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The Central Role of Meaning in Adjustment to the Loss of a Child to Cancer: Implications for the Development of Meaning-Centered Grief Therapy

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Abstract

Purpose of review—This review describes research on meaning and meaning-making in parents who lost a child to cancer, suggesting the need for a meaning-centered therapeutic approach to improve their sense of meaning, purpose, and identity and to help with management of prolonged grief symptoms.

Recent findings—Several studies have demonstrated that parents bereaved by cancer experience unique meaning related challenges associated with the caregiving and illness experience, including struggles with making sense of their loss, benefit-finding, their sense of identity and purpose, disconnection from sources of meaning, and sustaining a sense of meaning in their child's life. Meaning-Centered Grief Therapy, adapted from Meaning-Centered Psychotherapy, directly addresses these issues, highlighting the choices parents have in how they face their pain, how they honor their child and his/her living legacy, the story they create, and how they live their lives.

Summary—Given the important role that meaning plays in adjustment to the loss of a child to cancer, a meaning-focused approach such as Meaning-Centered Grief Therapy, may help improve parents' sense of meaning and grief symptoms. It seems particularly appropriate for parents who lost a child to cancer because it does not pathologize their struggles and directly targets issues they frequently face.

Keywords

bereaved parents; meaning; prolonged grief; existential; pediatric cancer

Introduction

The loss of a child goes against the natural order of life events. Parents commonly struggle to make meaning of their loss and to find meaning in their lives [1–3]. Making meaning after

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Conflicts of Interest

None

losing a child to cancer, specifically, results in unique challenges [4]. For example, after losing a child to cancer, parents must also relinquish the role of caregiver fighting tirelessly against the illness. Consequently, they may struggle with their sense of identity and purpose, with a desire to sustain meaning in their child's life, while faced with the task of finding sense and significance in the loss [1, 2].

There is a clear need to develop empirically-supported, conceptually-sound interventions that directly address parents' challenges following bereavement [5–8]. Many bereaved parents, however, drop out of treatment because they do not find it helpful [6]. To address this issue, interventions should be developed with input from bereaved parents. Care must be taken to validate, not pathologize, their unique challenges, and the intervention should target problems commonly experienced. Meaning-focused approaches achieve all three of these, making them particularly appropriate for parents who lost a child to cancer.

To support this stance, we will review the literature describing the role that meaning plays in a parent adapting to the loss of a child to cancer. We will present the evidence in favor of a meaning-centered therapeutic approach. We will then provide an overview of Meaning-Centered Grief Therapy (MCGT), an intervention designed for parents bereaved by cancer who are experiencing protracted, intense grief symptoms. We will begin, however, by clarifying certain key concepts found in the literature.

Clarifying Conceptualizations of Meaning in Bereavement

Making meaning of adverse events, including bereavement, is part of the normal process of coping and adaptation [9–14]. Bereavement researchers and clinicians alike have reported the therapeutic benefit of finding meaning in the loss experience and of restoring a sense of purpose in a world without the deceased [4, 9, 12–14].

The literature on meaning-making contains several key terms that describe its processes and outcomes [15–17]. For example, Park [18] highlighted the distinction between the concepts of *meaning-making efforts* and *meaning made*. *Meaning-making efforts* refer to the processes that one engages in to find meaning, whereas *meaning made* refers to the outcomes of such processes. *Meaning-making* can be further divided into different subtypes, and a research tool for coding various *meanings made* has been recently published by Gillies, Neimeyer, and Milman [19] for use with bereaved individuals.

Distress can be caused by a discrepancy between the appraised meaning of a challenging life event (*situational meaning*) and the existing cognitive framework used to interpret the event (*global meaning*). According to Park [18], we are driven to make meaning of such challenging life events as a way of reducing this distress. In this way, meaning-making can be an adaptive mechanism, although it is important to note that meanings-made are not always helpful [18, 20]. Davis et al. [21] contended that bereaved individuals are driven most often to search for the meaning of their loss when it shatters their preexisting assumptions about the way the world works or when their sense of identity depended on the lost relationship [16, 21, 22]. The latter idea is related to psychiatrist Viktor Frankl's existential notion of a "sense of meaning" [23, 24], which he defined as the conviction that one is fulfilling a unique role and purpose in a life. Frankl [23, 24] highlighted how

suffering can ignite the drive to find a sense of meaning. We address both meaning-making and having a sense of meaning in MCGT.

The Loss of a Child: A Crisis in Meaning

Parents bereaved by cancer face a particularly significant threat to their sense of meaning and identity. This is due partly to the unique challenge of making meaning of a loss that defies the expected order of life events, and due partly to the loss of their identity as protector and role in fighting for their child's life. Several qualitative and quantitative studies have demonstrated that bereaved parents experience a "crisis in meaning" [25] that often persists over time [25–30]. Studies focusing specifically on parents bereaved by cancer have similarly found challenges to meaning-making and parents' sense of meaning, some of which are related to the cancer experience. For example, Barrera et al. [31] found that some parents who had been the primary caregivers for their ill child found it difficult to reengage in new activities, because each hour of the day was still somehow marked by their child's previous care routine. The authors found that parents were better able to cope and create meaning when they could accept the loss, maintain a connection to their child and to others, and redefine their sense of identity [31]. Rosenberg et al. [32] described 23% of parents who lost a child to cancer in their study as "non-resilient", which they defined as the absence of moving forward or meaning/purpose and/or significant distress. Notably, we have found that a decreased sense of meaning in parents bereaved by cancer is associated with mental health service use [6], suggesting that parents want a way to manage this type of distress.

Unique Challenges in Meaning-Making Following the Loss of a Child to Cancer

Prior studies and our own research have demonstrated several facets of meaning that may be deeply impacted by the loss of a child [33], some unique to a cancer loss, including:

Sense-making

An important meaning-making process often challenged by the death of a child is *sense-making*, which describes the efforts to "make sense of the loss" based on one's worldview. *Sense-making* may include assimilation of the loss into one's existing beliefs (e.g., the belief that the death was God's will) as well as change in one's beliefs having experienced the loss (e.g., questioning whether God exists). Davis, Nolen-Hoeksema, and Larson [34] found that the ability to make sense of a loss was associated with better adjustment in bereavement [34].

The loss of a child often challenges sense-making, countering assumptions about the self and the way the world works [22]. In the throes of profound pain, bereaved parents may ask, "Why my child? Why me?" [14, 24, 35]. Parents who lose a child to cancer may wonder what if they could have been prevented the cancer or death, often experiencing self-blame or guilt. On the other hand, we found that parents who had lost a child to an anticipated cause such as cancer were better able to make sense of their loss by thinking that their child was no longer suffering as compared to parents who had lost a child to other causes [36].

However, many parents express emphatically that there is no making sense of the loss of a child [2, 36]. Barrera et al. [31] found that 35% of parents bereaved by cancer had difficulty reconciling their experience with their worldview. Our research has shown that parents often struggle to make sense of the loss of their child and that those who express they are unable to make sense of their loss have higher levels of prolonged grief disorder (PGD) symptoms [2].

Benefit-finding and posttraumatic growth

In order to restore a sense of order and purpose, bereaved individuals often consider the greater significance of the loss [34]. *Benefit-finding* is a type of meaning-making that involves identifying the positive consequences of the loss experience [34]. For example, parents bereaved by cancer have reported changes in priorities and an improved outlook on life [37]. We found that parents who lost a child to natural causes like cancer were more likely to report improved coping and personal growth than parents bereaved by other causes, perhaps a byproduct of learning to cope with continuous challenges throughout their child's illness [36]. Such positive outcomes have been referred to as *posttraumatic growth* [38–40], which, among bereaved parents, has been associated with less intense grief symptoms [41]. We have similarly found that benefit-finding is related to lower levels of PGD symptoms in bereaved parents [2]. However, it should be noted that this is a sensitive topic and that parents understandably may have difficulty identifying any positive outcomes associated with their loss [2].

Identity and sense of purpose

Parents' sense of meaning and purpose is inextricably linked to their sense of identity. Parents bereaved by cancer lose not only their beloved child, but also lose their role as devoted caregiver to their ill child. After the child's death, they are forced to relearn the world without that caregiver role and without the presence of their child. As they attempt to maintain a bond to their child, their identity as "parent" to that child may also be challenged [33, 42]. Barrera et al. [31] found that 40% of parents who lost a child to cancer 6 months earlier reported challenges to their sense of identity. Examining parents' sense of identity at 6, 12, and 18 months post-loss, O'Connor and Barrera [43] identified patterns of identity disintegration [44] "in which establishing a new purposeful life after the child's death is equated to denying the deceased child's existence and the parental role" (p. 405). Notably, more parents reported characteristics of identity disintegration at 18 months than had at 6 and 12 months, suggesting that challenges to one's sense of identity are dynamic and may worsen over time [43].

Disconnection from sources of meaning

According to Frankl [24], a person's will to live is often linked to sustaining a connection to sources of meaning, such as work, hobbies, love, and beauty. Disconnection from meaningful activities, experiences, roles, and relationships often begins while parents are providing care to their ill child [45, 46]. After their child's death, they become disconnected from close relationships with the staff in the institution where their child was treated [7]. This is a significant loss, as the child's medical team is usually an important, regular source

of support to parents in their child's illness and dying [46, 47]. Parents' sense of purposeless can intensify following the child's death, as time spent caring for their child may be left unoccupied [31]. Parents sometimes feel increasingly isolated from friends and family, who may have difficulty grasping their profound pain [46]. In two-parent homes, they may feel disconnected from their partners, who may grieve in a different way [48, 49].

Legacy and meaning in the child's life

Bereaved parents often struggle to find meaning in the life of their deceased child, whose early death robs him/her of many usual opportunities to further develop a sense of identity and meaning. They report a deep fear is that their children will be forgotten [50]. Yet parents are irrevocably changed by their child's existence. Wheeler [25] found that parents expressed the importance of learning from the way their children lived and died, highlighting the significance of their child's life and the desire to keep the memory of their child alive. Recent studies have highlighted how parents often accomplish this by becoming active in causes related to their child's death [51–53]. In this way, they adaptively continue their bond with their child, even when the reality of the death has been accepted. [54–56]. However, for some parents, reminders of their child are discomforting, and so creating meaning is further challenged [55].

Meaning-Centered Grief Therapy (MCGT)

Meaning-Centered Psychotherapy (MCP), developed by Breitbart and colleagues [57–61], provides a therapeutic model for addressing challenges in finding meaning frequently faced by bereaved parents. MCP is a brief, manualized, existentially-oriented intervention originally designed to enhance advanced cancer patients' sense of meaning [59, 60]. Individual (7 sessions) and group (8 sessions) formats have been developed, and both have demonstrated efficacy in reducing psychosocial and spiritual suffering among advanced cancer patients [57–61].

MCGT was adapted from MCP for bereaved parents reporting elevated prolonged grief symptoms [62] in order to facilitate the construction of meaning and to help broaden possible sources of meaning through didactics, written responses to reflection questions [63] and discussion, and experiential exercises [64, 65]. Neimeyer's [9, 12, 66] meaning reconstruction is key, as MCGT fosters creation of a coherent narrative of the loss and of the parent's and child's life. MCGT also incorporates attachment theory [67] and cognitive-behavioral/schema therapy approaches [68–72]. It shares features with acceptance and commitment therapy [73] and restorative retelling [74]. Because it is a structured intervention, MCGT allows the therapist to systematically uncover important meaning-related content while also creating a sense of predictability and a roadmap to assist in navigating intense emotional terrain. This being said, MCGT is principle-driven, flexible, and involves substantial provision of support, bearing witness to the parent's painful grief and respecting that the parent is truly the "expert" in his/her grief [64].

The 16-session, one-on-one intervention was designed using expert feedback from bereaved parents and grief therapists. MCGT applies the MCP conceptual model with an emphasis on Frankl's [24] conviction that meaning and purpose can be found through connectedness with

valued relationships and roles in the world. A central principle is that individuals have the freedom to choose their attitude toward their suffering, and that this attitude can be a source of meaning in and of itself [75]. There is an emphasis on parents' ability to author their and their child's story [24, 35]. Despite all that has been beyond their control with their child's illness and death, how they face their pain, how they honor their child and his/her living legacy, and how they live their lives is within their control [64, 65].

MCGT additionally relies on the *Reciprocal Pathway Theory of Meaning-Making*, which we developed based on qualitative interviews conducted with parents bereaved by cancer [33, 76]. This theory highlights the overlap between various meaning-related constructs described above (e.g., sense-making, benefit-finding, identity, legacy) as well as their reciprocal, dynamic relationship, positing that enhancing one aspect of meaning can positively impact another (e.g., facilitating sense-making *through* benefit-finding, reconciling one's sense of identity *by* exploring the child's legacy and choosing one's attitude). This suggests there are multiple "clinical entry points" at which a therapist can intervene to enhance meaning [33, 76]. Improvements in various facets of meaning are believed to mediate improvements in prolonged grief symptoms [64].

Conclusion

Research has demonstrated that parents who lose a child to cancer desire support [5], but that many existing interventions do not appear to meet parents' needs [6, 8]. Given that meaning appears to play such a central role in coping with the death of a child to cancer, it follows that addressing meaning-centered themes can assist parents with coping with an unthinkable loss without pathologizing their struggles. MCGT targets these themes, highlighting the choices parents have in their day-to-day lives, the opportunities to honor their child, and ways to engage in life despite the tremendous pain they experience. In short, MCGT helps parents recognize opportunities for meaningful experiences as they learn to co-exist with their deep and painful grief.

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Key Points

- There is a need for theory-driven, tailored interventions for parents who lose a child to cancer to help them cope with their devastating loss and to improve continuity of care through bereavement.
- Parents who lose a child to cancer commonly face challenges to making meaning of their loss and to their sense of meaning and purpose.
- Meaning-Centered Grief Therapy has the potential to address meaning-related challenges for parents bereaved by cancer and to help with management of prolonged grief symptoms.