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Understanding bereavement and the grieving process through medical literature, observing practicing clinicians, and participation in support programs in the San Diego area (A Focused Clinical Multi-Disciplinary Independent Study Project)

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“Living with half a heart”—Confronting the challenge when the young do not outlive the old

**Purpose:** to learn about normal grief and complicated grief. I hope to accomplish this by reviewing the literature on bereavement and on the current, effective therapies for bereaved individuals to prepare myself for caring for these individuals in my future practice. I hope to utilize the knowledge I gain about strategies to help patients cope with their bereavement experience successfully. The focus of the literature selected for this paper is specific to bereaved parents grieving the loss of a child from a natural, anticipated cause. My interest in bereavement stems from my personal journey of navigating through the loss of my boyfriend, Kevin, in 2015 after a long battle with terminal cancer. Reflecting on my own bereavement experience and others close to Kevin, I hoped to learn more about the grieving process so I could guide others towards resilience and positive adaptation to their new life change. My continued relationship with his mother allowed me to witness the emotional challenges she faced in her grieving journey firsthand. I was moved by the difficulty of her situation and motivated to learn how I could better help her adapt to her loss ultimately leading me to focus my paper on bereaved parents who had lost a child from a natural, anticipated cause.

**Methods:**
A literature search was conducted with Pubmed, Psychinfo with the following search terms: “(study OR trial OR treatment OR therapy OR intervention) AND ((parents) AND ((complicated OR prolonged OR persistent OR pathological) AND grief)) AND ((los* OR death) AND child). Studies from 2000 to present were considered to better understand grieving process of parental bereavement and therapy approaches that have been effective in promoting resilience and effectively guiding bereaved parents to ease psychiatric distress and to prevent complicated grief. Additionally, bibliographies of located articles were searched for additional studies.
Background:

“Normal grief”
There is no one way to grieve. Everyone comes to terms with bereavement in their own way. An individual’s grief journey is influenced by their unique characteristics including their culture, gender, personality, and circumstances of life. Additionally the array of emotions, cognitions, and behaviors that accompany grief may change over time. Grief describes one’s reaction to bereavement. Immediately following a death, one experiences symptoms of acute grief which often are painful and debilitating. The hallmark of acute grief described by M. Katherine Shear, M.D., is recurrent intrusive thoughts and memories of the deceased. Acute grief and the period of time it occurs can vary depending on the closeness of the relationship to the deceased and circumstances of the loss [1, 2]. With time, acute grief evolves into integrated grief. Integration of grief occurs when the deep pain and disruption of acute grief lessen, memories become bittersweet and the bereaved person finds a place for the loss in her or his ongoing life [2]. Grief is not completed or resolved but is transformed as one makes peace with the finality and consequences of a death [3]. For most people who have lost someone very close, grief never fully ends.

Figure 1: The evolution of acute grief into integrated grief


A model that describes normal coping through the bereavement process very well is the dual process model of coping with bereavement described by Stroebe and Schut. This model outlines the experience
of coping with grief as a continuous oscillation between events surrounding both loss-oriented and restoration-oriented coping processes [4]. Loss-oriented coping includes ruminating about the loss, allowing oneself to grieve, wishing things had turned out differently or focusing on the negatives of the loss. Restoration-oriented coping processes refers to the bereaved individual developing their new identity and adapting to their life changes after their loss as well as distracting themselves from their grief and developing new relationships. [4, 5]

**Complicated grief**

A minority of bereaved individuals experience persistent, debilitating and painful acute grief symptoms, which lead to functional impairment known as the syndrome of complicated grief (CG). In these individuals, acute grief becomes chronic and leads to clinically significant distress as they cannot function in their daily activities and normal relationships. Symptoms of strong yearning for the person who died, frequent thoughts or images of the deceased person, and persistent feelings of intense loneliness or emptiness impede the expected response to bereavement and their healing [1]. More severe consequences of CG can even include suicidality, negative health outcomes, or increased use of tobacco and alcohol [1] [6].

Complicated grief leads to functional impairment beyond that accounted for by any comorbid depression, PTSD, and other anxiety disorders. Symptoms resembling depression can occur including: sleep disturbance, anhedonia, sad mood, guilt, and occasionally suicidal ideation symptoms, however, these symptoms have characteristics focused on the loss and help to identify complicated bereavement versus an MDD diagnosis. Anhedonia in the setting of bereavement is specifically linked to a longing for the deceased loved one. Sadness in grief has been described as coming in ‘pangs of grief’ or waves. In grief, feelings of guilt often include thoughts like not having done enough for the deceased loved one. Acute suicidality in grief, if present, is more likely to occur in a bereaved individual with comorbid MDD. Thoughts of dying in grief are more linked to a desire to reunite with their deceased loved one and not feelings of worthlessness or thoughts that others would be better off without them here. Nonetheless, MDD and bereavement can occur concurrently and the depressive symptoms and functional impairment tend to be more severe if they do. The depressive symptoms associated with bereavement-related MDD respond to the same psychosocial and medication treatments as do non-bereavement-related depression [1, 7].

Symptoms of CG have some overlap with PTSD symptoms, however, there are distinguishing differences that set the two conditions apart. The hallmark symptoms of PTSD are re-experiencing thoughts and images of the traumatic event, hypervigilance, and avoidance of potential threats [1, 7]. People with CG may experience intrusive images and preoccupation with the deceased person, but there is no confrontation with physical danger or fear that the threat may reoccur.

**Parental Bereavement**

Studies suggest that CG occurs in about 10% of bereaved people overall, with higher rates among individuals bereaved by disaster, violent death, and among parents who lose children [1]. Bereaved
parents may experience intense forms of grieving emotions such as anger, guilt, shock, helplessness, yearning and preoccupation with the deceased. The unnaturalness of a parent burying their child is frequently cited as a reason for the intensity of the struggle. Parental guilt is another common reason contributing to the psychological distress of parents’ loss—themes of having failed to protect their children from harm are cited in the literature[8].

In the literature, parents have reported their grieving process beginning as early as at the time of their child’s diagnosis. Grief may start at time of diagnosis, at the time of disease progression, at the end of life, or after their child’s death for parents [9].

Grief manifests in many ways and can often induce changes to the mind and body. The grief journey for bereaved parents has been described as “never-ending” and “the character and intensity of grief changes like a fluid emotion” [10].

Losing a parent as a child or the loss of a spouse has been shown to increase the risk of clinical mental illness later in life, but it is not widely studied if this association exists among bereaved parents. There are some sources that support that the death of a child is associated with an overall increase in mortality for bereaved parents. Complicated grief can worsen psychological health and physical health putting bereaved parents at an increased risk of chronic mental and physical morbidities [9].

Researchers examined a national Danish registry to investigate whether the loss of a child increased the risk of subsequent psychiatric illness in a parent by studying rates of psychiatric hospitalization. They found the relative risk of hospitalization for each psychiatric diagnostic group they examined—affective disorders, schizophrenia, and substance abuse—to be increased among both mothers and fathers who lost a child as compared with mothers and fathers who did not [11]. Of note, the age of the child at the time of death did not affect the risk of hospitalization, however, mothers were at highest risk of being hospitalized during the first year after the death of the child and rates of hospitalization declined with time since the loss. This study found fathers to be at an elevated risk of hospitalization for substance abuse up to 5 years after the loss of their child [11].

Age of the deceased child has been considered in the existing bereavement literature to better understand parental bereavement. A study published by Zetumer et al. subdivided the bereaved parent group they studied to understand whether the age of the child at time of death affected parental bereavement. Parents whose child was less than 25 years old and parents whose child was greater than 25 years old were studied. Their responses to investigators’ grief scales and interview content were evaluated and assessed for: major depression, maladaptive opinions, psychosis, mood, anxiety or substance use disorders, symptoms of complicated grief, suicidal thoughts and behaviors, guilty feelings and self-blame. They found that a larger proportion of the parents grieving a young child rather than the parent group of the older child endorsed a wish to be dead [12].

A study from 2008 examined 157 bereaved parents, ranging in age and length of time since the death, and qualitatively studied which risk factors increase the severity of the bereaved parents’ grief. They also examined whether making sense of their loss had any effect on the intensity of grief. In general, their results indicated that participants whose losses had occurred more years before the study and who reported making greater sense and finding greater benefit tended to report less grief on the scales used
to measure grief objectively, the Inventory of Complicated Grief (ICG)-measures maladaptive grief and Core Bereavement Items (CBI)-measures normative grief. The age of the child demonstrated that bereaved parents of older children had more severe grief symptomatology. Significant take-away points from their study to apply when considering clinical interventions were that parents who are more recently bereaved and who have lost older-aged children, especially to violent deaths were more likely to experience grief symptoms consistent with complicated grief criteria [13].

As health care providers the existing data on parental bereavement calls for an increased role on our part to help promote extension or support and resources for the grief journey[11] [9].

Mental health professionals’ role in caring for bereaved individuals
Clinicians working with bereaved individuals can help facilitate the natural mourning process, as described by Dr. Shear[3].

a. Support acute grief in its cultural context: Mental health providers should provide information about grief symptoms and explain these as natural experiences that helps adjust to the consequences of their loss. While there is no timeline or trajectory by which bereaved individuals should be monitored or tracked by, it can be expected that the bereaved individual will show progression over a period of months towards acceptance of the loss and healthy adjustment to life without the deceased.

b. Encourage effective mourning: Mental health providers should serve as a trusted companion who listens actively to their sorrows, longing and other emotions to foster good adjustment; there is little need to actively guide the discussion. Empathic listening, psychoeducation about grief and mourning, general support, symptom monitoring with attention to health behaviors such as sleep, nutrition, substance use and referral to a trained grief counselor are all recommended by the literature for clinical management of a bereaved person who seeks help [3].

c. Manage complications that can derail mourning: Maladaptive grief symptoms to be aware of include: excessive counterfactual thinking, excessive worries about the future, excessive avoidance, compulsive proximity seeking, or impaired emotional regulation.

d. Recognize and accurately diagnose concurrent psychiatric and medical conditions: Treating depression is important so the bereaved individual may have the capacity to experience their sorrow, savor memories of their lost loved one and begin to remake their lives. The stress of bereavement may trigger the onset of worsening symptoms of MDD, an anxiety disorder, or another psychiatric or medical condition, suicidality or negative health behaviors [2]. It is critical that the individuals who experience maladaptive mourning processes be identified and treated to prevent more suffering. There is evidence that antidepressant medications have positive effects with maladaptive grief symptoms and depression as well as good evidence for cognitive behavioral therapy. [3]
Goals of therapy to best aid a bereaved parent— How to accomplish posttraumatic growth?

The main goals of care are to help bereaved parents after their loss so that the intensity of their grief decreases with time. A positive association between meaning reconstruction and post-traumatic growth has been shown in existing literature on parental bereavement. From my understanding, meaning making presents an opportunity for a person who has experienced loss to understand the effect the loss has had on their life and to contemplate issues such as: why it happened, how has this impacted them, and what the significance is. Following the meaning-making theory, Meert et al described 4 major meaning making processes bereaved parents should address in their bereavement therapy [14]:

1. Sense making
2. Benefit finding
3. Continuing bonds
4. Identity reconstruction [14]

Sense making:

Sense making is described in the literature as the “…the survivor’s capacity to find some sort of benign explanation for the seemingly inexplicable experience, often framed in philosophical or spiritual terms [13].” For example, parents often find some understanding drawing upon their religious faith. An example of a more secular form of meaning-making could be parents drawing upon a biomedical explanation for the loss or understanding death better through personal reading of psychology literature pertaining to death and loss.

Benefit finding:

Benefit finding refers to exploring positive consequences of the death or “a silver lining.” Benefit finding should always be regarded with sensitivity to the seriousness of the parents’ loss. Positive consequences may include ways to help others such as giving feedback to the hospital, making donations, participating in research, volunteering, or mentoring other bereaved parents. A case study by Fletcher PN et al, interviewed parents who had lost their 5 month old to heart defect complications related to Down’s Syndrome. A little over a year after their loss, the mother had transformed her home daycare to serve children with special medical needs; a direct transformation influenced by their grief process [15].

Continuing bonds:

Continuing bonds refers to parents’ ongoing connection with the deceased child manifested by reminiscing about the child, sharing photographs, and discussing personal memories of their children with others. Parents who maintain connections with their deceased children, consistent with the concept of continuing bonds, experience comforting effects from these ongoing connections [10, 14, 16]. Grief support groups enable bereaved parents to find parents with similar loss who can help them continue their bonds with their children by discussing their late children.

Identity reconstruction:
In response to the loss, parents must adapt and redefine life plans in the absence of their child. Identify reconstruction allows parents to hold on to their relationship with their deceased child rather than letting go or getting over the death of their child. They learn to live with their new identity as a bereaved parent while assuming their everyday tasks and performing their other roles. Parents can honor their child by surviving and taking care of their other children, themselves, or their marriage [14].

Further literature supporting parental bereavement support

It is important to remember that there is no universal intervention to treat complicated grief. Treatment generally works best when targeting individuals experiencing marked difficulties adapting to their loss. The literature on parental bereavement repeatedly reflects on the great differences between individuals and their expressions of grief and advocates for individuals to be respected and to never be forced to “fit” an existing model or formula[20].

Complicated grief specific interventions such as CBT for complicated grief are being studied to help persons suffering from complicated grief and have shown promising results [21]. Shear et al developed an intervention for complicated grief called Complicated Grief Treatment, (CGT). CGT integrates interpersonal psychotherapy and cognitive behavioral therapy-based technique and is centered on Strut and Schoebe’s dual process model (DPM) of coping with bereavement. In CGT a therapist will teach the DPM to clients with complicated grief and emphasize the need to focus on restoration tasks. Their randomized control study compared CGT with interpersonal psychotherapy to treat a sample of bereaved individuals from a variety of relationships. They found the DPM-type CGT intervention was more effective than interpersonal psychotherapy [18].

Role of physicians

The role of physicians in supporting bereaved parents during and after the death of their child can also influence a bereaved parents’ grief experience. Communication skills surrounding the sensitivity of the end of life discussions, referrals to ancillary supportive care, and follow-up care for bereaved families have been identified as valued experiences bereaved parents shared on survey studies [22]. Focus groups that have been conducted among bereaved parents of children with cancer identified the deceased child’s health care providers and medical institutions as integral sources of support throughout the grieving process. Furthermore, resources for improved anticipatory guidance to prepare for death and bereavement and grief support services after the child’s death have been identified as service requests directly from bereaved parents [9]. An ongoing relationship with bereaved families and their child’s trusted health care providers is important to continue throughout the grief journey. Components of the relationship and bereavement support most appreciated by these focus group participants were intimacy, close bonds, shared understanding, physical presence and emotional availability of the health care providers. The therapeutic relationship transforms from medical provider to a present and understanding trusted individual who is available to walk with parents throughout the grief journey [9].
Barriers to parents utilizing bereavement aftercare

It is also important to understand the factors that play into patients not obtaining necessary support in aims to eliminate any disparities in access to care. Lichtenthal’s study looked at the main reasons bereaved parents were reluctant to seek out MHS resulting in unmet needs. The most common service use barriers reported in study were: too painful to talk about their loss, difficulties finding help, financial reasons, feeling like no one can help, stigma about MHSU [19]. Debilitating grief reactions fill parents with fear of confronting the reality of addressing the permanent loss of their child due to emotional pain thus contributing to their underuse of mental health care services [19]. Care should be available at the institution at which their child was cared for and offered community-based institutions as an alternative in the event that it is too painful for parents to revisit the setting in which painful memories may trigger pathologic grief [19].

Conclusion:

Losing a child is an extremely difficult experience for parents and I feel better prepared to provide care for this specific situation. The quote I chose for the title, “Living with half a heart,” is how a mother grieving the loss of her 21-year-old son described her grief experience to me. In my literature search, I found there is limited research available specific to parental bereavement, especially further specifics such as parents who have experienced the loss of a child from an organic, anticipated illness. Naturally, it is difficult to carry out controlled trials with such a sensitive topic and given the nature of the unique grief experience of all individuals. I would have liked to read more data on whether targeted grief therapies affect parents’ health outcomes. Future studies on the significance of anticipatory guidance for parents with children suffering from an incurable illness should be considered as it would be interesting to assess whether anticipatory guidance influences the grieving journey for bereaved parents. Other questions I have that I would like to explore with bereaved parents include whether bereaved parents feel we as providers are sensitive enough to the needs and feelings of their experience. This literature search has inspired me to continue to learn about what the natural mechanisms people utilize to cope successfully with adversity in the setting of bereavement. Identifying effective coping strategies and understanding resiliency factors will further enhance therapies directed for bereaved parents. I am intrigued by innovative therapies incorporating evidence-based techniques, such as culinary grief therapy, available for bereaved parents. These therapies are very significant because they diversify our existing therapies for preventing complicated grief and I am happy that such an important topic is being studied and strengthened for bereaved individuals.

References:


Bereavement Support Group Reflection:
Upon entering the bereavement support group, I was initially very intimidated. I was attending a spousal loss group that consisted of 7 other attendees and 2 therapists co-facilitating the group. I was much younger than all of the other attendees and yet as soon as I introduced myself and talked about Kevin’s illness and death, I was surprised to learn how relatable everyone else’s experiences were to my grief experience in some ways. It was comforting and I felt very safe. Themes discussed that I have always experienced myself included: feeling the heaviness of the loss greater during holidays when fond memories from prior holidays come out, guilt of moving on, staying very busy to distract from the grief, starting a new exercise plan and finding new hobbies to distract oneself from the grief, constant support from support group yet them not always knowing how to best support you through grief or knowing what to say, and hard days when getting out of bed seems impossible. The majority of these themes were all shared by each group member. I truly understood after attending group how bereavement support groups can help play a critical role in preventing feelings of isolation as well as provide learning from shared experiences. The shared experiences help make you feel “normal” in a way. It is also a safe space to continue to celebrate and remember the lives of loved ones. And of course with celebrating and remembering cherished memories came tears from the sadness of not having the ones we loved with us anymore. The group served as a dedicated, safe physical space to grieve with others who understand the experience. Some members shared more than others and some had been attending regularly for almost 2 years while others were new to support groups like myself. It was nice to see the more veteran attendees provide advice to members like myself that were new to attending groups. I would love to seek a group out that is designed for younger bereaved individuals to see how my grief experience compares to someone closer in age to me. However, I can imagine that this would probably not be as different from the older aged group I attended; it seems the experience of losing a loved one hurts about the same and leaves the bereaved with similar experiences as they mourn their loved ones and continue on with adapting to their new life without their loved one.