# Watching Someone You Love Die: An integrative approach for adolescents dealing with the traumatic impact of parental life-limiting illness

by

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A capstone submitted in partial fulfillment

of the requirements for the Degree of

Master of Counselling (MC)

City University in Canada

Vancouver, BC

June 2024

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**Abstract**

Facing the death of a parent is inevitable during one's lifetime. Research has primarily focused on grief and bereavement in older adults, leaving the voices of adolescents underrepresented in research studies. One of the main factors for this is tied to social and cultural conditioning. Death has typically been a forbidden topic of discussion in Western cultures and is especially considered a taboo subject for youth. Therefore, the focus of interest and study has been placed on the ill and dying parent, leaving young people's experiences out of the conversation. Adolescents have unique vulnerabilities to traumatic stressors due to age and emotional maturity and their voices need to be considered in research about bereavement. This capstone aims to better inform counselling practitioners on how to support young people ages 13 – 18 in bereavement. This capstone will discuss the benefits of using an integrative approach for adolescents including the application of continuing bonds and meaning reconstruction theory. Chapter three will conclude with a proposed bereavement group using a combination of expressive arts therapy, narrative storytelling, and acceptance and commitment therapy (ACT). May we all become more grief literate to better support our youth in their mourning.

*Key Words:* continuing bonds theory, meaning reconstruction, post-traumatic growth, parental life-limiting illness, adolescence

## Acknowledgement

Thank you to my Capstone advisor; Dr. Jill Taggart, and City University for making my educational experience accessible, creative, and fun. And a special thank you to my mum for helping me when I needed it and supporting me on my educational journey.

## Dedication

This Capstone is dedicated to my dad, Bill Kankewitt. His enduring strength, optimism, and unconditional love throughout his illness, until his death, made me who I am today.

He lives on in my heart and in the work that I do.

***"****I'm not God, but God is in me. I'm not powerful, but I have the power. I must surrender, but to do so is to win. I must die, but to do so is to live. I can't love others until I love myself. I've made mistakes, but I am not a mistake. When I forgive myself, God will be there."*

--Bill Kankewitt

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## Chapter One

The reality is you will grieve forever. You will not 'get over' the loss of a loved one, you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again, but you will never be the same again. Nor should you be the same, nor should you want to.

--Elisabeth Kubler-Ross, (2014, p.230)

Grief that begins in youth is a lifelong process that needs to be understood and honored. Our relationships and attachments do not end at death. It is a myth that we get over the loss of a loved one. We are permanently transformed for better or for worse by the removal of a human being that we have come to know and depend on. Moreover, loss forces us to face our mortality and the impermanence of life. The naivety and invincibility of youth is forever changed. As Elisabeth Kubler-Ross (2014) stated so eloquently in her quote, we will not be the same again, but we will somehow rebuild our lives to make meaning of our loss and to carry on the memory of the person who is gone.

While loss is devastating at any age "a natural death at the end of a long life tends to be much easier to accept" (Calhoun et al., 2010, p.131). Research literature has suggested that parental loss for older adults is among the easiest of bereavements to accept as it follows the normal developmental course of life and is the least likely to result in complicated grief symptoms (Kosminsky & Jordan, 2016). Adolescents have unique experiences with loss due to their specific age-related development and attachment needs (Balk, 2014; Kosminsky & Jordan, 2016). Adolescents compared to younger children have greater cognitive and emotional

capacities that make them highly sensitive and aware of what is happening around them and attuned to the imminence of death (Balk, 2014; Jessop et al., 2022; Kosminsky & Jordan, 2016). Yet, adolescents are at an age where they are still developing emotional intelligence and cannot always articulate their experiences in words. The illness and death of a parent can be detrimental to their mental health as it separates them from their peers, interferes with goals and ambitions, and brings up emotions that are beyond the realm of processing and integrating at such a young age (Balk, 2014). Researchers today consider bereavement for young people one of the most traumatic experiences that can occur and is a factor in assessing for adverse childhood experiences (ACEs) that can have lifelong implications leading to prolonged and unresolved grief (Lytje, 2017).

Often considered too young or too old in research studies, the voices and experiences of teenagers have been a minority in bereavement literature (Balk, 2014; Jessop et al., 2022; Kosminsky & Jordan, 2016). There is a need for sensitive, trauma-informed, and age-appropriate psychosocial support to help youth navigate the territory of illness, death, and bereavement (Jessop et al., 2022). This capstone aims to investigate the effectiveness of early grief interventions that can mitigate the complications and lifelong implications of the trauma from being exposed to a terminally ill parent and their subsequent death. Bereavement is a normal and natural response to loss. However, adolescent bereavement is an important topic to consider because studies have confirmed that compared to non-bereaved peers, youth who have been exposed to parental loss during middle and high school years had greater psychosocial

challenges, mental health and substance misuse concerns, and developmental regressions that continued into adulthood (Tuazon & Gressard, 2023).

In this chapter, I will introduce the guiding theories in bereavement that support the vulnerable process of grieving a loved one, including how we can de-pathologize the grieving process as something that someone "gets over." This will lay the foundation for chapter two, where I will review the literature that explains the interconnection between the developmental stages of youth, attachment theory, and continuing bonds after death (Balk, 2014, Field et al., 2005; Klass & Steffan, 2018; Kosminsky & Jordan, 2016). These three theories work in unison to distinguish the specific needs of youth and explain how the impact of parental illness and anticipatory grief is managed when loss is accepted as an ongoing and lifelong process.

**Overview of the Topic**

How people grieve and mourn a loss has garnered significant attention and speculation in the field of psychology and psychiatry (Rubin et al., 2020). Since the beginning of grief's introduction into psychological study, its nature has been mysterious, misunderstood, and misconstrued. Early twentieth-century psychological research constructed grief as a pathological condition needing immediate intervention for those in a capitalistic society to heal from as quickly as possible and get back to work (Granek, 2010). Adolescent bereavement has been particularly scrutinized and pathologized due to its higher prevalence of anxiety, depression, and mental health symptoms that extend beyond two years or more after the death of a parent, classifying it as an "abnormal" grieving pattern (Balk, 2014., Kosminsky & Jordan, 2016). For this reason, the historical context of grief literature is important to understand.

In 1917, the psychoanalyst Freud wrote that grieving requires breaking bonds with the deceased while quickly and efficiently recovering from loss (Balk, 2014., Yousuf-Abramson, 2021). Similarly, in 1944, the psychiatrist Erich Lindemann proposed that grief work involves forming new relationships to replace the departed within a short time after death (Balk, 2014., Calhoun et al., 2010). The legacy of moving on quickly after a death in early grief theory is reflected in literature today. The revised 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) now includes prolonged grief disorder which is considered "disruptive" grief that lasts beyond a year (2022). Rather than considering the context of developmental delays that contribute to a longer mourning period, traditional grief therapies tended to overlook the distinct grief responses of youth.

Adolescents already face a developmental struggle for identity and self-image. However, when faced with an existential crisis due to parental terminal illness, they are more inclined to exhibit symptoms such as eating and sleeping changes, shifts in behavioral patterns, and a loss of meaning and direction in their lives placing them behind the scholarly and career trajectory of their friends (Balk, 2014). This setback at a crucial time in life can take years to fully process, and often requires trauma-informed grief interventions and the ongoing patience and support of loving friends, family, and community members. Newer grief models and theories incorporate developmental models (Balk, 2014) and attachment theory (Kosminsky & Jordan, 2016) that explain the reason why adolescents are more likely to process their grief later in life.

Modern grief literature has worked at shifting the narrative in bereavement to normalize and humanize the grieving experience. Bereavement theories such as continuing bonds, meaning

reconstruction, and posttraumatic growth will be explored in this capstone. These theories work at de-pathologizing early grief literature and support the psychological human need to maintain a relationship with the deceased for the remainder of one's lifetime by honoring and keeping their memory alive (Hedtke 2012, 2016; Klass & Steffen, 2018; Neimeyer, 2006, 2019). Grief therapies work as an intervention to reconstruct beliefs, recreate a sense of meaning, and develop a new life narrative (Calhoun et al., 2010). The grief therapist's role is to assist the client in weaving new meaning into their lives by offering hope and possibilities (Penwarden, 2022). It is not always easy to convince youth to engage in a therapeutic process, let alone share their feelings with others. Thus, an integrative approach to cope with bereavement that reflects their distinct maturation levels and incorporates empirical evidence with how grief collides with identity formation and ego development in adolescence is needed (Balk, 2014; Kosminsky & Jordan, 2016).

One way that loss can be processed and has been found beneficial with youth is through the expressive arts. Traditionally, art and storytelling have been used as an alternative modality in place of talk therapy (Peterson & Goldberg, 2016). Literature has shown that creative expression is one of the most impactful means of processing grief, especially at times when grief is so profound that it overrides basic cognitive abilities to communicate through language (Peterson & Goldberg, 2016). For centuries, art has been used as an avenue of expression to communicate complicated emotions and create a continued connection whilst providing meaningful insight beyond the tragedy of loss (Thompson & Neimeyer, 2014). Some of the greatest plays, musicals, ballets, movie scripts, songs, books, poetry, sculptures, and paintings

were inspired by hardship, trauma, grief, and loss. Expressive creations of loss have long been utilized in cultures all over the world (Thompson & Neimeyer, 2014). Born of incredible pain, the expression of grief through art can create a transmutation of post-traumatic stress into post-traumatic growth (Hedtke, 2012; Tedeschi et al., 2017; Thompson & Neimeyer, 2014).

**Purpose Statement**

While there has been much research in the topic of bereavement, few studies have focused primarily on the developmental impacts of grief during adolescence, and specifically from witnessing the physical decline and death of a terminally ill parent (Balk, 2014; Jessop et al., 2022). Therefore, this capstone aims to answer the questions "What are the impacts of bereavement on the developmental stages of adolescents?" and, "How can counsellors utilize bereavement theory in a therapeutic context that is appropriate for adolescents dealing with parental illness and death?"

The definitive stage of adolescence can differ culturally and globally. The World Health Organization has defined adolescence as a stage from the onset of puberty to young adulthood (Jessop et al., 2022). For the purposes of this capstone, I will be focusing on the developmental ages of 13- 18, which are typically middle-school to high-school ages in North America. The reason for this is that middle and high school are critical developmental years in identity formation towards independence and adulthood. At this stage, youth begin to re-define their attachments to family and create new attachments with peers, romantic partners, and social groups outside of the family system (Balk, 2014). The death of a parent can be one of the most stressful events any young person could experience and causes psychological

vulnerability impacting the normal trajectory of identity formation, cognitive functioning, and social development (Balk, 2014; Jessop et al., 2022).

Bereavement is not a one size fits all process and varies greatly between age-groups, cultures, circumstances of death, and relationship with the deceased. There has been much debate in bereavement literature and within psychological research about the nature of grief since the onset of its study in the early twentieth century (Balk, 2014; Jessop et al., 2022; Klass & Steffen, 2018; Neimeyer 2006; Thompson &Neimeyer, 2014). The purpose of this capstone is to de-pathologize and normalize the grieving process for young people, and to inform and equip counsellors with therapeutic techniques that are sensitive, trauma-informed, nurturing, and healing for youth. Knowledge in this area can equip counsellors with age-appropriate tools and resources to assist youth in adjusting to their life with a terminally ill parent and thereafter.

**Theoretical/Conceptual Framework**

The guiding theoretical concepts for this capstone project are rooted in bereavement literature and consist of continuing bonds theory, meaning reconstruction, developmental theory, attachment theory, and post-traumatic growth (Balk, 2014; Hedtke 2014; Klass & Steffen, 2018; Thompson & Neimeyer 2014). These theories intersect and work collaboratively to provide a deeper understanding of grief and utilize a strengths-based approach to inform and guide therapeutic modalities like expressive arts therapy for bereavement. Klass (1996) states that "Grief is a lifelong developmental process that enables us to maintain a continuing bond with the deceased. Despite cultural disapproval and a lack of validation by professionals, survivors find places for the dead in their ongoing lives and even in their communities" (as cited by Witztum &

Malkinson, 2009, p. 132). Early literature suggests that we should move on after the death of a loved one and that grief beyond a year is considered prolonged and problematic, while continuing bonds theory argues that our attachments do not end at death and that grief is lifelong (Klass & Steffen, 2008).

Research studies in bereavement aim to understand how people make sense of their worldviews after traumatic events and how they strive to give meaning to their experiences (Nelson et al., 2022). In bereavement literature, meaning making intersects with continuing bonds theory as an exploratory means to understand a new worldview that incorporates an ongoing relationship with the deceased (Klass & Steffan, 2018). Death creates the severing of a meaningful attachment (Kosminsky & Jordan, 2016). As this capstone is centered around adolescents, developmental systems theory and attachment theory are relevant for understanding the symptomology of bereavement in youth (Balk, 2014; Kosminsky & Jordan, 2016). Grief psychologists, such as Neimeyer (2006) state that research has documented greater separation anxiety and traumatic distress at the loss of a parent in adolescence than in later adulthood, showing that youth still rely heavily on their attachment figures (p.735). Finally, studies on the theory of post-traumatic growth found that over time youth may find a positive integration of their loss through a reorganization of self-identity for the better, a multidimensional quest for meaning, and security of attachment through continuing bonds (Neimeyer, 2006; Tedeschi et al., 2017).

**Contribution to the Field**

The objective of this capstone project is to provide a case for an integrative approach

for adolescents that considers the impact of grief on their developmental and attachment needs with a trauma-informed lens. Talk therapy has not always been an effective path of therapeutic intervention for youth, and this capstone incorporates bereavement theory with expressive arts therapy, narrative storytelling, and Acceptance and Commitment Therapy (ACT) as an alternative source of healing. This project aims to give a voice to adolescents and their experience of grief as it has been underrepresented in research. Furthermore, much of bereavement literature has focused on grief post-death and interventions thereafter. Research shows that anticipatory grief from parental life-limiting illness contributes to the experience of complex post-traumatic stress and compounds bereavement after death. Therefore, there is a need to understand the pre-phase of grief and possible interventions at this stage to better prepare youth for the inevitability of the loss of their parent. Most importantly, this project is intended to contribute to the growing body of grief literature that normalizes the life-long relationship that people have with the deceased and finding meaning in their lives after loss.

**Reflectivity and Positionality Statement**

The social lens for this research paper comes from my lived experience and perspective of being a fifth-sixth generation Canadian settler on my maternal side with Scottish, British, and Irish ancestry. This Eurocentric, middle-class, heteronormative upbringing shaped my worldview and early understanding of illness, grief, and death. I am second-generation Canadian settler with Polish and Jewish Ancestry on my paternal side. Our Jewish traditions were not carried on and were assimilated into Canadian culture. In my adolescence, I had a curiosity about my Jewish roots which gave rise to my interest in the Holocaust and my passion

for Viktor Frankl (1959) and his book Man's Search for Meaning. I read this book as a teenager, and to this day it remains a go-to in times of stress and sadness. Frankl is the inspiration and guiding theorist behind my interest in counselling and his work is reflected in this capstone with the use of meaning reconstruction.

I acknowledge that my passion for this research comes from the loss of my own father to Amyotrophic Lateral Sclerosis (ALS). I was roughly ten-years old when my dad was diagnosed with ALS and given the prognosis of three to five years to live. Beating the odds of his prognosis, which is rare with ALS, he ended up passing away when I was a young adult. Although he did not die when I was in adolescence, I witnessed the slow, but worsening deterioration of a terminal illness and had the awareness that death could come on any day. I have intimate experience with what I have come to understand as anticipatory grief and post-traumatic stress. During my youth and young adulthood, I was met with many cultural messages around death that permeate in a Eurocentric, capitalistic and colonial culture. Some of these messages about "moving on" and "keeping a stiff upper lip" create fear of speaking about death, apprehension about openly sharing and communicating feelings of loss, wearing a social mask to conceal grief, and isolation from peers and community members.

My personal experience with a terminally ill parent, early parental death, and the aloneness that I faced in adolescence about this topic is the backbone of this research paper and drives my enthusiasm for advocacy in this area. There are many aspects of the grief process for youth that are invariably different from losing a parent in older adulthood that need to be understood and practiced in community. Conversely, I am aware that my personal experience

may cause me to be biased about grief and death. I must make a conscious effort in my work to address the fact that grief presents differently for all persons and there are a multitude of diverse ways that people choose to heal. Lastly, I recognize my privilege in being able to say goodbye to my dying parent and having had closure provided by that experience. At my father's deathbed in hospice, I was acutely aware of the gift of being there, as tragic as it was, because it is not an opportunity afforded to everyone. There are those who lose someone in tragic circumstances without saying goodbye, and that is another level of grief that I humbly acknowledge.

## Definition of Terms

### *Adolescence*

A period after childhood, and before adulthood, typically between the ages of 13 –18. It is a coming-of-age transition marked by a desire for increased independence and autonomy, when youth begin to assert their own agency, form their own opinions, and carve out their unique identity and who they want to be in the world (Balk, 2014; Marshall et al., 2021). Adolescence includes an early, middle, and late period each with a distinct set of biological, cognitive, and social changes (Balk, 2014; Matthews et al., 2022).

### *Anticipatory Grief*

It is the anticipation of a death, defined as the awareness of proximity in another's death. Anticipatory grief is the process of grieving the loss of a relationship while that person is still present and alive. This grief triggers a primal survival response, and the nervous system becomes highly activated at this time to prepare for the threat of death. Often, in the anticipatory phase,

people go into an active role of caregiving and supporting the dying person (fight) or avoiding the feelings and experience altogether (flight), and others may go into a state of complete shock (freeze). People will experience vicarious suffering from witnessing the terminal illness and share a similar experience about death anxiety alongside the ill person (Coelho et al., 2019). Anticipatory grief allows a person to adapt to the concept that their loved one is dying and can provide a sense of relief and peace when someone passes away, in that they are no longer suffering (Coelho et al., 2019). An assumption is that anticipatory grief is easier than grief after a sudden death, however watching someone die from an illness can be equally traumatizing (Balk, 2014).

***Complex Post-Traumatic Stress***

Acute stress that impacts psychosocial functioning and well-being. Anxious symptoms are caused by repetitive exposure to instability, uncertainty, unpredictability, and graphic stimuli of illness and death. (Fearnley & Boland 2016).

***Continuing Bonds Theory***

The concept that a relationship is not severed at death. Love for the deceased carries on and is redefined and transformed over time. Continuing bonds are not pathological. In the early twentieth century when grief was first introduced into the field of psychology, it was believed that the purpose of grief was to learn to detach as the object no longer exists (Klass & Steffen, 2018). Rather, in continuing bonds theory, modern researchers suggest that keeping the memory and legacy of the deceased person alive as one moves forward in their lives is a necessary and essential requirement for managing grief and mental health

(Klass & Steffen, 2018).

***Expressive Art Therapy***

Natalie Rogers, the daughter of Carl Rogers, one of the founding fathers of humanistic psychology, described expressive art therapy for grief as "a language to release and transform the emotions that well up around the loss of a loved one or around the loss of some aspect of oneself" (Thompson & Neimeyer, 2014, p.20). Expressive arts therapy is often used as a therapeutic modality in bereavement because grief can be so profound that it requires an expressive outlet beyond talk-therapy when words are not enough. There are many forms of expressive art therapy including but not limited to; creative writing, poetry, drawing, painting, photography, dance, theatre, gardening, music, and movie making (Thompson & Neimeyer, 2014).

***Meaning Reconstruction***

When the process of grieving has called for a reconstruction of a world of meaning that has been lost. Viewed as a coping resource, meaning making is the integration of loss into the survivors' meaning systems with how they process their identity, worldview, and navigate life choices (Neimeyer, 2006; 2019). Viktor Frankl (1959) was one of the founders in introducing the philosophy of meaning-making into the canon of psychology.

***Parental Life Limiting Illness***

A diagnosis of a terminal illness without the chance of survival. Parental illness transforms all aspects of daily life for children and adolescence, including activities, roles, and relationships. Family members often become caregivers, and parental illness impacts not only the

emotional and psychological health of the patient but also the entire family system (Sommers-Spijkerman et al., 2022).

### *Post-Traumatic Growth*

A theory that positive changes are born from the fear and devastation of post-traumatic stress. Bereavement studies using the Post-Traumatic Growth Inventory (PTGI) specifically with adolescents have been able to measure personal growth, increased independence, health awareness, and maturity from their experiences with loss (Jessop et al., 2022; Tedeschi et al., 2017).

## Outline of the Capstone Project Chapters

The following literature review will explore and provide an overview of bereavement theories that are relevant and important for adolescents with grief. Attachment theory, continuing bonds, and meaning reconstruction are modern theories that are most used in the therapeutic context of grief and loss (Balk, 2014; Klass & Steffan, 2014; Kosminsky & Jordan, 2016; Neimeyer, 2006, 2019). Understanding continuing bonds and meaning reconstruction is crucial when working with adolescent attachment to their caregivers and how to mitigate their loss (Balk 2014; Field et al, 2005). Through the influence of psychologists like John Bowlby, attachment theory was introduced in grief literature during the 1980s (Balk, 2014; Kosminsky & Jordan 2016) Around this time, other grief researchers began to advocate for a continuing bonds theory that supported the idea of maintaining ties to the deceased as a normal human response to grief (Klass & Steffen 2014; Kosminsky & Jordan 2016). As such, the

following chapter will critique early bereavement literature that has had tendencies to perpetuate the notion that there is a normal and an abnormal way to grieve (Granek, 2010).

Adolescence is a time when many developmental changes occur, and chapter two will discuss why loss is so significant at this stage in life. Research that studies youth with a terminally ill parent provides insight into what happens when grief interrupts adolescent milestones in development and attachment. Therefore, chapter two explores how parental life-limiting illness impacts the home-life and social life of youth. Additionally, several aspects of death and dying that are specific for youth with a terminally ill parent such as anticipatory grief, and responses to graphic stimuli from the illness that may cause post-traumatic stress. Although, through tragedy, youth may also experience post-traumatic growth which will be discussed as a strengths-based outcome after loss. This leads to the last portion of chapter two that introduces an integrative approach to working with adolescents in bereavement. Research has shown that counsellors need to have a variety of techniques and tools available for youth that differ from working with adults. Expressive art therapy, narrative storytelling, and Acceptance and Commitment therapy will be suggested as therapeutic interventions for youth. Finally, in chapter three, these techniques will be brought to life in a bereavement group for youth. This six-week group offers creative practices and strategies appropriate for youth to explore the expression of their loss and create ways to remember their loved one in the presence of their peers who have had similar experiences.

## Chapter Two: Literature Review

Therapeutic work with bereaved youth requires counsellors to have a toolbox of theories and modalities that are appropriate and sensitive to the needs of adolescents who are dealing with parental life-limiting illness and the aftermath of a significant death (Matthews et al.,2022). First, it is impactful to understand how grief manifests for adolescents based on their development and attachment needs (Balk, 2014). This chapter will review literature that explores the complexities related to grief symptoms of bereaved youth and how it interferes with aspects of their emotional, psychological, and physical well-being (Arnold, 2020; Balk, 2014; Matthews et al., 2022). I will explain how theories in bereavement psychology have moved away from a more pathologizing approach and towards modalities like continuing bonds theory, meaning reconstruction, and the expressive arts. These modern modalities acknowledge the lifelong relationship that one has with grief as opposed to it being worked through and then ceasing to exist afterwards (Arnold 2020; Klass & Steffen, 2018; Thompson & Neimeyer, 2014). The final part of this chapter discusses how traumatic stress from bereavement can be transformed into post-traumatic growth. As devastating as loss is, the research literature shows that when youth receive therapeutic support and a means to express themselves through creative practices, they grow in self-awareness, deeper relationship development, and find meaning and purpose in their lives that ripples out and touches the lives of those around them (Arnold 2020; Balk,2014; Tedeschi et al., 2017).

### Historical context of grief counselling

In early twentieth-century bereavement literature, Sigmund Freud (1957) as cited in

Neimeyer et al. (2006), discouraged ongoing attachments with the deceased by encouraging the formation and investment into new relationships (p.716). It was previously believed in this era of psychotherapy that bonds with the deceased were pathological in nature and a form of unresolved and unhealthy grief. Freud (1917) wrote in his essay *Mourning and Melancholia* that the process of grief was for detaching from the deceased because it was an object that no longer exists (Klass & Steffen, 2018). Psychological literature such as *Mourning and Melancholia* (1917) started a narrative that those who "fail" at doing their grief work in certain ways were at risk of pathological grieving and psychiatric illness (Granek, 2010, p.51). Freud along with other psychoanalysts of his era thought that any longing or ongoing attachment was a hallucination or a sign of maladaptation from being unable to move on (Klass & Steffen, 2018).

Freud's (1917) early influence on bereavement literature continued to inform psychologists for several decades. Lindemann (1944) monitored grief reactions in his psychiatric practice and insisted that "patients" should be doing their grief work "properly" (Granek, 2010; McKinnon, 2015). It was incited that the length of grief depended on how well someone did their grief work, setting up a dynamic of success and failure in healing. Lindemann (1944) insisted that psychiatric interventions were superior to the support of social workers, ministers, and family members, removing agency and self-determination in the grieving process (Granek, 2010; McKinnon, 2015). Leeat Granek (2010) noted that the pathologization of grief is a widespread phenomenon, influenced by cultural, historical, and social contexts that turn regular anxieties and sadness into disorders that need to be managed

and treated by professionals. As such, from the early 1900s and into the early 1960s and ’70s, it was thought that grief was linear and could be easily categorized into phases that are managed and solved within a relatively short time frame.

**Stages of grief model**

The literature on grief began to shift in the 1970s with the introduction of Elisabeth Kubler-Ross (1969) who wrote about five stages of grief in her book O*n Death & Dying (*Kosminsky & Jordan, 2016). These five stages are denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969). Modern bereavement theorists and researchers have disputed Kubler-Ross's work because grief cannot follow such a linear and structured formulation (Balk, 2014, Klass & Steffen, 2018). However, Kubler-Ross's (1969) stages of grief model was originally intended for the terminally ill patient with the aim for them to come to terms with their inevitable death. Kubler-Ross's work was later reinterpreted by her fellow professionals and applied to grief in general (Daniel, 2023). As a result, her work has unfortunately been misunderstood. Bereavement specialists today still refer to her stages as they can be useful in validating and normalizing a client's experience; however, an emphasis is placed on the fact that the stages are not linear and not everyone goes through every stage (Daniel, 2023; Klass & Steffan, 2018).

Additionally, William Worden’s (1988) work was popularized in his published book *Grief Counselling and Grief Therapy* (cited in Kosminsky & Jordan, 2016). Worden (1988) wrote about The Four Tasks of Morning which are; accepting the reality of the loss, processing the pain, adapt to a new life imposed by the loss and carry on the memory of the loved one. In

the same vein as Worden's (1988) task model, Dr. Therese Rando (1988) describes grief in a series of six processes called the R's; recognize the loss, react to the separation, recollect and re-experience, relinquish old attachments, readjust, and reinvest. Although Worden's (1988) and Rando's (1988) work still aligns with Freud's (1917) and Lindemann's (1944) concept of taking action and working through the loss to move on, their work has been a bridge between the original pathological model and the newly emerging modern therapies for grief (Kosminsky & Jordan, 2016; McKinnon, 2015; Yousuf-Abramson, 2021).

The intention of Kubler-Ross (1969), Worden (1988), and Rando (1988) was to construct an evidence-based practice using previous grief theories but to integrate them into a more practical and compassionate bereavement model. Post-modern theories such as Continuing Bonds (Klass & Steffan, 2018) consider Kubler-Ross's final stage of acceptance as part of the unfolding process of a continued bond (Field et al., 2005). Similarly, Worden's first task of acceptance, states that what might start as an intense longing and desire for proximity, may relax and integrate into a form of acceptance of the separation and permanency of the loss leading to task four which considers ways to remember a lost loved one for the remainder of one's lifetime (Field et al., 2005; Yousuf-Abramson, 2021).

**Continuing Bonds Theory**

The concept of continuing bonds has been around for many centuries and is culturally diverse (Edgar-Bailey & Kress, 2010). There are many cultures in the world where ongoing memories and tributes to the deceased are normalized, and other cultures where this is not the case. Moreover, a person's religious and spiritual beliefs will often influence how they interpret

and integrate continuing bonds after the death of a parent (Field et al., 2005). Cross-cultural studies of grief have found a wide variety of grief responses and meaning making that are dependent on cultural, religious, social, and political influences (Klass & Steffan, 2018). Cultural guidelines inform meaning systems and construct grief narratives; therefore, it is impossible to define how an individual will connect with the concept of a continuing bond as it is dependent on social and cultural conditioning, and family beliefs and values (Klass & Steffan, 2018). What is appropriate in the therapeutic context is to normalize that grief can come in waves throughout someone's lifetime, and that the individual gets to define how they want to maintain a connection and remember their loved one.

Advocates for continuing bonds theory such as Dennis Klass (2014) have reshaped modern grief literature through research that acknowledges the necessary continuation for a deep, meaningful, and ever-shifting relationship with the deceased that can mitigate grief complications or prolonged grief. Continuing bond's theory became clinically accepted in 1996 and introduced as an evidence-based therapeutic technique into the field of bereavement (Kosminsky & Jordan, 2016). Rather than the Freudian and Lindemann concept of detaching and focusing on other relationships and goals, continuing bonds theorists suggest that by promoting an on-going and continuing connection such as talking about the deceased, recalling memories, and visiting places where the deceased used to visit help facilitate grief in a way that the mourner can maintain an attachment and integrate their loss on their own terms (Field et al., 2005; Klass & Steffan, 2018).

While there are no set stages of grief in continuing bonds theory, researchers have

measured the process of grief in stages or tasks that can be noted in continuing bonds theory through how the bereaved interact with objects that are symbolic of the deceased (Field et al., 2005; Klass & Steffan 2018). For example, in the early stages after death, a mourner may sleep with a shirt of the deceased that has not been washed to gain a sense of proximity through smell and touch. The bereaved may eventually reach a point in their grief where the shirt ends up hanging on a door or in a place of view creating proximity through sight. Lastly, the shirt may end up in a box or a drawer, and the bereaved may choose a new object to symbolize their relationship with the departed (Field et al., 2005; Klass & Steffan 2018). With this process in mourning as a consideration, continuing bonds theory honors the need for symbols and objects and views it as a relationship with the deceased that is normal, healthy, fluid, uniquely expressive, and transformative over time (Klass & Steffen, 2018). Another example of continuing bonds after death is through the expression of how one adopts certain aspects of the deceased's personality, career goals, hobbies and passions during their lifetime. In a narrative study on bereavement, one participant described how she maintained a connection with her deceased mother by adopting positive aspects and characteristics of her mother within herself (Clabburn et al., 2019). This helped her to shape and influence her daily life in remembrance of her mother through her values, actions, and goals.

Conversely, not all bonds are positive. Young people may feel conflicted depending on the relationship that they had with their deceased parent. Some limitations in studies done on continuing bonds theory for adolescents were that samples typically did not include high-risk youth with adverse relationships with their caregivers (Clabburn et al, 2019). Therefore, it

would not be conducive to suggest that continuing bonds theory would be suitable for everyone. In fact, it could be harmful in instances where youth have experienced abusive and traumatic treatment from their caregivers. In some instances, the death of a harmful caregiver could provide relief and peace. More studies on this topic, with youth at risk would be needed. The scope of studies in continuing bonds theory thus far have looked at youth who may have had negative experiences with their deceased caregiver, but overall had a loving and caring bond. Finally, continuing bonds are not reserved for biological family members. Anyone who was a caring and supportive attachment figure for a youth can be remembered through the continuing bonds model.

**Meaning Reconstruction**

Viktor Frankl stated in his famous book Man's Search for Meaning (1959); "Love goes very far beyond the physical person of the beloved. It finds its deepest meaning in the spiritual being, the inner self. Whether or not he is present, or whether he is still alive at all, ceases somehow to be of importance" (p.38). The holocaust stripped Frankl (1959) of his worldly possessions, his career, and the life of his parents, brother, wife, and children. He witnessed horrendous and tragic events that can make someone wonder how anyone could possibly resume a normal and fulfilling life afterward. Yet, Dr.Frankl (1959) went on to become a successful and influential psychologist and writer. His driving force of motivation was to create a life with meaning and purpose in the memory of his loved ones; a living legacy. Even negative experiences can cause a shift in identity in a way that causes one to reexamine the meaning of their life. Grief shatters "world assumptions" which give narrative to our

life experiences, predictability of events and understanding how things are meant to unfold (Calhoun et al., 2010). Especially for youth, assumptive world beliefs, such as my parent or caretaker will live to old age loses meaning when it is challenged by an uncontrollable event.

Dr. Robert Neimeyer (2007) lost his father to suicide at the age of 12. As an adult he became a scholar and psychologist and further developed Frankl's work. Neimeyer (2007) founded the Meaning Reconstruction theory. Neimeyer (2007) has exemplified Frankl's (1959) philosophical, psychological, and spiritual framework, notably known as "existentialism" by adding meaning reconstruction into psychological literature (Supian, 2019). In meaning reconstruction, grieving is thought to be "the act of reconstructing a world of meaning that was challenged by the loss" (Witztum & Malkinson, 2009, p. 131) Neimeyer (2014) states that integrating loss into one's systems of meaning is associated with greater reductions in psychosocial distress. Some questions that arise in loss are; "How do I make sense of what happened, and what is the meaning now in its wake?" and, "How do my spiritual or philosophic beliefs help me accommodate this transition?" (Thompson & Neimeyer, 2014, p.30).

Meaning reconstruction and continuing bonds theory work together synonymously as a culturally responsive model of bereavement to honor the grieving process and foster and support the mourner's ongoing relationship with the deceased (Klass & Steffan 2018; Hedtke 2014; Neimeyer 2019). Originally, there was little to no research on the therapeutic benefits of meaning in bereavement psychology. To make meaning reconstruction an evidence-based approach, Neimeyer (Gillies et al., 2014), along with his colleagues, created the Grief and

Meaning Reconstruction Inventory (GMRI). Components of measuring meaning-making through the inventory included; sense-making, benefit finding, and progressive identity change (Balk, 2014; Neimeyer et al., 2006). Through systematic content analysis using the GMRI, it was concluded that people who were able to make meaning in response to loss by reshaping their identity and interacting with a continuing bond with their loved one had fewer symptoms of complicated and prolonged grief (Neimeyer et al., 2006).

For youth, when building a continuing bond with their deceased parent, they may make sense of the death by constructing the core values that they admired in the person who died and relate that to characteristics they want to build in themselves. This can motivate them to work towards a desired career to construct meaning from the loss (Balk, 2014). For example, many people who have experienced a traumatic loss go on to become counsellors, doctors, nurses, policemen, or other positions of service where they can give back to the community in a way that they will give service to their loved one and how they died (Klass & Steffan, 2018; Neimeyer et al., 2006). Often, tragedy invokes motivation to find purpose through meaningful work to cope with loss by helping others. Neimeyer (2006) calls meaning-making a backstory of a relationship that regains attachment security and addresses unfinished business. Therefore, in grief therapy, continuing bonds and meaning-making intersect with attachment theory.

**John Bowlby – Attachment Theory**

> We're wired for attachment in a world full of impermanence.
>
> --Robert Neimeyer (2006, p.165)

Attachment theory was created to understand the earliest relational experiences and

how this can influence development (Kominsky & Jordan, 2016). British psychoanalyst, John Bowlby (1977) developed attachment theory as a response to the psychoanalytical model and argued that attachment was "a fundamental form of behavior with its own internal motivation wired to survival" and distinct from a secondary drive such as simply attaching for the need for food in infancy or for sex in adulthood as previously theorized (Bowlby, 1977; Kosminsky & Jordan, 2016). As such, Bowlby objected to Freud's (1957) analytic approach to relationships, such as the ability to sever ties and move on after loss and made the primary purpose of his career to advance the understanding of relational connections throughout the life cycle (Bowlby, 1977; Kosminsky & Jordan, 2016). Bowlby (1977) focused his work on early separation and loss while working as a psychiatrist with children in British hospitals and with 'delinquent' youth in London's Child Guidance Center John Bowlby (Klass & Steffan, 2018; Neimeyer et al., 2006).

Bowlby (1977) has been highly criticized for his work with sick children and youth as it was thought that they would recover faster if they were separated from their caregivers and were prevented from seeing them (Kosminsky & Jordan, 2016). Moreover, Bowlby (1977) has been critiqued for creating "mother blaming" by focusing specifically on the relationship between mother and child (Kosminsky & Jordan, 2016). Despite this backlash, his work is still regularly used in academia and research, including bereavement studies, and has been fundamental in understanding the relationship between youth and their caregivers (Allen, 2023). Furthermore, it is important to note that the term "caregiver" can be interchangeable with any attachment figure that the child equates with safety and security for example; a

grandparent, a sibling, or a great aunt, and can still be applied to attachment theory in the same way (Allen, 2023).

Through his research, Bowlby (1977) observed what he coined as an "attachment behavioral system" which acts as an internal survival instinct connected to the nervous system (Kosminsky & Jordan, 2018). Bowlby (1977) premised that young children are wired to attach to their primary caregivers, specifically the mother, and respond based on how their need for security, protection, and comfort are being met (Field et al., 2005; Klass & Steffen 2018; Neimeyer et al., 2006). Children and youth need security for survival. This felt sense of safety allows the child to explore the world freely and become less vigilant for the need to assess for danger and allows them to develop their own thoughts, feelings, and desires (Kosminsky & Jordan, 2016). It was noticed in research that children became dysregulated when under stress and separation (Klass & Steffen, 2018). Based on this observation, Bowlby (1977) theorized that because the attachment behavioral system is primed for survival, it becomes activated within the nervous system when the threat of loss or abandonment is present, and he called this response "separation distress" and a form of anxiety (Field et al., 2005).

Bowlby (1969, 1973, 1980) as cited in Field et al. (2005) describes that an individual threatened by the loss of a caregiver will try to regulate their attachment behavioral system through what is called its "proximity maintenance function" to re-establish the connection. In a relationship that provides security and a haven from threat and fear, proximity maintenance is easily established and creates a positive and close attachment bond that can be described as secure (Field et al., 2005). In a secure attachment under separation distress

utilizing the proximity maintenance function, the child would become calm if the caregiver returned; however, if the caregiver did not return or did not respond to the child's attempt at regaining connection, the child's behavior would increase to what is known as "protest behavior" (Kosminsky & Jordan, 2016). Most importantly, it was noticed that a child's sense of felt security was not only contingent on if the caregiver returned but on how the caregiver responded to the emotional needs of the child when they were under distress in the stage of protest (Smigelsky et al., 2020). Therefore, if the protest behavior, such as tantrums, angry outbursts, or uncontrollable crying was not soothed whether the caregiver was present or not, the child would then exhibit an abandonment response that looked like despair, disengagement, and depression (Kosminsky & Jordan, 2016). Bowlby (1977) labeled these stages as protest, despair, and detachment, and these stages have been expanded over time in modern research to include four distinct categories of attachment labeled secure, avoidant, anxious, and disorganized (a combination of anxious and avoidant) (Kosminsky & Jordan, 2016). Thus, unmet needs result in insecure attachment bonds such as avoidant and anxious attachment styles.

Bowlby (1998) considered the reactions to bereavement a natural and normal response to an attachment bond that has been severed (Balk, 2014). Loss leaves a permanent crack in the foundation of world assumptions, and one struggles to grasp the finality of death which may be too great to cope with. From an attachment theoretical perspective, grief is "the loss of an attachment relationship and all that it provided" (Klass & Steffen, 2018, p.112). It is psychologically disorienting for youth because it nullifies any possibility of gaining physical

proximity or regulating a felt sense of security through connection (Field et al., 2005). When youth are facing the loss of an attachment figure who they are both individuating from and dependent upon, even the most securely regulated attachment behavioral system will be disrupted by parental life-limiting illness and death (Field et al., 2005; Kominsky & Jordan, 2016).

Another component to consider in attachment and bereavement is the relationship closeness before death. Bugen (1977) who created The Coping with Death Scale used in research, postulates that the attachment style before death will impact the intensity and duration of grief (Robbins, 1991; Smigelsky et al., 2020). Bereavement often requires a reorganization of the attachment behavioral system, and youth will interact with grief much like their attachment style based on the relationship with their caregiver. Grief symptomology can manifest in ways that resemble the protest, despair, or detachment phases (Smigelsky et al., 2020). Specifically, the despair phase in grief, as described by Bowlby (1998) shows signs of depression and withdrawal that can lead to a sense of hopelessness and become present even in a very secure child but can be mitigated based on the strength and security of the other attachment figures in a child's life (Field et al., 2005).

Preoccupation with the deceased has been heavily pathologized in grief literature as a prolonged and complicated form of bereavement, however, the loss of an attachment figure creates proximity-seeking behaviors noted by Bowlby (1998) as an innate human response (Smigelsky et al., 2020). In adolescence, the attachment figure serves as a regulatory function,

and finding comfort, closeness, and protection can still be achieved through a mental representation of the person who provided physical and emotional responsiveness (Smigelsky et al., 2020). Intense longing is a physiological and emotional response from the attachment behavioral system in an attempt to self-regulate and soothe when managing separation anxiety and stress (Smigelsky et al, 2020). Therefore, to combat the myth that youth are resilient when dealing with emotional loss and have the capacity to overcome bereavement as quickly or efficiently as adults, one must understand the attachment and developmental stages of youth in order to reduce pathologizing or stigmatizing the bereavement process as a "disorder" (Balk, 2014; McKinnon, 2015).

**Adolescent Development**

Adolescence is a time of great transition. Flooded with hormones and body changes, youth leave behind the innocence and naivety of childhood and face their unknown and mysterious adult future full of possibilities. It is a potent, yet fragile time, as youth strive towards independence while continuing to seek stability and security from their attachment figures. The journey for personal identity is the defining marker of adolescents as they explore autonomy and independence through self-discovery (Milam et al., 2004). This coming-of-age story of the struggles and growth of youth between leaving childhood and entering adulthood is a popular trope displayed countless times in arts and culture throughout books, movies, and music.

Erik Erikson (cited in Balk, 2014) coined the term "identity formation" and became best known for his work in developmental theory and believed the developmental task of

adolescence was to create a clear sense of self (Balk, 2014, p.20). Erikson said that adolescence is a time when personal character is built through facing crises and learning to make decisions or commitments (Balk, 2014). Erikson viewed "crisis" as a fork in the road that led to making specific decisions (commitments) that would propel growth and development (Balk, 2014). Building on the work of Erikson, David Balk (2014) broke down adolescent "identity formation" into five distinct developmental stages; 1. predictability of events, 2. self-image, 3. a sense of belonging, 4. mastery/control, and 5. fairness/justice (p.146). Like Erikson, Balk (2014) explained that life crises will impact these five developmental stages and inform how youth will make decisions. According to developmental theory, "Grief and loss during adolescence can impact overall development." (Matthews et al., 2022, p. 261). Parental life-limiting illness would be a crisis; a fork in the road, that will redefine the five developmental stages. An unwell parent can sideline normal change and growth makers during adolescence (Cafferky et al., 2018). In terms of developmental stages, the biggest strain of parental illness on youth is how it impacts their sense of self, their worldviews, and how they engage with their social life (Marshall et al., 2020).

When research measured parentally bereaved high school youth, they scored higher on the Beck Depression Inventory (Beck, 1993) and their grades plummeted following their parents' deaths (Balk, 2014). Bereavement during high school dramatically impacted the key developmental tasks for youth with self-concept and preparing to go to college, discovering career goals, and entering the workforce for the first time. Furthermore, attachment and

development are delicately interdependent as parental illness during adolescence affects developmentally appropriate separation (Jessop et al., 2022). Attachment bonds form in childhood and serve as a survival function to protect vulnerable children as they depend on their caregivers (Balk, 2014). Youth begin to widen their attachment circle from the insular dependence of their parents towards their peers, romantic relationships, and new attachment figures (Allen, 2023). Parental-life-limiting illness during adolescence can complicate these newly formed attachment bonds with peers by separating youth from others through premature and early parental bereavement, resulting in social isolation (Balk, 2014). Bereaved adolescents are often acutely aware that others do not understand what they are going through and feel that they have few whom they can speak or relate to (Balk, 2014). The tragedy in social development for adolescents is how the death of a parent leaves them feeling different than their non-bereaved peers (Balk, 2014).

Developmentally, youth depend on their peers for social acceptance and belonging, and out of fear of abandonment and social rejection, youth will camouflage and mask their grief to fit in with normal social functioning with their peers (Balk, 2014). They do not want to appear different; however, a sense of being different is heightened when an adolescent is grieving (Balk, 2014). Evidence has shown that having a parent with a terminal illness does make youth different from their peers. In a study about Amyotrophic-Lateral Sclerosis (ALS), a mother worried that her child would get bullied at middle school because her dad was in a wheelchair (Sommers-Spijkerman et al., 2022). Parental bereavement not only creates a perceived level of difference

between adolescents and their peers, but Cafferky et al. (2018) found that youth face teasing in school creating stigmatization and isolation (p.181).

In comparison to young children, adolescents have developed a capacity to tolerate mild to moderate levels of stress without an attachment figure (Allen, 2023). It is still under exploration in research how much youth turn to their social network for support under extreme stress, and in such circumstances, if that is defined as attachment behavior (Allen, 2023). Because adolescents can manage a level of stress on their own, they may tend to keep to themselves and store up what is happening to them in cases of extreme stress. As the grief is suppressed, this causes other coping behaviors to emerge, and as a result, many young people don't receive support for early parental loss until they are well into adulthood.

Researchers examined these coping skills in bereaved adolescents by looking at internalizing and externalizing symptoms (Balk, 2014). Internalizing symptoms are typically personal thoughts and feelings that manifest as anxiety or depression but are effectively hidden from other people, whereas externalizing behaviors are expressions of hostility, misusing substances, or failing in school and cutting classes (Balk, 2014). Additionally, youth exhibit symptoms such as loneliness, isolation, lowered self-esteem, and somatic symptoms with problems sleeping, eating, and concentrating (Balk, 2014). Many of these symptoms and behaviors can be mistaken or misunderstood as youth being typical or moody teenagers rather than noticing the severity of their symptoms as grief that is being hidden and masked. In studying grief in youth with a terminally ill parent, Jessop et al. (2022) found that 49% of young people reported unresolved grief 6-9 years after the loss. These adolescents had higher rates of

depression, insomnia, and fatigue growing into adulthood (Jessop et al., 2022). In these cases, interventions for symptoms of grief did not occur until the teens were adults and had been struggling with their grief for years pointing to more need for earlier interventions.

Evidence suggests that support from family, friends, peers, teachers, and professionals can reduce symptoms of depression and other negative consequences of having a terminally ill parent, yet there are many barriers to adolescents gaining efficient support (Cafferky et al., 2018). Studies have shown that adolescents prefer to speak with people with a shared experience, but this can be harder to find among their peer group (Cafferky et al., 2018). As such, youth may be resistant and reluctant to ask for help (Cafferky et al., 2018). Researchers have concluded that a model of grieving specifically for adolescents and their developmental needs is necessary (Balk, 2014).

**Dealing with Parental life-limiting illness during adolescence**

Research suggests that an estimated 3.5 percent of adolescents in the United States alone, experience the death of a parent before the age of 18 (Edgar-Bailey & Kress, 2010). In the UK, approximately 41,000 young people under 18 are bereaved of a parent each year (Cafferky et al., 2018). Cafferky et al. (2018) state that adolescents are considered the most susceptible to negative outcomes when a parent is unwell, yet they are the age group most neglected in bereavement literature (p. 180). While there are many circumstances of these deaths, including sudden and traumatic loss, terminal illness has garnered much research and medical attention in post-bereavement and anticipatory grief studies to understand the needs of dying patients (Jessop et al., 2022). Focus and funding have primarily been resourced to this area, and

while there is merit in this for obvious medical reasons and to reduce the stress of terminally ill patients, we must also recognize and address the specific needs of the families and children that are impacted by the illness of their parent (Jessop et al., 2022).

Nation-wide population studies have recognized illness and the death of a parent as an adverse childhood experience (ACE) that impacts daily functioning, mental health, and family cohesion (Jessop et al., 2022). Adverse childhood experiences include situations that create instability such as socio-economic stress, discrimination, abuse, violence, substance misuse, separation, divorce, and death, all of which increase the risk for problematic outcomes in youth (Sandler et al., 2016). The impact of parental terminal illness disrupts the entire home environment and creates a ripple effect of issues in attachment and security for adolescents who face detrimental relationship changes to everyone affected in their family system (Sandler et al., 2016). Life is disrupted. Leisure time and other pleasurable activities are sacrificed (Coelho et al., 2019). Research shows that households with a terminally ill patient typically have lower levels of effective parenting, and higher levels of stress, anxiety, depression, and other traumatic symptoms in the surviving family members (Sandler et al., 2016).

The confusing feelings that emerge from grief in adolescence can come out in ways that are behavioral responses to the situation such as dysregulated anger, risky behaviors such as engaging in substance use, and other acts of self-harm. Conflicted feelings such as “I am angry at them for leaving me” can be too hard to understand and cope with (Edgar-Bailey & Kress, 2010). Cafferky et al. (2018) stated that adolescent participants in a bereavement study said that they had a hard time understanding and articulating what they were feeling during the

overwhelm of their parents' illness. Another trauma response from witnessing a terminal illness is that some youth become extremely hypervigilant, using excessive caution out of fear of sickness and death (Balk, 2014). Youth can become consumed by thoughts of death, and an increased preoccupation with their mortality and the meaning and purpose of life (Cafferky et al., 2018). Clabburn et al. (2021) identified “negative legacies” that are passed on to youth after a parent has died from a terminal illness such as continued fear and a sense of dread that they will develop the same illness and condition that their parent had.

Avoidance is another factor in parental life-limiting illness (Coelho et al., 2019). Youth may try to establish a sense of normalcy through maintaining their daily routines and activities outside the home to cope with the growing changes in their environment (Cafferky at al., 2018). Adults trying to maintain a sense of normalcy may leave youth out of conversations around illness and death. This can be equally confusing for young people who are trying to make sense of what is happening in the environment around them. They may fear asking questions or reaching out for help if talking about these issues isn’t common in their family system. This is not always done intentionally as cultural and religious aspects can be a factor. Parents and people of support may feel that they are protecting children and youth from emotional distress when they leave them out of difficult topics around the illness and dying process (Coelho et al., 2019). As a result, young people are frequently met with barriers to feeling supported both at home and amongst their peers and can feel alienated and isolated during this tragic time in their lives.

**Parental Terminal Illness and the Family System**

The centrality of the crisis that parental terminal illness places on the nuclear family system has been of growing interest in psychological literature and research. This situation affects approximately 5 – 15% of children and adolescents (Testoni et al., 2023). Adolescents living in a household with a terminally ill parent have higher scores of stress, anxiety, depression, social isolation, avoidance, somatic disorders, and excessive worry and guilt than their peers (Testoni et al., 2023). Adolescent distress is increased with the worsening deterioration of their ill parent and the interfamilial structural changes (Cafferky et al., 2018; Marshall et al., 2021). Adolescents are a part of a larger system that needs to be considered. A significant hallmark of a teenager's life is to carve out their independence and identity from their families. The complexity of parental life-limiting illness disrupts this natural maturation milestone for youth by propelling them back into their family life with increased challenges and responsibilities that they had worked at breaking away from (Cafferky et al., 2018).

Changing family dynamics is an inevitable part of parental illness and loss. Teenage youth may face more pressure around their parent’s illness than their younger siblings. Younger siblings will have less awareness about what is happening. and the older youth, developmentally aware, will struggle with a premature sense of illness and death (Cafferky et al., 2018). Youth also face becoming a caregiver of their ill parent and having more responsibilities (Sommers-Spijkerman et al., 2022). Caring can include anything from supporting their ill parent at home, to increased responsibilities of helping with household chores, or emotional support for other family members, and looking after the well-being of younger siblings (Marchall et al., 2021).

These new responsibilities will impact time for homework and can impact school performance and time spent with friends, highlighting the intense sacrifice that youth must make between their independence and autonomy, and that of their new family role. They are forced to grow up beyond their years. In cases of parental divorce, youth may have even more pressure to step into the role of caregiver. Additionally, parental issues not addressed before the illness can surface, such as feelings of anger and resentment from the adult caregiver towards the ill parent. Youth are sensitive to picking up on tension and what is "unspoken" in the family household. Moreover, traumatic illness can complicate bereavement when there is a conflictual and troubled relationship between the dying parent and the adolescent child (Rubin et al., 2020).

Adolescents also experience secondary traumatic stress as they watch their parent succumb to their own fears about death and dying (Saldinger et al., 2003). A traumatized dying parent may become emotionally or physically unavailable and the illness can impact the efficacy of their parenting, destabilizing the relationship with their child and impacting the attachment bond (Fearnley & Boland 2019). The physical and mental changes of an illness stop youth from finding their parent as a source of comfort and security and there is a sense of the parent being lost even before their death (Cafferky et al., 2018). In an anticipatory grief study done by Coelho et al. (2019), one adolescent girl stated in terms of grief about the role reversal with her father; "Now, I have to be the one to help him. The strong man, to whom I have so often asked for help, "Daddy, come help me, something happened in my life. "Now I cannot do that anymore." (p.696). Parents are equally impacted by their own impending death and how it will affect their relationship with their children. In a study on ALS patients, a married father with two children in

early and middle adolescence said, “If you become disabled, if you lose functionality, that sometimes causes frustration and irritation. Then you sometimes take it out on another, and then I don’t feel like such a good parent” (Sommers-Spijkerman et al., 2022, p.7).

Some dying patients become very altruistic at the end of their life, finding solace in spiritual topics or religion. Dying parents may apologize and seek forgiveness in ways that they have harmed others during their lifetime. Studies have shown that dying patients can show more care and concern than they ever have before in their final years, months, and days of life (Coelho et al, 2019). This shift in an ill-parent can be very healing for adolescents who may have struggled with their dying parent, offering a chance for repair and bonding. Many adolescents who have this experience with their parent at the end of life, have a better time developing a continuing bond after death. Some spiritual elements or life epiphanies the dying parent teaches become values the youth will carry with them throughout their lives (Neimeyer, 2019).

## Responses to Death and Dying

### *Anticipatory Grief*

It is rare for youth to be asked about their experience when a parent has a life-limiting illness, and most primary research in this area occurs after the death and when the bereaved youth has reached adulthood (Marshall et al., 2020). Many studies on grief have focused on young children or adults, but few have focused primarily on adolescents' experience of living with a terminally ill parent (Jessop et al., 2022). Young people’s accounts of how they interpret and understand the issues of living with an ill parent are fundamental to addressing this gap in bereavement literature (Fearnley & Boland, 2019). In traditional healthcare and research,

the patient's needs have been paramount during the anticipatory phase, yet research has shown that the period prior to a parent's death may be of particular significance in how youth cope with bereavement (Fearnley & Boland, 2019; Marshall, et al., 2020). Newer research has shown that the anticipatory phase can be just as intense, if not more, than following the death of a loved one (Overton & Cottone, 2016).

Anticipatory grief is a healthy and normal preparatory bereavement phase of losing a loved one, yet anticipatory grief becomes complex when managing the stress of a youth's exposure to the graphic physical, emotional, and mental deterioration of the dying parent (Saldinger & Porterfield, 2003). There is an ever-present anxiety, dread, and fear that permeates all aspects of life when growing up with a terminally ill parent (Lisiecka et al., 2020). In combination with loss of control, death anxiety, graphic stimuli from the illness, and the severing of meaningful attachment, describing the experience for youth as anticipatory grief is too simplistic. As opposed to anticipatory grief for adults, research has shown that this form of acute grief for a young person should be defined as traumatic stress (Fearnley & Boland, 2019; Jessop et al., 2022; Marshall et al, 2020; Saldinger & Porterfield, 2003). Scholars have found that anticipating a loved one's death is not grief but anxiety (Balk, 2014).

Although limited, the research that has been done on this matter has concluded that adolescents living with a terminally ill parent have higher levels of stress and depression than their peers (Jessop et al., 2022). Separation anxiety and avoidance are key factors of anticipatory grief for youth (Coelho et al., 2019). Illness and death impact the entire family system, and part of anticipatory grief is mourning the changes in all the family members

affected. Grief transforms everyone. Youth grieve not only for the impending loss of the dying parent but for the changes in the supporting parent, siblings, and life as they knew it (Overton & Cotton, 2016).

Families facing the death of one of its members requires a significant amount of support that is not always provided or available (Overton & Cottone, 2016). A terminal diagnosis in a family system creates new demands, such as a shift in roles, rules and responsibilities. Even prior to parental death, there is an ambiguous loss of family life that will never be the same again (Overton & Cottone, 2016). Families mourn the loss of a future and grieve the happy and important memories from the past (Coelho et al., 2019). They are thrust into the present condition of uncertainty, the unknown, and the inevitable experience of death (Overton & Cottone, 2016). Overton & Cottone (2016) discuss that in the anticipatory phase in cases of terminal illness, families try to reconcile their grief to get through the terminal illness and caretaking part to try to resume a sense of normal family functioning. In other words, grief gets postponed as family members switch into survival mode to get through the illness. Survival mode, when the nervous system is heightened to the threat of immediate danger, is an aspect of anticipatory grief.

Additionally, it is important to remember that no two families are alike. Loss is handled uniquely based on the dynamics in a family system, cultural differences, and religious beliefs. Moreover, each family member will process their grief differently (Overtone & Cottone, 2016). As bereavement therapists, there is no set formula when working with grieving youth or their families. Literature has focused on individual bereavement rather than group involvement, and

youth in particular benefit from the support of family members, friends, and community members given their developmental and attachment needs for social supports at this time in life (Overton & Cotton, 2016). More research on the efficacy of receiving interventions during the anticipatory phase rather than focusing primarily on bereavement after the death may help inform professionals to better understand and reduce symptoms of anticipatory traumatic stress for youth.

***Processing graphic stimuli from the illness***

Current literature has focused on the care needs of terminally ill patients, and not on the caregivers and surviving family members (Sommers-Spijkerman et al., 2022). When a primary caregiver such as a parent is diagnosed with a terminal illness, the whole family is faced with invasive medical procedures, hospitalization, and constant changes in the sick person causing concern and tension for everyone involved (Testoni et al., 2023) Often, adults, family members and peers do not know how to communicate and support adolescents, moreover, how to talk about the physical and emotional deterioration of the ill parent and the prospect of parental loss. Youth are left feeling confused and without guidance, managing the impacts of the illness on their own as caregivers struggle to support the terminally ill parent (Sommers-Spijkerman et al., 2022).

In illnesses such as Amyotrophic lateral sclerosis (ALS), a motor-neuron disease, youth are exposed to physical deterioration and events such as choking and fear that their parent will suffocate (Sommers-Spijkerman et al., 2022). Ambulance and medical presence can be frequent, increasing an adolescent's exposure to traumatic images and events. Smells, sounds,

and images are ingrained in youth who are around a dying parent wasting away before them. An active, and vibrant parent is reduced to being bed-ridden, frail, and weak needing help with being fed, getting dressed and bathing (Balk, 2014). Images of degradation contribute to the traumatic stressors of the anticipatory phase of grief for youth. This phase can conjure up emotions and fears that are hard to manage and difficult to process resulting in feelings of anger, rage, or conversely numbing and shutting down. A common and confusing reaction to witnessing the deterioration of a parent is wanting them to die to be relieved of their pain. This is something that is often not spoken about with terminal illness, and mourners carry the shame of these feelings into the bereavement phase after death. One youth in a research study stated; "I swear, I'll never have the courage to say this to anyone else, but I just wanted my dad to die fast." (Coelho et al., 2019, p. 696).

Part of the complex post-traumatic stress that can develop in adolescents dealing with,a terminally ill parent begins from witnessing very shocking images of the deterioration of their parent (Coelho et al., 2019). As the illness progresses, youth are unable to recognize their loved one due to extensive body deterioration, and sometimes a rapid change in personality and behavior due to mental decline and medications (Coelho et al., 2019). This process is traumatizing and emotionally straining for youth and causes shock (Coelho et al., 2019). Witnessing the suffering of someone that you love can cause vicarious suffering (Coelho et al., 2019). The images turn into traumatic memories and can show up in flashbacks and nightmares after the death (Coelho et al., 2019). Negative images developed during the physical degeneration of their parents' illness shape recent memories and can overshadow and

temporarily erase positive and happy memories from the past causing youth to overidentify with the final months or weeks of their parent's life (Clabburn et al., 2021).

Some acute mental and physical symptoms of witnessing a traumatic illness are mood instability, appetite and digestive changes, dissociation, disorganized speech, and recurring dreams, a feeling of helplessness, loss of meaning, and suicidal ideation (Coelho et al., 2019). Avoidance of anxiety can happen, and youth may try to find ways to not be at home or around the illness. The more visibly serious the illness, the more it can create defense mechanisms in youth like removal of self from the situation, and denial that things are fine (Testoni et al., 2023). Going out with friends, playing video games, and other activities where they can avoid what is happening may become common (Coelho et al., 2019). A youth in late adolescence stated in a study by Testoni et al. (2023); “I don’t want to study when I come home. There is this situation with dad that makes me sad, so I would rather play video games or spend time with my friends” (p.476). Additionally, hypervigilance and isolation can become a factor from being exposed to unpredictability and loss of control resulting in a heightened state of arousal and awareness (Coelho et al., 2019). A 14-year-old youth stated: “I used to spend a lot of time with my mum, but now I prefer to be alone because I don’t like to see her like this. I suffer too much. I try not to think about it, and I try to detach from reality (Testoni et al., 2023., p. 477). Youth are plagued by the uncertainty of the future, keeping their nervous system on alert for far too long.

Studies used to determine complex post-traumatic stress in youth follow a three-principal measurement rule of traumatic distress, separation distress, and level of emotional

dysregulation (Coelho et al., 2019). Traumatic distress is measured through the uncertainty of the illness and related to the ambiguity and unpredictability of events (Coelho et al., 2019). The belief that adolescents should not be spoken to about death and illness, and protected from it, is prevalent in Western society, yet it is unavoidable when a youth has an ill parent at home (Testoni et al., 2023). The literature in death education suggests that speaking to youth in age-appropriate ways does not hurt them, but in fact, helps them to reduce their death anxiety and worries about the illness, and helps them to appreciate and value life, and find meaning and significance in what is happening (Testoni et al., 2023). Minors who understood what was going to happen and were able to talk about it were more prepared to face the worsening of their parents' condition. On the contrary, youth who were left out of care planning, and discussions about death were more likely to feel ambiguity and uncertainty, resulting in a higher prevalence of mental health issues and traumatic stress (Testonu et al., 2023).

### *Traumatic Stress and Prolonged Bereavement*

One must consider that all losses through death are on some level traumatic. There is no “escape” from the threat of losing a loved one, therefore grief is a spectrum and varies based on circumstances and the people affected (Fearnley & Boland, 2016). There are varying degrees of traumatic deaths that cause traumatic responses such as homicides, suicides, accidents, natural disaster-related deaths, war, and terrorism (Fearnley & Boland, 2016). Traumatic bereavement can have a significant impact on the nervous system (Edgar-Bailey & Kress, 2010). Anticipating a death can provide some relief of preparation in reducing traumatic symptoms, but research does show that prolonged terminal illnesses can induce an acute trauma

response including nightmares, and intrusive and disturbing memories (Fearnley & Boland, 2016). Traumatic grief is considered when youth have lost a loved one and have subsequently developed trauma-related symptoms when dealing with the loss (Edgar-Bailey & Kress, 2010). Youth often experience overwhelming and sometimes unmanageable feelings of separation distress, and even disturbing thoughts about the deceased (Alves et al., 2013). The threat of separation and the permanence of loss threatens the attachment system causing psychological pain and anxiety (Fearnley & Boland, 2016).

The teen years are already riddled with stressors between friendships and school, home life, and environmental pressures. It is not uncommon for youth to experience anxiety during the best of times, given the developmental, physical, emotional, and psychological changes that occur between the ages of 13 and 18 (Lohmann, 2015). Trauma during these stages can intensify anxiety that naturally occurs in the complicated teen world. A parental life-limiting illness during adolescence means that every aspect of normalcy and stability will be disrupted, and life becomes unpredictable, placing the whole family system at risk of psychological issues including acute stress disorder (Fearnley & Boland, 2016). Common symptoms of traumatic stress are depression, anxiety, substance misuse, risky behaviors, rage, hypervigilance, dissociation, hyper and hypo arousal, somatic (physical) symptoms, loss of meaning and purpose, and suicidal ideation (McLean & Follette, 2016).

Trauma and Post Traumatic Stress Disorder (PTSD) is defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) Fifth Editon (2013), as occurring when an individual is being exposed, via direct experience, to the aversive aftermath of an actual

death, threatened death, sexual violence, or serious injury. According to the DSM-5 (2013) "a life-threatening illness and debilitating medical condition is not necessarily considered a traumatic event" (p.274). On the other hand, Complex PTSD is not currently in the DSM-5 (2013) but is the result of ongoing exposure to repeated traumatic events such as violence in the home, bullying, being a prisoner of war, racialized oppression, discrimination, and prolonged terminal illness (McLean & Follette, 2016). Complex PTSD can be linked to a long-lasting hostile environment, rather than a single traumatic event like PTSD.

Many people who experience traumatic events do not necessarily develop complex post-traumatic stress disorder but still report similar symptoms of psychological distress (McLean & Follette, 2016). Most adolescents will not develop long-term post-traumatic stress disorder but will exhibit acute stress symptoms during the anticipatory phase and following the death, which is considered normal bereavement given the traumatic circumstances (Edgar-Bailey & Kress, 2010). Youth who experience the death of a parent will experience a level of distress and difficulty, but only about 20 percent will experience severe grief reactions leading to impairment resulting in various psychosocial challenges (Tuazon & Gressard, 2023). Grief becomes severe when it impairs a person's global functioning (Alves et al., 2013). Complex post-traumatic stress or prolonged bereavement is when trauma and grief become fused (Fearnley & Boland, 2016).

The DSM–5 (2013) considers bereavement-related symptoms that extend beyond six to twelve months to be persistent complex bereavement disorder or prolonged grief (Boelen.,

2019; Djelantik et al., 2018). However, there is a danger to this. Neimeyer (2019) explains that some mental health professionals are quick to pathologize traumatic stress from bereavement as a disorder. This places a focus on "something being wrong" and needing fixing, versus a normal traumatic reaction to a traumatic event. It is not uncommon for youth to experience symptoms of complex post-traumatic stress and grief concurrently following the death of a loved one, but generally, this does reduce over time (Djelantik et al., 2018). Thus, as stated by Edgar-Bailey & Kress (2010) "It is necessary to provide the appropriate bereavement interventions, and to not over-pathologize a client's experience" (p.159). With that said, risky behaviors that often exist within complicated bereavement such as acting on suicidal ideation or harmful substance misuse still need to be monitored and addressed, as they can escalate and cause further harm if not met with compassionate intervention.

Another complication in acute stress for adolescents is the factor of being isolated in their grief and unequipped to deal with their emotions and self-regulation. Adolescence will often mask their grief to fit in with others, or to not appear different. Adolescents report finding it difficult to talk about their feelings about death, as there are few people around them willing to listen, and most shy away from the topic not knowing how to talk about it (Balk, 2014). Cultures where illness and death are not talked about openly cultivate an environment of social isolation for those who grieve which can directly contribute to physical illness and mental health issues (Balk, 2014). Balk (2014) believes that trauma attacks adolescent development through core relationships that define existence, leaving youth questioning their relationship to the external world and assumptions about reality (p.24). Further, when youth are unable to find

meaning in their world or struggle with how to deal with negative feelings about loss and death, they are more susceptible to symptoms of prolonged grief disorder and unresolved grief (Balk, 2014).

Bereaved youth who have experienced a major life event such as the death of a parent, based on their level of development, may not fully process their grief until they reach adulthood, they may however be able to manage and reduce their traumatic stress related symptoms with social and peer support (Djelantik et al., 2018). Therefore, symptoms that persist for more than six to twelve months need to be met with care, concern, and compassion, rather than over-diagnosis and overtreatment (Boelen et al., 2019; Maciejewski et al., 2016). Youth who receive clinical approaches that are trauma-informed, and have access to a circle of support, have a higher chance of moderating and mitigating traumatic stress Responses that are persistent, debilitating, and interfere with daily functioning (Tuazon & Gressard, 2023).

**From post- traumatic stress to post-traumatic growth**

"What is to give light, must endure burning."

--Viktor Frankl (1965, p.57)

Post-traumatic growth can be defined as "positive changes experienced as the result of the struggle with a major life crisis" (Calhoun et al., 2010, p.126). Like the metaphor of a butterfly emerging from the chrysalis, it gives rise to the notion that there is the possibility for healing and transformation alongside incredible hardship and pain. Posttraumatic growth is the result of picking up the pieces after one has been ripped apart by grief. It is the rebuilding after

the hurricane. The positive existential changes that individuals make in the wake of trauma is the transformation of the relationship that they have with themselves and others, and an understanding of their purpose and place in the world (Tedeschi et al., 2017). Recent bereavement research and theories like meaning reconstruction and continuing bonds have sought an evidence-based understanding of the positive changes that can occur after traumatic events (Calhoun et al., 2010).

Models of post-traumatic growth in research have shown that traumatic events disrupt existing world beliefs causing the shattering of world assumptions that eventually leads to post-traumatic growth (Calhoun et al., 2010; Tedeschi et al., 2017). In the past, this phenomenon has been termed in psychology as an "existential crisis" (Black et al., 2022). That is, life is no longer what someone has known it to be. Healing from the post-traumatic stress of a devastating loss requires a complete overhaul of one's self-identity and worldview. Assumptive worldviews and life narratives are reconstructed (Calhoun et al., 2010). When a death occurs, people have a realization that life can end sooner than they think, they have a new appreciation for life, and they start to live from a different perspective (Calhoun et al., 2010).

Jessop (2022) conducted a study addressing parentally bereaved adolescents and found that these youth, in addition to post-traumatic stress, experienced statistically higher levels of posttraumatic growth (p.934). An example of this is that they developed greater personal strength for being able to overcome the fear of change and to explore new possibilities in their lives (Jessop et al., 2022). The outcome in career decisions was a major determinant of post-traumatic growth after parental death, as many adolescents who have gone through this

experience choose altruistic, helping, and charitable vocations in their adulthood, and in this way, the suffering of bereavement was made meaningful (Balk, 2014). One youth stated; “I’ve become very empathic towards anybody in pain and anybody in any kind of grief” (Calhoun et al., 2010, p.128). An increase in compassion and awareness, feelings of inner strength, closer relationships with friends and family, and a greater appreciation for life are common transformations with post-traumatic growth (Tedeschi et al., 2017).

Unfortunately, fewer studies address posttraumatic growth among adolescents in bereavement as it has been believed among researchers that posttraumatic growth increases in adulthood (Lundburg et al., 2023). Therefore, more research is needed to understand the importance of post-traumatic growth from a developmental perspective during adolescence before reaching adulthood (Milam et al., 2004). That said, studies on adults have confirmed that post-traumatic growth is a continuum that occurs throughout one's life and increases at different developmental stages explaining why it is not uncommon for youth to process their grief throughout their lifetime and come to different epiphanies and realizations at different stages (Tuazon & Gressard., 2023).

There is value in understanding post-traumatic growth for counsellors and mental health professionals (Lundberg et al., 2023). Lundberg (2023) states that “research has shown that receiving support from helping professionals has been associated with more posttraumatic growth” (p.12). Sources of support are crucial for youth in bereavement because a helping professional may be the bridge for a youth to transform their traumatic grief into post-traumatic growth (Lundberg et al., 2023). Using theories such as meaning reconstruction and continuing

bonds as modalities in counselling fosters an understanding of how to facilitate post-traumatic growth within a session when clients are facing adverse experiences (Tuazon & Gressard, 2023). Additionally, it is important to note that post-traumatic growth does not diminish or take the place of the trauma from losing a parent, rather they co-exist together (Tedeschi et al., 2017; Tuazon & Gressard, 2023). Grief services should be available to youth to assist them at different development stages when their grief gets triggered and resurfaces, normalizing the ongoing process of grief (Tuazon & Gressard, 2023). Just as the stages of grief are not linear, post-traumatic growth is something that follows its own distinct trajectory based on an individual and their unique experiences.

## Interventions

### *An integrative approach for teens*

Adolescents may be the most difficult and resistant age group to engage in therapeutic interventions (Cafferky et al., 2018). Youth are striving for their own identity and independence and are less inclined to seek help from adults. They rely heavily on their peers for support. No longer children, and not yet adults, they are still trying to figure out who they are and who they want to be in the world. (Balk, 2014). Scholars such as Balk (2014) have intensively researched how grief can impact identity formation in youth making them more vulnerable to loss.

Therefore, counsellors that work with grieving adolescents need to take a different approach to honor the unique developmental challenges and attachment needs of this age group (Matthews et al., 2022). Bereavement literature suggests that counsellors must seek to understand the complexities that youth face and have an array of techniques and resources to best

support and engage adolescence (Balk 2014; Matthews et al., 2022; Thompson &Neimeyer, 2014).

***Expressive Arts Therapy; using creativity to heal after loss***

Research that has examined therapeutic interventions for youth confirms that youth need support work that includes their peers who are experiencing similar situations and involves a "third party activity' aside from the group facilitators (Matthews et al., 2022). There are no words to console grief. It is a deep physiological response to emotional pain in the body that leaves mourners without language to process their experience. There is evidence that creative practices offer the bereaved an avenue to express emotions and make meaning in their loss (Thompson & Neimeyer, 2014). Adolescents often have conflicted feelings in their grief and creativity can be an excellent outlet to channel pent-up emotions making them easier to identify and manage (Edgar-Bailey & Kress, 2010). Pollock (as citied in Witztum & Malkinson, 2009) concluded after studying many gifted artists and scientists that grief enhanced creativity (p.136). Pollock (1982) called this "the mourning liberation process." Artistic expression in its variety of unique forms can provide an alternative avenue for emotions when it is difficult to express feelings simply by talking about them (Edgar-Bailey & Kress, 2010).

In expressive therapies, there is a three-way relationship between the therapist, the client, and the piece of art or creative story (Nelson et al., 2022). This modality works particularly well with youth because it removes the pressure from solely having a conversation with the therapist and sitting face-to-face in conversation. The expressive art piece as a third partner in the therapeutic process provides some safety for the youth to have an object outside of the therapist

to touch, look at, and interact with. Moreover, youth may prefer peer support over confiding with adults. Group or community involvement has been proven to be effective in grief so that people can be in a shared space with others who have had a similar experience (Nelson et al., 2022). In a creative art group study, one participant said; “There is huge power in being with others whose experiences are similar to yours” (Nelson et al., 2022, p. 14). Others shared the same sentiment and expressed feelings about the power of sharing their story in the presence of others with similar experiences (Nelson et al., 2022). Another powerful attribution of storytelling and art making in a group setting, is that many participants formed friendships and circles of support that extended beyond the group (Balk, 2014; Nelson et al., 2022). This allowed participants to reduce social isolation and increase their community connections through walking on their journey with others.

Art as a therapy emerged in the United States around the same time as the field of psychiatry in the late 1800’s and early 1900’s (Peterson & Goldberg, 2016). Psychiatrists and psychologists realized that they could use patients’ art as a form of medical treatment (Peterson & Goldberg, 2016). While there are positive benefits to art in therapy, given its historic convergence with psychiatry, it is equally important to be cognizant of the potentially pathological use of art in a psychological context. Grief can render someone into a state of powerlessness. The creation of art should be used to empower an individual through the exploration of their own process (Peterson & Goldberg, 2016). With the client held in the position of the expert on their own grief, the therapist can work collaboratively to foster the creative process. As such, there is a healing element in the creative process (Nelson et al., 2022).

The core application of any therapeutic expressive art technique is grounded in the foundation of Carl Rogers's person-centered approach by meeting people exactly where they are at and conveying empathy, understanding, and acceptance (Merrill and Andersen., 1993). Carl Rogers's daughter, Natalie Rogers (1985), has continued in her father's footsteps of positive psychology but built on its foundation by creating person-centered expressive art therapy (Merrill and Anderson, 1993).

Natalie Rogers (1985) theorized that combining different expressive modes of visual arts, creative writing, acting, dancing, and singing integrates body, mind, and spirit to open new channels of energy that change and shift our feelings (Merril and Andersen, 1993). Research by Matthews et al. (2022) found that through utilizing creativity in counselling with adolescents, expressive art awakened their capacities to explore and reshape their grief experiences and provided a healthy means of coping with loss (p.265). The combination of a person-centered approach with expressive art therapy for youth gives them an avenue to explore their self-expression and identity on their own terms and in their own unique way of being in the world (Matthews et al., 2022; Merrill & Andersen, 1993). Therefore, in the chaos and unpredictability of grief and loss, the therapeutic process allows youth to have agency and control in choosing an artistic modality that resonates with them and gives them a voice for expressing what is unexpressed (Matthews et al., 2022).

Therapy infused with the creative arts enhances the use of meaning reconstruction by promoting the development of imagination, and creativity and providing an avenue to convey meaning through thoughts and feelings (Neimeyer., 2019). Additionally, creativity helps to

facilitate continuing bonds by carrying on memories and legacies in artistic forms that are visible and tangible like paintings, books, and film (Matthews et al., 2022; Thompson & Neimeyer., 2014). The American Art Therapy Association (2013) verified the use of art as a therapeutic tool in mental health that reduces psychological symptoms like depression, suicidal ideation, and prolonged grief anxiety and brings deeper meaning and a renewed relationship with loss (Davis & Tungol, 2019).

***Narrative Expressive Art Therapy***

Narrative therapy is a postmodern counselling approach developed by Michael White and David Epston (Peterson & Goldberg, 2016). Like Neimeyer's (2001, 2006, 2019) meaning reconstruction theory, narrative therapy was created with the understanding that humans give meaning to their lives from their personal experiences. Experiences become cognitively organized in the brain in the form of "storytelling" as a way in which people adapt or construct a narrative of their life (Smith-Adcock & Tucker., 2017). Neimeyer (2001) described meaning reconstruction and narrative therapy as the therapist's ability to carefully listen, understand, and reflect the layers of multiple meanings in the overarching story of someone's life and offer a fresh perspective (p.264). The job of the narrative therapist is to listen to the client's story to detect problems and contradictions while noticing resiliency and resourcefulness that may not be evident to the client (Smith-Adcock & Tucker., 2017). Narrative practices embody the belief that we are always in the process of becoming and our identity is continually under construction and reinterpreted over time (Hedtke, 2014). Therefore, the opportunity to redefine oneself is

ever-present, and our stories can change and shift with new awareness and developments (Smith-Adcock & Tucker., 2017). Storytelling is an age-old art that has been around for centuries and gets passed down through generations either orally, in written form, or with visual art (Matthews et al., 2022, p. 263). Evidence suggests that the combination of expressive art and narrative therapy work naturally together as a pathway toward healing incorporating various ways to tell the client's life stories and reconstruct their meanings (Matthews et al., 2022; Peterson and Goldberg, 2016).

For the bereaved adolescent, Thompson and Neimeyer (2014) state that although creativity cannot return a loved one, their memory can be experienced through art making and creative storytelling (p.81). This process of creating a new reality through expression incorporates both losses and joys (2014, p.81). Journal writing, for example, has evidence-based research that shows its healing qualities that enhance sense-making and benefit finding in loss (Thompson & Neimeyer, 2014). A key component in narrative therapy is to externalize the problem, and this process reshapes the language of loss, allowing someone to not only understand their traumas but to reconstruct them (Nelson et al., 2022). Adolescents may choose to explore their internal narratives through Journaling, creative writing, or drawing to prepare and bring ideas to share in counselling and groups. Sharing thoughts and feelings out loud and having them exposed openly with others in narrative therapy offers an opportunity for a client to re-author their story (Smith-Adcock & Tucker., 2017). Studies in narrative expressive art therapy have shown there is power in doing this work in a group’s presence. Participants found social benefits such as increased inspiration from others, a sense of encouragement, and an ability to

express themselves more openly in an environment that was non-judgmental and safe (Merrill and Andersen, 1993).

Hedtke (2012) uses narrative expressive art therapy as a modality in bereavement therapy and says that through storytelling, people can introduce the deceased to their social world and preserve their legacy. Hedtke (2012) calls this the practice of Re-membering. Through Re-membering conversations, the person who is gone is brought to life through their legacy and how their values and good qualities were imprinted on the survivor (Penwarden, 2022). In this way, Re-membering serves as a form of a continuing bond by gaining a sense of connection with the deceased and sharing their memory with others (Clabburn et al., 2021). Survivors create an ongoing celebration of life by re-writing their story with the deceased and taking ownership of their narrative around grief (Penwarden, 2022). Re-membering is another form of counterbalancing the narrative that we say goodbye after death and move on with our lives (Hedtke, 2014). Hedtke (2012, 2014) believes that storytelling and narrative legacies of the deceased provide meaning and purpose that are therapeutic and healing, but more importantly; potentially lifesaving from the traumatic pain of loss.

***Acceptance and Commitment Therapy (ACT); finding meaning after loss***

Russ Harris studied under Dr. Stephen Hayes, the original creator of the Acceptance and Commitment therapy model developed in the mid-eighties (Harris, 2021). ACT is part of the third wave of cognitive behavioral therapies, incorporating the exploration of thoughts, feelings, and behaviors, with the added element of existential philosophy and mindfulness-based techniques. Harris (2021) studied the effectiveness of using Acceptance and Commitment

therapy with clients who have trauma and complex post-traumatic stress symptoms. As this capstone has discussed, historically, the psychiatric and medical model has viewed the presence of distressing thoughts and feelings as psychologically abnormal (McLean & Follette, 2016). This viewpoint has contributed to the shame that people feel when they have had adverse experiences impacting their thoughts and feelings. Often, societal pressures to put on a brave face, and keep moving forward, forces folks to keep silent about their struggles. ACT works towards using a non-pathologizing approach (McLean &Follette, 2016). Compassionate validation is one of the most crucial approaches of ACT (Harris, 2021). This is when the therapist normalizes the clients' feelings and validates their human experience and suffering (Harris, 2021). In other words, there isn't anything wrong with them. Grief is an inevitable human experience and they are having a real and valid reaction to traumatic events. Normalizing the client's reaction to their experience is the first step toward de-pathologizing the manifestation of traumatic symptoms that are impacting their lives.

ACT has deep existential roots connected to the work of Viktor Frankl (1959). Frankl (1959) stated in *Man's Search for Meaning* that "the last of human freedoms is to choose one's attitude in any given set of circumstances" (p.104). The Acceptance part of ACT is based on Frankl's (1959) work, in that we must accept that we have little control over outside forces. Yet, we do have control over our thoughts and feelings, and how we can make meaning from the bad things that happen to us (2021). Learning that we aren't meant to be happy all the time reduces the shame and stigma associated with traumatic symptoms. In addition, the ACT model uses somatic and polyvagal theories to work with the physical and emotional sensations of grief

and trauma in the body (Edgar-Bailey & Kress, 2010; Harris, 2021). ACT uses mindfulness practices, such as sitting in the present moment, and working with breath as a tool for regulation while sitting with uncomfortable thoughts and feelings and allowing them to surface to be processed (Harris, 2021). ACT can work in conjunction with expressive creative practices to attain a connection with the body through calming music, guided meditation, walking in nature, or orienting clients to their environment through the senses (Edgar-Bailey & Kress, 2010; Harris, 2021). Therefore, combining the use of ACT in an expressive art group can creativity and create a sense of safety around the trauma that can arise from the outer exploration of the inner experiences of trauma and grief (Edgar-Bailey & Kress, 2010).

Understanding the cognitive behavioral therapy aspect of ACT with the thoughts, feelings and behaviors triangle can be particularly useful in conjunction with body awareness for working with traumatic grief (Edgar-Bailey & Kress, 2010). For youth, developing emotion-regulation techniques, creating a strong therapeutic bond, and ensuring safety are precursors for using creative interventions in a respectful, and trauma-informed manner (Edgar-Bailey & Kress, 2010). Therefore, using ACT in conjunction with narrative expressive arts therapy provides an added layer of protection around exploring difficult emotions. Thus, an integrative approach is necessary.

**Considerations**

Navigating bereavement during adolescence is one of the most traumatic experiences that youth can have. Yet, researchers have focused primarily on grief that occurs in adulthood even when it begins in adolescence (Lytje, 2017). Models for grief have been created

and structured primarily for an adult's developmental maturity and emotional intelligence (Lytje, 2017). Thus, more research for better grief models that are applicable for youth are needed. Evidence within this capstone suggests that interventions that occur during adolescence are more likely to ease the transition into adulthood and equip youth with the tools to manage their grief symptoms throughout their life, rather than reaching a breaking point in later years that impacts functioning and needs immediate therapeutic attention.

Further, this capstone discusses youth ranging from the ages of 13-18. Balk (2014) describes this period from early to late adolescence with many different developmental needs within that age span that are far too varied and great to cover within this capstone. Therefore, it is also important to consider appropriate interventions that benefit youth from early, middle, and late adolescence based on their developmental and attachment needs (Kosminsky & Jordan, 2016; Lytje, 2017). It is also worth noting that age is not the only factor, but culture, religion, social-location, and socioeconomic status all contribute to how a youth will navigate their grieving process. This Capstone focused on youth within a westernized culture, who had a relatively close relationship with their ill parent. For that reason, it is crucial to consider that studies and research will vary depending on which social and cultural lenses are applied.

**Summary**

The intention of this capstone is to give a voice to adolescence and their experience of bereavement. In a study by Lytje (2017), youth made statements like; “I think listening to adolescents is important” (Lykke, age 13, p.294) and “I think the best support is asking how this is affecting me and then letting me decide what it is that I need” (Clara, age 14, p. 294). For

too long, youth have been kept silent and their grief hidden due to cultural taboos around speaking about death openly and having an ongoing relationship with someone who is deceased. This taboo has been enforced by early twentieth century bereavement literature, however; ongoing relationships with the deceased are now becoming normalized in modern grief theories. Adults and counsellors can learn from youth as they inform and teach us about their experience, while we empower them as young people to speak out about what they are going through. Unlike young children, youth have the awareness and creativity to write their own meaning in the wake of their loss, and it is a gift and a privilege to be invited into their world and bear witness to their stories (Neimeyer, 2001). This chapter, albeit sad and tragic, took a positive spin by challenging the notion that we can turn grief into growth. The bereaved can evoke a keen reminder that life is fragile, and yet strength can emerge from what is fractured and become a resilient form of activism and art by keeping the memory of our loved one's alive (Field et al., 2005).

## Chapter Three

In this final chapter, the concepts of bereavement theory explained in chapters one and two will be brought to life by practical application in a six-week expressive art bereavement group for youth (13-18). The group will explore continuing bonds theory, meaning reconstruction, and acceptance and commitment therapy using creative and narrative practices. I will discuss practices that are appropriate for adolescent development, for example, the groups will be ages 13-15 for early and middle adolescents, and 16-18 for middle to late adolescents as there is a slight adjustment for each group. And, how development as we have discussed in chapter two, applies to engagement and appropriate group practices geared towards youth. This chapter will also explore gaps and limitations in the literature, clinical implications, and ethics. The chapter will conclude with a final summary of this capstone.

### Discussion

This literature review has explored the reality that grief will be a lifelong process for youth. Neimeyer (2001) states that "from a relational constructivist view, we are shaped and sustained by our shifting patterns of attachment to people, places, projects, and possessions that largely anchor the meaning of our lives" (p.289). He goes on to say that the loss of our attachments challenges our meaning and conversely our life narrative (Neimeyer, 2001). In bereavement, it is imperative to keep life stories accessible and create a path for remembrance and legacy to regain new meaning and recreate a new life narrative (Hedtke, 2012). Grief literature has shown that narrative expressive art activities have helped bereaved youth externalize their emotions and has been effective at reducing depressive symptoms, suicidal

ideation, and substance misuse through meaning reconstruction and developing a continuing bond (Hartwig & Marlow, 2022).

The foundational therapeutic modality in any bereavement group is built from the person centered, humanistic model of meeting people exactly where they are in their grief, by engaging empathic listening, and conveying unconditional acceptance and positive regard (Rogers, 2007; Thompson & Neimeyer, 2014). Everything else is built around this. Additionally, grief when combined with art, becomes an expression of storytelling that provides an avenue with what is difficult to state merely by explanation. Grief lies beyond words (Rogers, 2007). Grief counsellors have the unique and challenging position of holding space for that which may not only be difficult to say, but difficult to hear. Listening to unpleasant stories of death, and traumatic images of illness that the bereaved person carries with them requires unquestionable care and safety. This sacred container provides the griever with an opportunity to release stored trauma into the open so that they don't have to carry that heavy burden alone (Calhoun et al., 2010). The final years, months, days, and hours of being with the dying are also filled with moments of beauty, profound love, and deep spiritual awareness that the bereaved often keep close to their hearts (Testoni et al., 2022). Having the opportunity to share not only the difficult traumas but also the loving and beautiful moments within a safe, and supportive social network of other grievers has evidence-based therapeutic power and healing (Hedtke, 2012; Testoni et al., 2022). In the presence of others, adolescents can develop new coping strategies, meaningful insight into their lives, and recreate a narrative of their identity (Neimeyer,2001).

**Application**

The artistic modalities presented in this capstone do not require one to be a skilled artist or writer. Art for the sake of therapy is purely an energetic transference of an inner reality into an outer form. Art involves play and is meant to invoke a sense of fun and enjoyment without a goal of creating work that is meant to be perfect or for public purposes. Playing with art for the sake of expression is merely a vehicle for expressing our stories (Rogers, 2007).

When the expressive arts are combined with continuing bonds theory the bereaved can develop a connection with the deceased that is tangible through the senses (Clabburn et al., 2021). Clinicians working with bereaved youth can assess attachment styles in the group that may play an important role in developing a continuing bond and if it will be effective in coping with loss (Field et al., 2005). Facilitators can use continuing bonds theory with an attachment lens and assist youth who may be in the protest, the despair phase, or are showing signs of detachment (Field et al., 2005). If youth struggle with connecting to a continuing bond, then there are other therapeutic techniques used within the group that youth can benefit from like meaning reconstruction and applying techniques from acceptance and commitment therapy (Hedtke, 2012). Cultural sensitivity must also be applied. Youth will react to and engage with continuing bonds theory based on their religious, spiritual, and social worldviews.

**Building the group**

Six-Week Expressive Art Bereavement Group for Youth (13-15) & Young People (16-18).

Six sessions for youth 13 – 15 & 16 -18 – slight adjustments based on age and developmental stages.

This capstone has focused on adolescent attachment and development from the ages of 13-18, however there are slight differences between attachment and developmental needs from early to late adolescents that are relevant to consider for group cohesion (Balk, 2014). For best group dynamics and delivering age-appropriate content, the six-week bereavement group will be divided into two age ranges that mirror the daily interactions for youth between middle-school and high school. This division is primarily so that older youth don't feel like they need to caretake younger youth, and younger youth may feel safer to be themselves without older youth present. Because youth are heavily reliant on their peers for self-acceptance and how they monitor their behavior in their social world, this slight distinction in age groups makes a big difference for an adolescent. Additionally, youth between the ages of 13 – 15 are still working through separating emotionally and reducing dependence on their parents, whereas youth between the ages of 16-18 tend to have a greater sense of autonomy and independence as well as higher emotional maturity and language development (Balk, 2014). Group facilitators will need to be mindful of and modify their language regarding discussion and exploration of difficult topics based on age appropriateness and emotional readiness of group members. Activities will also have a slight adjustment between groups and older teens will have a larger component of writing and journaling with a stronger focus on art for the younger group.

Among all the expressive art practices, creative writing and art journaling will be the main thread throughout the group sessions. Research on the effects of writing has shown that journaling can have positive implications toward growth (Rogers, 2007). Studies on a structured emotional writing intervention for bereaved youth that had elements of other creative practices

showed that they had a greater reduction in grief symptoms (Thompson & Neimeyer, 2014). In session one, the use of weekly journaling will be introduced and will be provided. Facilitators will explain how journaling can be practiced throughout the weeks to record thoughts and feelings and bring them to each session. Journals can be written creatively or using poetry or can include art journaling like drawing and coloring. Journaling is a therapeutic tool used inside and outside of the session (Matthews et al., 2022). Journaling has been found as a useful tool to assist people in expressing what they may not feel comfortable sharing with others (Matthews et al., 2022). Participants can use their journal as a guide if they need something to refer to in expressing their thoughts and feelings during the group's opening and closing circle. Youth can read directly from their journal or can share their poetry and art with the group without having to speak directly to the group on the spot about what is going on for them. Youth will also have time to journal in the sessions to record their experiences and to give them time to process the feelings and thoughts that the group has aroused. Having a tool like a journal will help youth with feelings of being uncomfortable and vulnerable when learning how to express themselves with others (Rogers, 2007). The journal serves as a companion in the journey through loss.

**Creating Safety and Ethical Considerations**

Best practice requires the do no harm approach (Wilson et al., 2016). The priority of group facilitators are to create safety, offer structure, and bear witness to the stories of people (Rogers, 2007). To assist youth as compassionately and safely as possible, groups will always be facilitated by two trained counsellors. Safety in the group will not occur unless facilitators outline and commit to strict ethical standards and guidelines. In a group therapy program for

adolescents who have experienced a significant loss, emotional safety is imperative, and group guidelines around ethical conduct will be explored in the first session to establish a circle of safety. The group will be given the guidelines around the limits of confidentiality in developmentally appropriate ways, involving protecting clients from harm to self and harm to others and giving youth agency by explaining that confidentiality would never be broken without their knowledge (Smith-Adock & Tucker, 2017). Youth will also be made aware of the confidentiality of group members and that what is shared in the group is meant to stay within the group setting.

Another point to consider that is crucial with adolescents is that they are minors and do not always have the same legal rights as adults. Facilitators will need to consider when to have informed consent between youth and their guardians based on the legal considerations of the Infants Act and consent for mature minors (Smith-Adcock & Tucker, 2017). While younger youth may need the permission of their guardians to attend the group, confidentiality will still be explained to youth and their guardians that what is shared in group remains confidential unless it falls under the limits to confidentiality. Moreover, it is quite frequent that youth will be referred to grief group services by their concerned guardian. It is incredibly important that youth, based on their developmental stage for needing autonomy and independence, feel empowered and safe to share things that they may not even tell their guardians, and are attending group because they want to be there and not just because an adult referred them. The BC Association of Clinical Counsellors Code of Ethical Conduct (2014) states that when a

client is unable to give informed consent on their own, then when interacting the "designated substitute decision maker" all attempts to protect the youth's dignity and promote the highest degree of self-realization should be made (p.5).

There are ethical considerations towards the confidentiality and use of art in an expressive art therapy group (Malchiodi & Perry, 2015). Art and writing become physical records of the client's confidential life experience, and these pieces produced in therapy need to have the same confidential boundaries as anything that is verbally shared or recorded in client notes and files (Malchiodi & Perry, 2015, p.26). As counsellors using expressive art therapy in bereavement, we need to consider how art leaves the counselling room with an adolescent and can be interpreted by parents or guardians as it is no longer in the confines of confidentiality once it enters spaces outside therapeutic space. Group facilitators must also be vigilant at not imposing interpretations, assumptions, and biases onto the meaning of the expressive artwork. Art is explicitly left for the youth to give it their own interpretation and meaning. Anything that we say as counsellors and facilitators holds weight that can be harmful and damaging and can come back to haunt us if we are not careful with giving youth full autonomy and direction over their art and writing. Much of the artwork in the six-week group sessions that I have outlined are meant to go home with the youth, including their private journal. Therefore, all expressions of art need to have a clear explanation with informed consent. Youth are always given the choice to opt out of anything they are uncomfortable with, and they have creative license and freedom of choice in their expression. Providing choice builds empowerment and self-confidence. Youth get to practice being directive in how they want to create and share their

project and how they would like to maintain confidentiality of their pieces once they leave the therapeutic space.

Finally, it is ethically important to have a screening process to assess for signs of group readiness to protect all group members from any potential harm. Youth experiencing emotional dysregulation, extreme social anxiety, substance misuse, and severe depression with suicidal ideation may not be appropriate or ready to enter a six-week bereavement group (Rogers, 2007). They may need individual counselling first, and support for their mental health and any substance issues before being ready to enter a bereavement group that will bring up difficult feelings and emotions that they are not ready yet to process. Youth who have a difficult relationship with the deceased parent may also want to have individual counselling before attending a group about continuing bonds. Moreover, depending on how soon the loss happened could also be a factor for group readiness. These are all considerations that group facilitators will consider in their intake process prior to the six-week closed group environment.

**Six Week Workshop Outline**

It is notable to mention that many hospice societies provide free individual and group counselling services, as well as grief camps for children and youth. Adding expressive arts to counselling increases the cost of services and reduces accessibility due to the additional fees for art supplies. Thanks to the generous funding and donations that hospice societies receive, accessible and affordable art therapy is available for all ages in the field of bereavement (Peterson & Goldberg, 2016).

*Please see Appendix A for a more in-depth description and procedure for each group.

***Session 1***

**Theme-** Introductions and creating the circle of safety.

**Purpose -** The intention during the first session is to build group cohesion and develop safety. Topics explored will be ethical considerations, group confidentiality, and limits to confidentiality. The youth will be guided to discuss what safety means to them and group goals for establishing safety will be created collaboratively.

**Goals -** To introduce the concepts of expressive art therapy and begin practicing journal writing or art journaling. The journals will be used as part of the group process throughout the six weeks and writing, poetry, and art will be offered as avenues of expression in the journal. Counsellors will prepare youth that the journaling and the following activities during the six weeks will evoke strong emotions and members will be given tools for anxiety management such as breathing exercises and self-care activities will be explored (Edgar-Bailey & Kress, 2010). Youth will be guided to share their experiences during an opening and closing check-in of each group session utilizing their journal as a tool to aid in expressing themselves (Malchiodi & Perry, 2015).

**Materials Needed –** Blank journals or notebooks, pens, pencil crayons, and art supplies to decorate the journals.

***Session 2***

**Theme -** Mindfulness, Music, and Creative Collage

**Purpose -** This group will introduce anxiety management tools using mindfulness techniques from Acceptance and Commitment Therapy. This second meeting is more psychoeducational

than any of the other groups because the intention is to develop some strong emotional regulation techniques before delving into deeper topics and activities about grief and death (Hedtke, 2012).

**Goals -**The expressive art technique used in this group will be creative collages. Music will be played and guided mindfulness techniques will be taught throughout this process so that youth can practice and choose from the options that work best for them while focusing on a project. Combining music and art fosters creativity while youth are making a grief collage (Malchiodi & Perry, 2015). Integrating music into the creation of art is an important part of the therapeutic Process.

**Materials Needed -** Poster boards, scissors, glue sticks, magazines, scrapbooking supplies, and art supplies.

***Session 3***

**Theme-** Nature walk, gardening, horticulture therapy.

**Purpose-** To experience being out in nature, as bereavement walks are very common in grief therapy and most hospice societies have a garden.

**Goal-** To take the youth out for a nature walk and experience talking about problems and emotions in a soothing environment with the backdrop of pleasing visual stimuli in nature. Being in nature provides a therapeutic holistic space that differs from being in a more formal setting such as the counselling space or at school. After the nature walk, youth will be invited to plant a seed in the garden. Intentionally planting a seed of their choice that represents an aspect of the person who passed away provides meaning and commemoration of the lost loved one

(Edgar-Bailey & Kress, 2010). This is the first introduction of continuing bonds theory and meaning making.

**Materials Needed:** A variety of seeds such as flowers, gardening tools.

***Session 4***

**Theme -** Drawing or Writing using the grief creature (13-15) and the furniture game (16-18)

**Purpose-** To introduce the art of storytelling visually or orally. Storytelling has been an art form used to express one's experiences throughout culture and history. Talking about a personal story through an avenue like expressive arts assists in creating meaning and restructuring a sense of identity after loss (Hedtke, 2012, 2014).

**Goal -** This session will incorporate the cognitive behavioral aspect of ACT by helping youth identify thoughts, feelings and behaviors through drawing and writing. This is a guided activity that builds on emotional intelligence and developing language around loss. The grief creature and furniture game are guided exercises that are a form of storytelling and meaning reconstruction (Edgar-Bailey & Kress, 2010; Matthews et al., 2022

**Materials Needed:** Hands-out of the grief creature coloring page, blank note paper, coloured crayons and pencils, writing pencils and pens.

***Session 5***

**Theme -** Continuing bonds, meaning reconstruction, ACT (Values), beaded memory bracelet

**Purpose –** This session will link continuing bonds and meaning reconstruction with the concept of identifying values of the deceased person that the youth would like to carry on. These values

will be represented by beads on a memory bracelet. The intention of this group is to link continuing bonds through a tangible and meaningful object that can provide comfort and a sense of connection to the lost loved one (Neimeyer, 2006).

**Goal –** Youth will be provided with a list of values from ACT to help identify the ones that represent their loved one. Beads will be provided, and youth will have the freedom to choose how they want to create their bracelet to represent their loved one. As with other sessions, music will be played during this process. The goal is to build on the idea of preserving the memory of their loved one, and to give space for youth to share their bracelet with the group and talk about the things that they love and remember about the person who passed away (Edgar-Bailey & Kress, 2010).

**Materials Needed –** Values handout, a wide selection of beads, string.

***Session 6***

**Theme -** Closing Ritual, Memory Box.

**Purpose –** To introduce closing rituals and saying goodbye. This is also a final commemoration ceremony for the person that was lost, much like a celebration of life.

**Goal –** Youth will decorate a memory box for their loved one. Inside they will place items that represent their loved one from pictures personal items of the deceased to anything the youth has found or created that represent their loved one. The memory box ritual is an opportunity for youth to talk about their loved one, and to have a memento that they can keep with them to remind them of their loved one (Edgar-Bailey & Kress, 2010).

**Materials Needed –** Boxes of varying sizes, scissors, glue, art supplies.

**Clinical Implications and Cultural Considerations**

Working with grieving adolescents in bereavement can be impactful and rewarding work (Balk, 2014). Teens are the forgotten mourners, and they frequently experience a loss of control in their lives beyond their comprehension when dealing with death (Edgar-Bailey & Kress, 2010; Rogers, 2007). They have been lost in the shuffle of parental illness overshadowed by outpourings of support for the dying, and their expressions of unmet needs and feelings are often labeled as "typical teenage behavior." Many people do not know how to comfort them or engage in difficult conversations about their experiences. Most often, people say, "I'm so sorry for your loss" and the conversation ends there (Hedtke, 2012). The therapeutic space can make up for this gap in support that meets them in their social world, but undertaking the task of working with bereaved youth is a niche in counselling that not everyone dares to go. It is sacred work that requires acknowledging the importance of working within our scope to give youth the utmost care and attention that they deserve (Matthews et al., 2022). Therefore, specializing in bereavement and specifically with youth requires ongoing personal and professional development (Matthews et al., 2022; Smith-Adcock & Tucker, 2017).

Working with adolescents and bereavement requires detailed examination of one's core beliefs and attitudes. Counsellors working in the field of bereavement need to be cognizant and mindful of their own biases and assumptions about death and the process of grief (Smith-Adcock & Tucker, 2017). The use of our language develops through our experiences (Hedtke, 2012). Adolescents understand more than small children, and although they are not yet adults, they deserve to be treated as capable and self-reliant developing individuals. This developmental

stage for teenagers, of being in between children and becoming an adult, makes them extra sensitive to any infantilizing language and attuned to picking up on biases and judgments coming from adults. Counsellors need to build a new skill set to adapt and shape their language to be able to speak fluently in developmentally appropriate adolescent language to effectively engage with them (Smith-Adcock & Tucker, 2017). Adolescents may struggle to communicate, and counsellors need to have language that is cognitively and emotionally accessible for them including conveying understanding and compassion in tone, inflection, body language, and facial expressions that will be different from working with adults (Smith-Adcock & Tucker, 2017).

Counsellors working with youth and bereavement also need to be adept at cultural competency. Bringing the concept of continuing bonds into the therapeutic process for youth can have cultural implications. Continuing bonds for youth must be developmentally appropriate and culturally sensitive. Maintaining bonds with the dead is not pathological but plays an important and positive role in people's lives (Klass & Steffen, 2018). However, it is important to respect the various cultures of young people's lives and honor their unique perceptions and worldviews providing space for them to define continuing bonds as they see fit (Smith-Adcock & Tucker, 2017). Similarly, meaning reconstruction having a direct connection with continuing bonds also carries different cultural meanings depending on the individual processing this concept. Just like continuing bonds, the idea of meaning-making is conceptualized, structured, and varies depending on the culture, thus it is socially constructed (Klass & Steffen, 2018). Counsellors may introduce the ideas of continuing bonds and meaning reconstruction using developmentally appropriate language for youth, but cultural competency will be applied by facilitators in giving

youth the freedom and space to define and utilize the concepts in a way that is respectful and meaningful to their own culture (Klass & Steffen, 2018; Smith-Adcock & Tucker, 2017). In addition to cultural competency, counsellors must also be skilled and trained in trauma-informed practice. It is paramount that youth experiencing traumatic bereavement feel safe and have techniques presented to them that guide them to learn how to self-regulate, reorient in their bodies, and become grounded when they are highly activated and triggered by traumatic memories and strong emotions (Edgar-Bailey & Kress, 2010).

Lastly, this capstone has explored the concept that there are no stages or linear tasks in grief (Rogers, 2007). While understanding the stages (Kubler-Ross, 1969) and tasks in mourning (Worden, 1988) can be helpful when working with clients, modern literature shows that grief has a life of its own, unique to everyone, that needs to be honored. The meaning of grief itself has fluctuated and changed through cultural, historical, and social contexts. Therefore, it is of top priority for counsellors and facilitators to resist the temptation to define and pathologize the grieving experience. The additional role of a bereavement counsellor is to work on behalf of the youth as an advocate, which involves de-pathologizing literature to reduce the widespread over diagnosing of the length and symptomatology of grief (Granek, 2010). Viktor Frankl (1959) stated in *Man's Search for Meaning* "An abnormal reaction to an abnormal situation is normal behavior." To live is to grieve, and our job as helpers on this journey is to provide unbiased and non-judgmental support.

**Limitations**

There are several limitations to this literature review that need to be considered. Most of the research literature on this topic that I found came from North American and European cultures with middle-class socioeconomic status. Generally, in dominantly Eurocentric studies the voices of youth have been a minority because they have been culturally considered "too young" or "too old" for research interest (Jessop et al., 2022). Therefore, this capstone is lacking in demographic diversity. Early parental death and bereavement processes are complex and variables such as culture, race, religion, and social status would impact the bereavement process and how adolescents are included and taught about illness and death (Tuazon & Gressard, 2023). Cross-cultural studies of grief would expand on the concepts in this capstone and provide varied and diverse responses to loss and if and how adolescents are encouraged and supported to create rituals and meaning in various and unique ways depending on how their communities respond to death (Klass & Steffen, 2018). Additionally, supportive families play an important role in the outcomes and recovery from bereavement (Balk, 2014; Klass & Steffan, 2018). This capstone focused on youth with a relatively stable home and a relationship with their dying parent. The research also focused on heteronormative families with two caregivers. Divorce, separation, and parent and child estrangement would impact attachment styles in the grieving process. As such, not all parental loss facilitates the same response as outlined in this capstone.

The literature on adolescent bereavement and parental illness suggests that roughly twenty percent of youth will lose a parent by the end of high school. (Rogers, 2007). Youth with a terminally ill parent is a very specific aspect of loss, and many other forms of loss are much

more traumatic, sudden, and difficult to overcome. The statistics of loss for adolescents increase when we factor in that many will lose a sibling, a close friend, or a beloved guardian that they consider a parental figure. Attachment and development are influenced by many types of bonds outside of the parental relationship. Attachment extends to other parental figures or caregivers and any other relations that evoke a sense of love, protection, and safety. Therefore, research on loss and bereavement with youth in general is needed especially when applying and adapting continuing bonds theory and meaning reconstruction as it will vary depending on the nature of the relationship, how the loss occurred, and cultural and social worldviews.

**Conclusion**

Although there are devastating impacts on development and attachment during adolescence from parental illness and death, early intervention and support can mitigate the consequences of suffering with anticipatory grief and traumatic stress. Youth who can access support have a better chance of emerging into adulthood with tools to address their feelings and process their grief. Grief is an isolating experience, and youth feel different than their non-bereaved peers at a time in life when fitting in means everything. They learn how to cover grief with a social mask and hide their pain. The work that counsellors can do to advocate for youth is to normalize conversations about death and dying and to teach others how to encourage youth to talk about their loved one openly. The great benefit of the expressive arts is it allows youth to do that in a way that suits their developmental understanding of loss. Moreover, in a group setting, the lonely feeling of grief becomes a collective experience and healing occurs by being with others experiencing the same feelings of loss. Art therapy becomes a public way to cope and

grieve and helps to restore meaning in unfathomable situations. Malchiodi & Perry (2015) explain how creative expression plays an important role in healing by helping to provide comfort and gives voice to philosophical and spiritual questions when explored in the presence of others. Adolescents can access individual counselling and groups throughout the anticipatory phase of their parent's illness and thereafter. Teaching that continuing bonds are normal and that we can creatively make meaning of our loss throughout our lives empowers young people at a time in their lives when they may feel hopeless, unseen, unheard, and devalued.

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# Appendix

## A Group Counselling Curriculum for Grief

## Youth Ages 13 – 15 & 16- 18

### Week 1

The first week of the group is to build group cohesion, create safety, and go over ethical guidelines and confidentiality. The session begins with an opening for youth to share something about who they are and what comes up for them organically with each member of the group. The goal is to begin the process slowly so that safety can be established, and relationships can be built for deeper stories to come out as the weeks develop.

The concept of Journaling will be introduced. Time will be provided for an activity to decorate the journals and to begin writing the first entry, youth will also be given the option to create an art journal in place of writing. An opportunity to do some art or writing while music is playing will give the youth an opportunity to begin getting to know each other in a relaxing environment with no pressure to share intimate details of their loss. Youth will always have the option to pass on sharing if they wish.

### Week 2

The mindfulness group is intentionally structured at the second session so that youth can learn interventions to assist with emotional regulation and develop tools to manage difficult feelings that will emerge as the weeks progress. This will prepare participants for triggers that can happen from not only the telling of their own story, but from hearing the traumatic details and experiences from other participants (Gillies et al., 2015).

**Week 3**

Weather appropriate, youth will have an opportunity to get outside in the garden at the bereavement center and go for a walk in the surrounding area. In expressive arts therapy, this concept is called the grief healing garden. Planting and horticulture are included under the expressive art therapy umbrella (Matthews et al., 2022). Youth are used to being cooped up inside a learning environment at school, and nature has been well-known as a companion on the grievers' journey (Mathews et al., 2022). Trees and gardens are often planted in memory of a loved one. Youth will have an opportunity to plant some flowers for their loved one. This is an example of how a planting ritual can be used to foster healing and to help youth become more in tune with their loss and its meaning (Matthews et al., 2022).

**Week 4**

Drawing and visual art has been widely used with adolescents across various cultural backgrounds (Matthews et al., 2022). This week's activities will have a slight variation between the developmental level from early adolescents to late adolescents.

- Youth ages (13-15) will be provided with a sheet that has a drawing of a cave and some nature. They will be guided to draw a grief creature, and asked specific questions around it such as: what does it look like? How does it sound? What does it do? How does it feel? And does it have a name? (The Dougy Center, 2024).
- Youth will be provided with a feelings chart to help identify thoughts, feelings, and behaviors through the ACT model. The grief monster is a narrative exercise to help externalize negative

feelings and experiences of grief from who the youth is and their identity. Young youth learn what their grief monster needs when it shows up and how to take care of it.

- The furniture game is for youth (16-18) who tend to have higher development in emotional intelligence and language. They may find the grief monster too simplistic or childish. The furniture game involves writing and can include drawing. Youth are invited to explore their feelings for the day through guided writing based on how they would feel if they were for example; a piece of furniture, a flower, a time of day, the weather, an item of clothing, and so on. The idea is to provide youth with an outlet to express their feelings when they are having a hard time articulating what they are going through. Youth will also be provided with the thoughts, feelings, and behaviors chart from ACT. Clients are invited to share what they have written with the group at the end of the exercise (Thompson & Neimeyer, 2014).

**Week 5**

The continuing bonds bracelet activity allows youth to explore the values of the person who passed away that they want to remember and incorporate into their lives using the beads on the bracelet as symbols or representations of these aspects of their loved one. Moreover, this activity gives young people the time and space to speak about loved one and to share their memory with others

- A values handout will be given at the beginning of the group to help youth understand and identify what values are, and concepts of continuing bonds will be explored with cultural sensitivity.

- A mindfulness meditation activity at the beginning of the group will guide youth to connect with images and representations of their loved one that they want to carry on in the world, or youth can choose to connect to the values that they identify with on the handout.
- After the group opening and values exercise, music will be played, and the youth can take time to choose the beads that represent their chosen values that represent their loved one to create meaning and a living legacy of their bond with their loved one through their actions in the world. - Using the concepts from narrative expressive art therapy, the group will close by sharing their beads and the meaning they have given to them for the life narrative that they want to create for themselves.
- Homework – youth will be asked to gather photographs and various objects that remind them of happy times with their loved one for the memory box making at the next session.

**Week 6**

Introduction of closing grief rituals. Rituals have therapeutic properties that provide comfort and closure (Rogers, 2007).

- This session offers bereaved young people an opportunity to create a memory box that contains the objects and photographs that they were asked to bring from the previous group. Youth will be provided with a box and supplies that they can use to decorate it. The group will design their boxes with music playing and then place the objects in their box. In a closing ceremony at the end of the group, youth will be asked to show the contents of their box and share the memories and meanings that they carry with them.

- The memory box is a token of something that bridges the gap between the past and the present (Clabburn et al., 2021). Boxes have been used in art therapy for various purposes that represent security, structure, and safety. The boxes are vessels that hold important and sacred memories containing objects and items of special significance (Rogers, 2007).

WATCHING SOMEONE YOU LOVE DIE

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