Essence of the Findings

In an attempt to speak to the essence of this research practicum, the following paragraphs provide a summary of the findings. The lived experiences shared by the caregivers of children
who have attended grief and bereavement programming at GBC vary among caregiver, child and family. All eight of the respondents expressed that Camp provided the children with a surrogate support system. Caregivers felt that the camp experience assisted with both answering difficult questions, and with providing support when their child needed it most. Caregivers expressed that their children all felt that, by attending Camp, they realized they were not alone and thus, normalized their grief. For many families, attendance at the Camp created open communication among various family members. Most families also found a way to continue to share memories of their deceased loved ones through this process. Along with the benefits, challenges were also expressed. Some caregivers noticed changes in sleeping behaviours. Overall, the benefits were far greater than the challenges and, further to this, each struggle was acknowledged as a form of 'grief work'.

When discussing evaluation within children and teen bereavement, timing and convenience were shared as having high importance. However, contrasting views were expressed in regards to timing. Some participants felt that, the sooner the evaluation, the more practical this would be for the caregiver to complete. Other participants felt that it would be best to wait at least a few months as, with more time, they may be able to provide a better evaluation based on changes they have noticed with their child and their family. Triangulation was discussed as a method to address the data collection; the use of the caregiver, the child and the volunteers to assist with the evaluation. In conclusion, discussion about the experiences of caregivers whose children have attended grief and bereavement programming at GBC allowed for a deeper understanding of the nature of children's grief and how current support programs can best be evaluated.

4.6 Outcomes

Outcomes are achieved based on the intervention successfully addressing the project
objectives. Both the research objectives and the learning objectives were identified at the beginning of this report. By completing the literature review, interviewing eight different caregivers whose children attended *Caring Hearts Camp*, and reviewing past evaluations from the children and teen programming at GBC, the learning objectives and the learning activities of this research project have been completed. Through the successful completion of the objectives, this research practicum has provided practical tools and knowledge in a practice area with limited research; the practice area of evaluating children and teen grief and bereavement programming. The general outcomes arising from completion of this research practicum are further discussed in the next chapter.

**Chapter Five: Discussion**

This research practicum combined current literature with the lived experiences of eight caregivers whose children attended grief and bereavement programming at GBC. The purpose was to inform the development of an evaluative tool that will measure the 'success' of the programming at GBC. As many leaders in the field of death, dying and bereavement have discussed, it is very difficult to measure grief and the success of grief and bereavement programming. The findings from the current literature were presented and discussed in Chapter Two.

Although the data gathered from the qualitative interviews for this research project are specific to GBC programming, the themes and lived experiences of the eight participants are congruent with that which is found in the literature. Emerging themes validated the need for appropriate support for grieving children. The themes also validated the positive impact these support programs can have on a family system. Responses from past GBC evaluations that were reviewed as secondary data, and experiences shared by caregivers during the interview process
for this research project, acknowledged the benefits, some life changing, for the children who attended Camp.

Developing an evaluative tool would identify these benefits and validate what those in the field already know; that grief programming does make a positive change in a grieving child's life. For the front line practitioner, knowing what is successful will enhance the quality of care provided to the client by informing the practitioner of the most appropriate skill set needed.

The completion of this practicum has provided pertinent information for the development of an evaluative tool for the children and teen programming at Greystone Bereavement Centre. In speaking with the Coordinator of *Caring Hearts Camp*, and also with the other staff of GBC, it was apparent that the objectives of children and teen programming were congruent with the Ruffin- Zimmerman model (2010) of children's bereavement therapy. Each activity that is completed at *Caring Hearts Camp* serves the purpose of addressing at least one of the objectives. Further, each activity is flexible and can be modified to address the needs relevant to the developmental ages of the participants.

In a camp setting, grief work can be balanced with fun; thereby “meeting the children's need for a kinetic reprieve from painful emotions, while providing information about the feelings associated with grief as children acquire the language skills necessary to gain the attention of caregivers (Ruffin & Zimmerman, 2010, p. 305). The need for kinetic reprieve provides insight when developing an evaluative tool. This reprieve has been suggested as measuring children’s grief programming on a pendulum; evaluating the experience as children move between grief orientated activities and fun orientated activities.

Children who attend *Caring Hearts Camp* are essentially 'scheduled' into oscillation. The format of Camp is a balance of activities that teach children about their grief, provide them a safe space to share their grief, but also integrate activities that are fun as a way to normalize their
grief. Because professionals assist in facilitating this process, the children are assisted with moving between a loss-orientated focus and a restoration-orientated focus. Measuring their ability to continue with this oscillation once they have been removed from the routine environment of camp may answer how grief and the success of these programs can be effectively measured. As discussed in Chapter Two, Stroebe et al. (2001) supported this notion of incorporating the Dual Process Model as a form of measurement for children's grief.

As discussed previously, grief is a dynamic process; not only does it vary from person to person but also from hour to hour (Stroebe et al., 2001). Therefore, an evaluation needs to address the fluid nature of grief. The Dual Process Model provides a method of evaluating the movement between grief activities but it does not have the ability to evaluate the outcome of the grief and bereavement programming over time. The literature, together with the findings of this study, suggests the use of a pre-test and a post-test over the course of multiple time periods. The use of a pre-test would allow for a baseline measurement for each individual. This baseline would then be compared with the post-test. Multiple time periods would be used to evaluate the grief and bereavement programming over time. The intent is to provide an understanding as to how successful the programming has been in assisting with each individual's grief process.

Greystone Bereavement Centre has a partnership with the Regina Qu'Appelle Health Region as well as a mandate to provide services to the province of Saskatchewan. For this reason, GBC has maintained its commitment to further education for employees of the Regina Qu'Appelle Health Region, as well as to the residents of Saskatchewan wanting to acquire knowledge in the area of death, dying and bereavement. The Agency continues to fulfill this mandate with the support of this research practicum. In turn, GBC also has potential to be a leader in showcasing current programming for children and teen grief and bereavement, and in evaluating these programs. As Participant LP acknowledged:
I really want to say when I got that letter in the mail from you asking if we wanted to do this, I just thought for sure because I mean, the more information that you take back from the different people attending something, the more that you're going to learn about the best way to help these kids... I just really appreciate you are working towards giving better care and better help to the kids... It is great you are putting the time into making it better. If you don't ask the questions, you can't make it better.

With the support of the Agency, as well as the clients who have come in contact with the services, the potential is limitless. Those who have experienced a death loss are the experts in the field of death, dying and bereavement. Therefore, with their stories and their experiences, progress in the field of children and teen grief and bereavement will continue to evolve.

**Chapter Six: Recommendations**

Through the compilation of the previous chapters, the recommendations for the creation of an evaluative tool have been developed. The recommendations discussed below are focused on those specific to GBC and those specific to the development of an evaluative tool for children and teen programming at GBC. It is with the intent of completing this practicum that the Agency will move forward in following through and pursuing the recommendations listed below. For the purpose of this research practicum, the following recommendations mark the successful completion of this practicum. In section 6.1 I have developed a list of nine practical recommendations to contribute to the field of children and teen grief and bereavement programming. In section 6.2, I have introduced a pilot evaluation that has been constructed based on the suggestions and research compiled through this research practicum.

**6.1 Recommendations**

Through the process of completing this research practicum, nine recommendations specific
to the development of an evaluative tool for children's grief and bereavement programming at GBC have been developed. The recommendations are:

1) Develop and document goals and objectives for each program offered by GBC,
2) Update current website - create an interactive website for *Caring Hearts Camp*,
3) Provide opportunities for field placements for Social Work students at GBC,
4) Start small and then expand,
5) Combine qualitative and quantitative methods of evaluation,
6) Include both children and caregivers in the evaluation process,
7) Incorporate triangulation,
8) The use of a pre-test and post-test, and
9) Integrate the dual process model as a method of measurement.

The nine recommendations, listed above, will be discussed in detail throughout this chapter.

1) Develop and document goals and objectives for each program offered by GBC

When I set out to explore topic areas for this research practicum I knew that I was interested in program evaluation and I wanted to engage in research within the area of death, dying and bereavement. GBC was a natural fit for me, and the Agency was supportive of assisting me in this endeavour. As I began the research process it became apparent that the programs offered at GBC were successful and valued by those who utilized them. But, no formal goals and objectives have been identified for each of the programs. As discussed in Chapter Four, a program cannot be evaluated in the absence of clear program objectives. As the Agency continues to mature, an evaluation of programs will become necessary. The development of goals and objectives now will ease the process of developing evaluation tools in the future.

2) Update current website - create an interactive website for *Caring Hearts Camp*
Participants interviewed for this research project identified convenience as important when completing evaluations. Further, electronic mail was a primary form of communication for those interviewed. During the interviews, participants were supportive of the suggestion of an interactive website for completing evaluations. As such, I recommend that GBC develop an interactive website for *Caring Hearts Camp*. By using the website, the evaluation would be integrated into the initial application form. By doing this, I feel that the response rate will increase.

The website can also be used as a method for maintaining a strong response rate with the post-tests. One recommendation from the research involved providing participants with a password that would 'unlock' pictures and videos of camp once they have completed the post-tests. Another suggestion would be having a prize draw that each participant could be entered into after completing the evaluation. The purpose of having these incentives is to increase the overall response rate. Further research needs to be completed that is focused on the public's opinion and preference for online evaluation options.

Benefits of an interactive website extend beyond the evaluation. The website would also provide information for those interested in attending Camp as well as those interested in volunteering at Camp. A message board, contact information, and personal stories and testimonials could also be included. The development of this website would be the best medium to access a large population. As supported in the findings, electronic communication is a preferred method of communication.

3) Provide opportunities for field placements for Post Secondary students at GBC

In order to move ahead with the development of an evaluative tool for children and teen programming at GBC, resources are needed. With evaluations that are qualitative in nature, time and people are the resources that are highest in demand. By providing student placements, the
benefits extend beyond that of GBC, but also to the individual student and to the University. Further, the benefits would also entail a partnership between the Agency and the University. In the context of research, this creates the ability for continued research and advancements in the field of death, dying and bereavement. A connection with an educational institution would enhance the current quality of education that the Agency provides to residents of Saskatchewan.

As the local university, the University of Regina would be the best candidate to provide a pool of social work students. In turn, this would create a strong partnership between GBC and the University of Regina. At this time, this is a lofty goal within GBC due to space constraints but should be considered within the long term agenda of the Agency.

4) Start small and then expand

The process of evaluation is complex and utilizes some elements of trial and error. For this reason, I recommend that the initial evaluative tool be developed specifically for *Caring Hearts Camp* prior to being expanded to other programming. *Caring Hearts Camp* involves 80 children between the ages of 5 and 17. The ages and developmental levels of these children vary significantly and therefore this must be adjusted for throughout the questions within the evaluative tool. I recommend initially starting with a tool that will evaluate children between the ages of 13 and 18. The logic for this recommendation is as follows: the reading level for the majority of the children will be at a level where the evaluation will not have to be adapted, the majority of children in this age range will be able to complete the evaluation independently, and children in this age range participate in similar activities and activity groups at *Caring Hearts Camp*.

5) Combine qualitative and quantitative methods of evaluation

Using the literature review as a primary source of information, I recommend that a combination of quantitative and qualitative data be gathered for an effective evaluation.
Quantitative data will be beneficial as it provides immediate data in a timely matter, specifically when gathering participant demographics. Further, by combining both methods, the data collected will be more robust. The recommendation to incorporate triangulation is discussed below and will elaborate on the methods of quantitative and qualitative data collection that could be utilized.

An outcome evaluation should be the evaluation application used. Outcome evaluations have become the central focus of the accountability movement - demonstrating responsible use of public funds (Patton, 2002). When asked ‘why measure outcomes’, the United Way responded “To see if programs really make a difference in the lives of people” (Patton, 2002, p.4). This response is at the root of the purpose of this research practicum. By combining qualitative and quantitative research methods, individual outcomes will be captured and reported.

6) Include both children and caregivers in the evaluation process

Within interviews, the theme *The grief haze* emerged and was discussed. This informed a need to include multiple sources for data collection; the more sources utilized in order to evaluate the grief process, the more accurate the evaluation will be. For this reason, children and teens must be included in the evaluation process.

Further, grief does not exist in a vacuum. While at Camp the children are in an environment where their grief work is balanced with fun. Further, they are surrounded by support workers who are there to facilitate this experience and peers who are experiencing similar pain. This is not typical of their everyday life which is why it is imperative that evaluations are completed by multiple sources, and throughout multiple time periods. For this reason, I recommend including both children and caregivers in the evaluation process.

7) Incorporate triangulation
Triangulation, as defined previously, is the combination of multiple data sources. Figure 6.1 below provides a visual representation of the methods that are recommended for the evaluation. Triangulation strengthens a study by combining methods (Patton, 2002). Combining qualitative and quantitative methods for data collection will be done through the use of: open ended and closed ended questionnaires, interviews, direct observation, Likert scales and standardized assessments. Standardized assessments are forms of measurement that have been tested for validity and reliability (Patton, 2002).

![Figure 6.1](image)

8) The use of a pre-test and post-test

As discussed in Chapter Two, Nabors et al. (2004) recommends the use of a pre-test and post-test method to evaluation for the purpose of gathering comparative data. This is also recommended for the creation of an evaluative process at GBC. A pre-test would enable the opportunity for the baseline of each child to be presented. It is very difficult, if not impossible, to measure outcomes of a program if one is unaware of the starting point.

A pre-test/ post-test evaluative design would be best facilitated with the development of an interactive website for Caring Hearts Camp. Further, I recommend that the application to attend
Caring Hearts Camp be moved to an online application that is completed on the website as well. Along with the application, each caregiver and child could then be required to complete a pre-test evaluation in order for their Camp application to be processed. It is expected that this would increase the response rate by making it a mandatory aspect of attending Caring Hearts Camp.

As caregivers move through the application form on-line, they will be prompted to answer questions specific to the evaluation. However, it is also a reality that internet access is not available to everyone. As such, paper copies of both the Camp application and the evaluation forms can continue to be provided on request. The use of technology should not hinder the attendance of any child at Caring Hearts Camp. I recommend that the application be completed online and that the initial pre-test consist of closed ended questions and Likert-scales. Further, because it is recommended that an initial evaluative tool include only those children aged between 13 and 18, I suggest that they participate in the pre-test through a separate and secure website log-in. This would serve the purpose of addressing bias and potential influence of the caregivers over the children in their responses.

Based on suggestions from The Dougy Centre in the U.S., I have included sample evaluation forms for both the children and the caregivers. These pre-test evaluations are attached in Appendices E and F of this report. Please note that all credit for that material is given to Dr. Coleman of The Dougy Centre. Some of the questions on the sample evaluation forms have been adjusted in order to make them specific to GBC, therefore they have not been tested for validity and reliability. Further, changes have been made from the original sample evaluation forms based on further discussion with Dr. Coleman. Prior to the evaluation being used by GBC, further research and development would be required.

As discussed in the chapter focusing on the findings of this study, convenience was identified as being important for families, especially those families immersed in the grief
process. For this reason, I recommend the child's portion of the first post-test be completed at Camp and within their activity groups. This way, volunteers are available to clarify any questions or assist any children who may have questions.

Further research will need to be conducted in order to establish the best timing for completion of the child's second post-test and the post-test for the caregiver. Currently, I recommend four months post Camp for the following reasons: 1) Four months provides children the necessary time frame to leave the environment of Camp and adjust back into their everyday lifestyle. I believe a time frame of four months will provide a more realistic understanding as to what 'stuck' with them from Camp as opposed to completed the evaluation only two weeks post camp. 2) In the course of four months; it is possible that a child has experienced an anniversary of the person who has died. For many, this can cause a 'stumble' within their grief journey. By completing the evaluation four months after Camp, it is possible to capture this 'stumble' within the evaluation. This would serve as a method of evaluating if their Camp experience assisted with coping in a difficult time as it pertains to their grief. 3) The family unit impacts children's grief. Four months will give families a chance to adapt post camp. Some families may not make any changes, whereas other families may seek further education and support. The recommendation to wait four months is with the intention to give time for each family to develop their new “normal”. 4) Due to Caring Hearts Camp being offered twice per year, it is necessary to complete an evaluation prior to the child attending Caring Hearts Camp for a second time. A sample of the post-tests for children and the caregivers are attached in Appendices G, H and I of this report. Within the post-test evaluations, credit is given to Dr. Daniel Coleman for the standardized assessment portion.

One caregiver who was interviewed for this research project suggested the use of a focus group. I would recommend that further research be conducted on the best post-test method
considering the use of a post-test focus group evaluation with a group of children and a group of caregivers, four months following the Camp experience.

9) Integrate the dual process model as a method of measurement

The dual process model of coping with bereavement provides a framework that acknowledges the range of emotional and practical 'tasks of adaptation'; categorized as loss-oriented or restoration-oriented. (Stroebe & Schut, 1999). Figure 6.2 below illustrates the oscillation between these two domains, addressing emotional issues, then redirecting focus to handle pressing practical challenges, then at some point returning to emotional processing, and so on (Stroebe & Schut, 1999).

![Figure 6.2](image)

From the initial design of Stroebe & Schut's (1999) dual-process model, I have developed a model that illustrates the tasks carried out at *Caring Hearts Camp* (see Figure 6.3). The title 'Grief Work' is representative of loss-oriented activities and 'Fun' represents restoration-oriented activities. The oscillation represents the format of Camp in that children oscillate between activities that focus on grief and activities that focus on having fun. By teaching children that it is possible to move between the two, it is with the intention that they can learn how to implement these coping techniques into their daily lives.
I recommend incorporating the dual process model into the evaluation process. This would require the children to construct their own diagram integrating tasks they intend to incorporate post-camp, completed in the initial post-test and then have them construct a diagram during the second post-test. Figure 6.4 illustrates the diagram that the children would complete as part of their two post-test evaluations. Further, by having them complete this activity twice, it can be used as comparative data.
For children who benefit from visual aids, this activity will also serve to provide them with a tactic to visualize their grief and identify any potential imbalances within their current strategies for coping. The children’s version of this recommended activity sheet is included with the post-test in Appendix G and H.

6.2 Pilot Evaluation

Based on the above nine recommendations and the suggestions from Dr. Daniel Coleman, a pilot evaluation has been attached in Appendices E, F, G, H, and I. Figures 6.5 and 6.6 provide a summary of both the Pre-Tests and the Post-test for the children and for the caregiver. Both of
the Pre-Tests suggest that they are to be completed with the camp application. For the child and the caregiver, this is a three part document.

The Post-Test for the children is to be completed twice; once on the last day at camp and once four months after the end of camp. Post-Test #1 is a four part evaluation and Post-Test #2 is a five part evaluation. For the caregiver, there is one Post-Test and it is to be completed four months after the child in their care has attended Camp. This Post-Test is a three part evaluation.

<table>
<thead>
<tr>
<th>Pre-Test Child</th>
<th>Pre-Test Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>(To be completed with Camp Application)</td>
<td>(To be completed with Camp Application)</td>
</tr>
<tr>
<td>Part I- Brief Demographic Information</td>
<td>Part I- Brief Demographic information about self</td>
</tr>
<tr>
<td>Part II- 48 Likert scale questions based on a combination of standardized assessments</td>
<td>Part II- In depth demographic information about child (8 questions)</td>
</tr>
<tr>
<td>Part III- Smiley Scale</td>
<td>Part III- 24 Likert scale questions based on a combination of standardized assessments</td>
</tr>
</tbody>
</table>

**Figure 6.5**

<table>
<thead>
<tr>
<th>Post-Test #1 Child</th>
<th>Post-Test #2 Child</th>
<th>Post-Test Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>(To be completed at Camp)</td>
<td>(To be completed 4 months after Camp)</td>
<td>(To be completed 4 months after Camp)</td>
</tr>
<tr>
<td>Part I- Brief Demographic information</td>
<td>Part I- Brief demographic information</td>
<td>Part I- Request for any demographic updates</td>
</tr>
<tr>
<td>Part II- 48 Likert scale questions based on a combination of standardized assessments</td>
<td>Part II- 47 Likert scale questions based on a combination of standardized assessments</td>
<td>Part II- 30 Likert scale questions based on a combination of standardized assessments</td>
</tr>
<tr>
<td>Part III- Scale Diagram</td>
<td>Part III- Scale Diagram</td>
<td>Part III- 6 open-ended questions</td>
</tr>
<tr>
<td>Part IV- Dual Process Diagram</td>
<td>Part IV- Dual Process Diagram</td>
<td></td>
</tr>
</tbody>
</table>
The purpose of this pilot evaluation is to provide a beginning framework for evaluation at GBC for Camp. Much of this process will be trial and error, but documents attached in the Appendices provide a starting point in the evaluation of children and teen programming at GBC.

**Conclusion**

Grief is a life long journey that a child should never have to navigate on their own. Children's grief is fluid, dynamic, changing and a process that is highly influenced by those who surround them. Although each individual must work through their own grief process, relevant programming that addresses their needs can assist in this journey. Although a unique evaluative tool cannot be developed for each individual child, a tool should be developed in a way that would measure the unique nature of each child's grief experience.

The recommendations that evolved as a result of this research project have been developed from the hours, days and months that have been spent researching children's grief as it pertains to evaluation. Over the course of this research practicum, I have had the opportunity to learn from the experts themselves - the parents, caregivers and families who have been battling within the trenches of grief. With their openness and honesty, each participant provided insight into an area of life that is common to all, but individually experienced. From these experiences, themes emerged that have validated what is currently being offered for children's grief as well as confirmed a need for evaluation.

As I started the research process for this practicum, I wrote the following statement in my field notes:

What I am doing is not answering all of my questions in one research practicum; I cannot. What I am doing is starting with the tip of the iceberg and starting with the source. I want
to develop an evaluative tool and I want to evaluate the programs. But like most things, first things first. I need to understand not only what is going to be evaluated but how it is going to be evaluated.

As this report comes to completion, with confidence, I feel that I have made recommendations that contribute to the development of an evaluative tool for children and teen programming at Greystone Bereavement Centre.

Within the field of social work there is great value in understanding how a person’s experiences are influenced to be that of positive or negative. In turn, this can help increase knowledge of shared experience, improve educational delivery, identify support needs, and develop necessary training. Understanding the lived experiences of caregivers whose children attended grief and bereavement programming at GBC has both practical and social relevance as this knowledge may assist in guiding future research and identifying other areas of grief and bereavement programs which can be enhanced.
References


DATE: January 20, 2011

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RPCI – Greystone Bereavement Centre
700B 4400 4th Avenue
Regina, SK S4T 0H8

FROM: Dr. Bruce Plouffe
Chair, Research Ethics Board

Re: Measuring Success: An Evaluation Tool for Children and Teen Bereavement Programming at Greystone Bereavement Centre (File #43S1011)

Please be advised that the University of Regina Research Ethics Board has reviewed your proposal and found it to be:

☐ 1. APPROVED AS SUBMITTED. Only applicants with this designation have ethical approval to proceed with their research as described in their applications. For research lasting more than one year (Section 1F). ETHICAL APPROVAL MUST BE RENEWED BY SUBMITTING A BRIEF STATUS REPORT EVERY TWELVE MONTHS. Approval will be revoked unless a satisfactory status report is received. Any substantive changes in methodology or instrumentation must also be approved prior to their implementation.

☐ 2. ACCEPTABLE SUBJECT TO MINOR CHANGES AND PRECAUTIONS (SEE ATTACHED). Changes must be submitted to the REB and approved prior to beginning research. Please submit a supplementary memo addressing the concerns to the Chair of the REB. **Do not submit a new application.** Once changes are deemed acceptable, ethical approval will be granted.

☐ 3. ACCEPTABLE SUBJECT TO CHANGES AND PRECAUTIONS (SEE ATTACHED). Changes must be submitted to the REB and approved prior to beginning research. Please submit a supplementary memo addressing the concerns to the Chair of the REB. **Do not submit a new application.** Once changes are deemed acceptable, ethical approval will be granted.

☐ 4. UNACCEPTABLE AS SUBMITTED. The proposal requires substantial additions or redesign. Please contact the Chair of the REB for advice on how the project proposal might be revised.

Dr. Bruce Plouffe

cc: Dr. Nuelle Novik – Faculty of Social Work

**supplementary memo should be forwarded to the Chair of the Research Ethics Board at the Office of Research Services (Research and Innovation Centre, Room 109) or by e-mail to research.ethics@uregina.ca**

Phone: (306) 585-4775
Appendix B- Initial Letter of Contact

Dear Parent/ Guardian

Enclosed is a letter requesting your participation in an evaluative research study that is supported by the Greystone Bereavement Centre (GBC). Your name was identified by the Greystone Bereavement Centre as our records show that a child in your care has participated in the children and teen programming at GBC.

If this information is incorrect or if you do not wish to participate in the evaluation outlined on the following page; please contact Kathy Geiger, Operations Assistant at Greystone Bereavement Centre (766. 6946) to remove your name from the participant list. Please note that if we do not hear from you within 10 days, you will be contacted by Lisa Greig.

I appreciate your consideration and should you have further questions, please do not hesitate to contact me at the information below.

Thank you,

Marlene Jackson, ME, CCC, MTA
Bereavement Coordinator, Palliative Care Services
Regina Qu’Appelle Health Region
Greystone Bereavement Centre
306.766.6947
marlene.jackson@rqhealth.ca
Dear Parent/ Guardian

My name is Lisa Greig and I am currently a Graduate student in the Faculty of Graduate Studies and Research at the University of Regina. As a requirement for the completion of a Masters Degree in Social Work, I will be undertaking a Research Practicum. As a volunteer with the Greystone Bereavement Centre, I have had the opportunity to work at Caring Hearts Camp and Grieve Outloud. I have great passion in the continued development of children and teen bereavement programming at the Greystone Bereavement Centre.

I am writing to ask your help in my research project titled *An Evaluative Tool for Children & Teen Programming at the Greystone Bereavement Centre*. The purpose of this research practicum is to develop a tool to evaluate the current children and teen programming at the Greystone Bereavement Centre. You have been identified as a caregiver of a child who has participated in children and/or teen programming at the Greystone Bereavement Centre.

By agreeing to participate in this research study you will be contributing to the evaluation of programming at Greystone Bereavement Centre. The requirement of participation is an interview with myself that will not exceed one hour in length. This interview can either be done face to face at your convenience or over the telephone. Please note that I will only be interviewing a limited number of participants due to time constraints of the practicum. Please contact me via the information listed below.

If Greystone Bereavement Centre does not receive a response from you within 10 days, I will be following up with a telephone call. I appreciate your consideration and look forward to working with you in the continued development and improvement of children and teen bereavement services.

Sincerely,

Lisa Greig, RSW, BSW  
Nuelle Novik, MSW, PhD, RSW  
Graduate Student  
Faculty of Social Work  
University of Regina  
University of Regina  
306.551.7813  
306.585.4573  
lisasgreig@gmail.com  
nuelle.novik@uregina.ca
Participant Consent Form

**Project Title:** Measuring Success: An Evaluation Tool for Children & Teen programming at Greystone Bereavement Centre.

**Researcher:** Lisa Greig, RSW, BSW, Faculty of Graduate Studies and Research, Social Work, University of Regina, Telephone: 305.551.7813, Email: lisasgreig@gmail.com

**Supervisor:** Nuelle Novik, MSW, PhD, RSW, Associate Professor, Faculty of Social Work, University of Regina, Telephone: 306.585.4872 ext.4554, Email: nuelle.novik@uregina.ca

**Purpose of the Research:**
- The purpose of this research is to develop an evaluative tool that will be used to evaluate children and teen programming offered at the Greystone Bereavement Centre (GBC).

**Procedures:**
- You are being asked to participate in this study because you have been identified by the GBC as having a child or teen who received care throughout 2009 and 2010. If you choose to participate, you will be asked to take part in a one-hour interview with the researcher. The interview can be conducted by telephone or face to face, and will be scheduled to your convenience. During the interview, you will be asked questions about the care your child received while at GBC. Each interview will be recorded with a digital audio recorder. In total, 8-10 participants will take part in this study.

**Potential Risks:**
- Due to the sensitive nature of grief and bereavement, certain questions in this research study may bring forth a variety of emotions for participants. For this reason, this research study is of minimal risk to the participants.
- If you feel the need for professional support during or after your participation in this study, the researcher will assist you with contact information and support that will best address your needs.

**Potential Benefits:**
- Benefits for the participants are based on their ability to share their experiences and opinions in order to contribute to the ongoing development and research of children’s grief and bereavement resources.
- There may be no benefit to participants.
Confidentiality:
- All information provided by participants will be confidential and secured at the GBC.
- All information will be confidential. The researcher will also use numbers and letters instead of names, to label all information gathered from the interviews. This is defined as ‘de-identified data’. The original participant list and the de-identified data will be stored separately in locked cabinets at the Greystone Bereavement Centre.
- All information will be destroyed 5 years after the approval of the research practicum as per the Faculty of Graduate Studies and Research at the University of Regina’s protocol.
- The participants are free discuss issues and will not be forced into providing information that is confidential or of a sensitive nature.
- If illegal activity is disclosed, the researcher must report this to the appropriate authorities.

Right to Withdraw:
- The participant has the right to refuse his or her assistance from this project at any time without penalty to himself/herself or his/her child, even after signing this letter of consent.
- The participant has the right to refuse to answer one or more questions without penalty and may still continue to be a part of the research practicum.

Follow-up:
- To obtain results from the study, please contact the researcher at the contact information on page 1 or the Greystone Bereavement Centre (306.766.2300).

Questions or Concerns:
- Please contact the researcher or the supervisor at the contact information at the top of page 1.
- This research project has been approved on ethical grounds by the University of Regina and the Regina Qu'Appelle Health Region Research Ethics Boards. Any questions regarding your rights as a participant may be addressed to the committee at (306.585.4775 or research.ethics@uregina.ca). Out of town participants may call collect.

Consent

My signature below indicates that I have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records

_______________________    ________________________   ___________
Name of Participant    Signature    Date

A copy of this consent will be left with you, and a copy will be taken by the researcher
General Interview Guide

1) Can you tell me what programming your child and/or teen participated in at the GBC?
2) How were you initially connected with the GBC?
3) In what ways did you find these programs beneficial to the needs of your child and yourself?
4) In what ways did you find these programs challenging to the needs of your child and yourself?
5) Have you ever completed an evaluation for the programs at GBC?
   1. If yes, for which programs?
   2. If no, why did you not respond?
6) Please comment on what you recall from the evaluations.
7) In what ways did you find the evaluations helpful?
8) In what ways did you find the evaluations not beneficial?
9) Please comment on if and how you felt the evaluations facilitated the required 'space' to express your opinions
10) Did you feel your voice was heard?
    1. If yes, how so?
    2. If no, what suggestions do you have?
11) What is the best medium to access your feedback and comments?
    1. Email
    2. Mailed Letter
    3. Telephone Interview
    4. Other:___________
Your name: ____________________
Note: This cover page will be promptly removed and your survey will only have a code number (see assent letter for details).

Evaluation of Caring Hearts Camp
Ages 13-18
(Caregiver also participating in Evaluation)

Research Consultation Provided by:

[LOGO]

Portland State University
School of Social Work
Regional Research Institute
Daniel Coleman, M.S.W., Ph.D.
Associate Professor
**Instructions:** Thank you for agreeing to participate in this study. *There are no right or wrong answers.* Please try to select the **best** possible answer that fits each question.

Please provide some information about yourself and the death:

Please circle: Male  Female  

**Age:** ________

**Who Died?**

___Parent(s)  Please Specify: Mother___ Father___  
___Sibling  
___Friend  
___Relative  specify_______________  
___Other  specify_______________

**II. Mark how true each statement is for you, in the past week.**

<table>
<thead>
<tr>
<th>Statement</th>
<th>NO!(0)</th>
<th>no(1)</th>
<th>yes(2)</th>
<th>YES!(3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel like crying.</td>
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<tr>
<td>2. I feel like running away.</td>
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<tr>
<td>3. I have lots of energy.</td>
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<td>4. I think life is not worth living.</td>
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<td>5. I enjoy the things I do as much as I used to.</td>
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<td>6. I like talking with my family.</td>
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<td>7. I feel very lonely.</td>
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<td>8. I am easily cheered up.</td>
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<td>9. I think about bad things that have happened.</td>
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<td>10. I’m bothered by thoughts about the person who died.</td>
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<td>11. I am unable to accept the death of the person who died.</td>
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<td>12. I feel comfortable talking about the person who died.</td>
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<td>13. I have learned to cope better with life since the death</td>
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<td>14. I feel as though I am a better person since the death.</td>
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<td>15. I have more compassion for others since the death.</td>
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<td>16. I feel bitter since the death.</td>
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<td>17. I am angry at others since the death.</td>
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<td>18. I’ve been doing risky or dangerous things since the death.</td>
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<td>19. I’m handling the death well.</td>
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<td>20. I’m satisfied with how I’ve dealt with the death.</td>
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<td>21. I’ve cried about the death.</td>
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<td>22. I have a ways to go to feel at peace about the death.</td>
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<td>23. I have trouble falling asleep because I’m thinking about the death.</td>
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<td>24. I’m upset about the death.</td>
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<td>25. I’m sad about the death.</td>
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<td>26. I frequently wish to see or be with the person who died.</td>
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<td>27. I feel connected to the person who died.</td>
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<td>28. I have dreams about the person who died.</td>
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<tr>
<td>29. In my head, or out loud, I talk to the person who died.</td>
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<tr>
<td>30. The person who died is still part of my life.</td>
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<tr>
<td>31. I think about what the person who died would want me to do.</td>
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</tbody>
</table>
Mark how true each statement is for you, in the past week.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Response</th>
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</thead>
<tbody>
<tr>
<td>32. I have close friends outside my family who care about me.</td>
<td>NO! (0)</td>
</tr>
<tr>
<td>33. I can count on my family to help me with problems.</td>
<td>NO! (0)</td>
</tr>
<tr>
<td>34. I feel very close to an adult in my family.</td>
<td>NO! (0)</td>
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<tr>
<td>35. I share my thoughts or feelings with an adult in my family</td>
<td>NO! (0)</td>
</tr>
<tr>
<td>36. There are adults outside my family who care about me.</td>
<td>NO! (0)</td>
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<tr>
<td>37. I appreciate talking with other kids at Caring Hearts Camp</td>
<td>NO! (0)</td>
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<tr>
<td>38. I am able to express myself at Caring Hearts Camp</td>
<td>NO! (0)</td>
</tr>
<tr>
<td>39. I’ve felt understood by other kids at Caring Hearts Camp</td>
<td>NO! (0)</td>
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<tr>
<td>40. I’ve felt understood by The Caring Hearts Camp staff or volunteers.</td>
<td>NO! (0)</td>
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<tr>
<td>41. I’ve learned about loss and grief at Caring Hearts Camp</td>
<td>NO! (0)</td>
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<tr>
<td>42. At Caring Hearts Camp, I feel less alone.</td>
<td>NO! (0)</td>
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<tr>
<td>43. At Caring Hearts Camp there are other kids like me.</td>
<td>NO! (0)</td>
</tr>
<tr>
<td>44. Since coming to Caring Hearts Camp I’m better able to express myself.</td>
<td>NO! (0)</td>
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<tr>
<td>45. I use alcohol or drugs.</td>
<td>NO! (0)</td>
</tr>
<tr>
<td>46. My use of alcohol or drugs has caused me problems.</td>
<td>NO! (0)</td>
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<tr>
<td>47. My belief in God or a higher power helps me cope.</td>
<td>NO! (0)</td>
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<tr>
<td>48. Going to church or a spiritual group helps me cope.</td>
<td>NO! (0)</td>
</tr>
</tbody>
</table>

How are you doing? How are things going in your life? Please make a mark on the scale to let us know. The closer to the smiley face, the better things are. The closer to the ‘frowny’ face, things are not so good.

Me
(How am I doing?)

Family
(How are things in my family?)

School
(How am I doing at school?)

Everything
(How is everything going?)
Your name: ____________________        Your child’s name:__________________
Note: This cover page will be promptly removed and your survey will only have a code number (see consent letter for details).

Evaluation of
Caring Hearts Camp
Pre-test
Caregiver Version

Research Consultation Provided by:

PORTLAND STATE UNIVERSITY
School of Social Work
Regional Research Institute
Daniel Coleman, M.S.W., Ph.D.
Associate Professor
Instructions: Thank you for agreeing to participate in this study. The questionnaire is broken into sections, each with its own instructions. Throughout this survey, you will be asked to rate yourself and your child on several different dimensions. There are no right or wrong answers. Please try to select the best possible answer that fits each question.

I. About yourself and your family.

Please circle: I am: Male    Female    My age: _______

How many of your children attended Caring Hearts Camp? _______

What is your relationship to this child?
    Biological Parent    Step Parent    Adoptive Parent    Grandparent
    Other_________________________

II. About Your Child

Your child’s age_______  Your child’s gender: Male    Female

Who Died?
    ___Parent(s) Please Specify: Mother___ Father___
    ___Sibling
    ___Friend
    ___Relative specify______________
    ___Other specify______________

Date the death occurred: _____ | _____ | ______
Month     Day     Year

What was the cause of the death? (Please check the one that best fits, and briefly describe below)
    ___Accident
    ___Illness
    ___Sudden Death (e.g., heart attack)
    ___Suicide
    ___Homicide
    ___Other.
Brief description:_________________________________________________________________

Was the child present at the time of death?        Did the child find the body?
    ___Yes                  ___Yes
    ___No                ___No

With whom does the child currently live? (Check all that apply)
    ___Parent(s) Please Specify: Mother____ Father____
    ___Sibling
    ___Friend
    ___Relative specify______________
    ___Other specify______________

What other losses has the child experienced in his or her lifetime? (Check all that apply)
    ___Death of parent (please specify:________________) Date of loss:__________
    ___Death of sibling (please specify age of sibling:____________) Date of loss:__________
    ___Death of friend (please specify:____________) Date of loss:__________
    ___Death of relative (please specify:____________) Date of loss:__________
    ___Death of other significant person (please specify:____________) Date of loss:__________
    ___Death of a pet (please specify:____________) Date of loss:__________
    ___Loss of home (please specify:____________) Date of loss:__________
    ___Separation from sibling(s) (please specify:____________) Date of loss:__________
    ___Loss of biological family unit (____Foster care or ____Adoption) Date of loss:__________
    ___Divorce. (___biological parents; ___other). Date:________________
Mark how well each item describes your child in the past week. Please circle your answer.

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<tbody>
<tr>
<td>1. My child is preoccupied with thoughts about the person who died.</td>
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<td>2. My child is unable to accept the death.</td>
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<td>3. My child can talk about the person who died without discomfort</td>
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<td>4. My child is angry about the death.</td>
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<td>5. My child shows more caring for others since the death.</td>
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<td>6. Since the death, my child copes better with life stresses.</td>
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<td>7. Since the death, my child engages in risky or dangerous behavior.</td>
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<td>8. My child acts like the death never happened.</td>
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<td>9. My child has handled the death well.</td>
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<td>10. My child has cried about the death.</td>
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<td>11. My child has a ways to go to feel at peace about the death.</td>
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<td>12. My child believes he or she can influence whether things go well or poorly.</td>
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<td>13. My child is upset about the death.</td>
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<td>18. In his or her head, or out loud, my child talks to the person who died.</td>
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<tr>
<td>19. The person who died is still part of my child’s life.</td>
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<tr>
<td>20. My child thinks about what the person who died would want him or her to do.</td>
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<tr>
<td>21. My child believes it doesn’t pay to try hard because things never turn out right anyway.</td>
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<td>22. My child is pessimistic about the future.</td>
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<tr>
<td>23. My child tends to expect bad things to happen, not good things.</td>
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<tr>
<td>24. My child is hopeful.</td>
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</tbody>
</table>
Evaluation of
Caring Hearts Camp
Post-test #1
Ages 13-18
(Caregiver also participating in Study)

Research Consultation Provided by:

PORTLAND STATE UNIVERSITY
School of Social Work
Regional Research Institute
Daniel Coleman, M.S.W., Ph.D.
Associate Professor
**Instructions:** Thank you for agreeing to participate in this study. There are no right or wrong answers. Please try to select the best possible answer that fits each question.

Please provide some information about yourself and the death:

Please circle: Male  Female  Age: _______

**Who Died?**

___Parent(s)  Please Specify: Mother___ Father___
___Sibling  
___Friend  
___Relative  Please specify_______________
___Other  Please specify_______________

**II. Mark how true each statement is for you, in the past week.**

<table>
<thead>
<tr>
<th>Statement</th>
<th>NO! (0)</th>
<th>no (1)</th>
<th>yes (2)</th>
<th>YES! (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel like crying.</td>
<td></td>
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<td></td>
<td></td>
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<tr>
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Mark how true each statement is for you, *in the past week.*

<table>
<thead>
<tr>
<th>Statement</th>
<th>NO!</th>
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<th>yes</th>
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<tbody>
<tr>
<td>32. I have close friends outside my family who care about me.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
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<tr>
<td>33. I can count on my family to help me with problems.</td>
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<td>no</td>
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<td>34. I feel very close to an adult in my family.</td>
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<td>35. I share my thoughts or feelings with an adult in my family</td>
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<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>36. There are adults outside my family who care about me.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>37. I appreciate talking with other kids at Caring Hearts Camp</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>38. I am able to express myself at Caring Hearts Camp</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>39. I’ve felt understood by other kids at Caring Hearts Camp</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>40. I’ve felt understood by The Caring Hearts Camp staff or volunteers.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>41. I’ve learned about loss and grief at Caring Hearts Camp</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>42. At Caring Hearts Camp, I feel less alone.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
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<tr>
<td>43. At Caring Hearts Camp there are other kids like me.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
</tr>
<tr>
<td>44. Since coming to Caring Hearts Camp I’m better able to express myself.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
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<tr>
<td>45. I use alcohol or drugs.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
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<tr>
<td>46. My use of alcohol or drugs has caused me problems.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
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<tr>
<td>47. My belief in God or a higher power helps me cope.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
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<tr>
<td>48. Going to church or a spiritual group helps me cope.</td>
<td>NO!</td>
<td>no</td>
<td>yes</td>
<td>YES!</td>
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</table>

How are you doing? How are things going in your life? Please make a mark on the scale to let us know. The closer to the smiley face, the better things are. The closer to the ‘frowny’ face, things are not so good.

<table>
<thead>
<tr>
<th>Me (How am I doing?)</th>
<th>I------------------------------------------------------------------------------------I</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>☹️</td>
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</table>

<table>
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<tr>
<th>Family (How are things in my family?)</th>
<th>I------------------------------------------------------------------------------------I</th>
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<th>School (How am I doing at school?)</th>
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<th>Everything (How is everything going?)</th>
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What can you do/have you done when you want to remember your special person who died?

What can you do/have you done when you want to take your mind off of your special person who has died?
Evaluation of
Caring Hearts Camp
Post-test #2
Ages 13-18
(Caregiver also participating in Study)
**Instructions:** Thank you for agreeing to participate in this study. *There are no right or wrong answers.* Please try to select the best possible answer that fits each question.

Please provide some information about yourself and the death:

Please circle:  Male    Female                                      Age: _______

**Who Died?**
- ___Parent(s) Please Specify: Mother___ Father___
- ___Sibling
- ___Friend
- ___Relative Please specify_______________
- ___Other Please specify_______________

**II. Mark how true each statement is for you, in the past week.**

<table>
<thead>
<tr>
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**Me**  
(How am I doing?)

I-----------------------------------------------I

![Sad face](image)

**Family**  
(How are things in my family?)

I-----------------------------------------------I

![Sad face](image)

**School**  
(How am I doing at school?)

I-----------------------------------------------I

![Sad face](image)

**Everything**  
(How is everything going?)

I-----------------------------------------------I

![Sad face](image)
Name: ____________________

Date: ________________

Everyday Grief Activities

What can you do/ have you done when you want to remember your special person who died?

What can you do/ have you done when you want to take your mind off of your special person who has died?
Evaluation of Caring Hearts Camp
Post-test
Caregiver's Version

Research Consultation Provided by:

School of Social Work
Regional Research Institute
Daniel Coleman, M.S.W., Ph.D.
Associate Professor
Instructions: Thank you for agreeing to participate in this study. The questionnaire is broken into sections, each with its own instructions. Throughout this survey, you will be asked to rate yourself and your child on several different dimensions. There are no right or wrong answers. Please try to select the best possible answer that fits each question.

If any of the below circumstances changed in the last 6 months for the child, please fill out the section below:

I. About yourself and your family.

1. Please circle: I am: Male Female  
2. My age: _______
3. Your Racial or Ethnic Identification: ________________________________
4. Please circle highest level of schooling completed:
   - Some HS
   - Grade 12 / GED
   - Some college
   - Bachelor’s
   - Master’s
   - Doctoral
5. What is your relationship to this child?
   - Biological Parent
   - Step Parent
   - Adoptive Parent
   - Grandparent
   - Other_________________________

II. With whom does the child currently live? (Check all that apply)
   - Parent(s)  Please Specify: Mother____ Father____
   - Sibling ___Relative specify_______________
   - Friend ___Other specify_________________

III. What other losses has the child experienced in the last 6 months:
   - Death of parent (please specify: ) Date of loss: 
   - Death of sibling (please specify age of sibling: ) Date of loss: 
   - Death of friend (please specify: ) Date of loss: 
   - Death of relative (please specify: ) Date of loss: 
   - Death of other significant person (please specify: ) Date of loss: 
   - Death of a pet (please specify: ) Date of loss: 
   - Loss of home (please specify: ) Date of loss: 
   - Separation from sibling(s) (please specify: ) Date of loss: 
   - Loss of biological family unit ( Foster care or Adoption) Date of loss: 
   - Divorce. ( biological parents; other). Date: 

Mark how well each item describes your child *in the past week.*
Please circle your answer.

<table>
<thead>
<tr>
<th></th>
<th>strongly disagree (0)</th>
<th>disagree(1)</th>
<th>agree(2)</th>
<th>strongly agree(3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child is preoccupied with thoughts about the person who died.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>2. My child is unable to accept the death.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>3. My child can talk about the person who died without discomfort.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>4. My child is angry about the death.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>5. My child shows more caring for others since the death.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>6. Since the death, my child copes better with life stresses.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>7. Since the death, my child engages in risky or dangerous behaviour.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>8. My child acts like the death never happened.</td>
<td>(0)</td>
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<td>9. My child has handled the death well.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>10. My child has cried about the death.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>11. My child has a way to go to feel at peace about the death.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>12. My child believes he or she can influence whether things go well or poorly.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>13. My child is upset about the death.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>14. My child is sad about the death.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>15. My child frequently wishes to see or be with the person who died.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>16. My child feels connected to the person who died.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>17. My child has dreams about the person who died.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>18. In his or her head, or out loud, my child talks to the person who died.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>19. The person who died is still part of my child's life.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>20. My child thinks about what the person who died would want him or her to do.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>21. My child believes it doesn't pay to try hard because things never turn out right anyway.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>22. My child is pessimistic about the future.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>23. My child tends to expect bad things to happen, not good things.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>24. My child is hopeful.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>25. My child appreciated talking with other kids at Caring Hearts Camp.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>26. My child is able to express their feelings since Caring Hearts Camp.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>27. My child felt understood by other kids at Caring Hearts Camp.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>28. My child felt understood by Caring Hearts Camp staff or volunteers.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>29. My child has learned about loss and grief at Caring Hearts Camp.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>30. Since going to Caring Hearts Camp, my child is better able to express themselves.</td>
<td>(0)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
</tbody>
</table>