2022

A Mother's Disenfranchised Grief: Pregnancy Loss

Madison Jones
jone23mr@dukes.jmu.edu

A Mother's Disenfranchised Grief: Pregnancy Loss

Madison Jones

A research project submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

Partial Fulfillment of the Requirements

for the degree of

Educational Specialist

Department of Graduate Psychology

May 2023

FACULTY COMMITTEE:

Committee Chair: Renee Staton, Ph.D.

Committee Members/ Readers:

Debbie Sturm, Ph.D.

Dedication Page

This paper is dedicated to everyone who is carrying more than they ever thought possible.

A. Table of Contents

Abstract

Grief is unique to each individual and in the way it manifests socially, relationally, and physically. There are varying different types of grief and this paper examines disenfranchised grief specifically, miscarriage. Miscarriage, although prevalent, has been understudied in its approach for support and its impact on mothers. The current literature is examined to highlight counseling considerations and approaches to support for this population. Limitations in the current research are identified as gender and racial minorities being understudied. Grief will be experienced by everyone at some point in their lives and counselors must be competent in appropriately supporting this entire population.

Keywords: Grief, Loss, Miscarriage, Pregnancy Loss

Introduction

Throughout our lives, we will all experience grief and loss. Grief is individually experienced and affects us all differently. Additionally, there are various reasons for loss. Grief has been defined as the normal process of reacting to a loss (Casarett et al., 2001). Within this definition, it needs to be acknowledged that grief can be an individual's unique response to a physical, social, or relational loss (Casarett et al., 2021).

One loss that is often underexplored is the loss of a pregnancy. Although miscarriage is not often mentioned throughout our culture, the prevalence is high enough to suggest this subject deserves recognition and awareness. Quenby et al. (2021, p. 1659) reports, "miscarriages are very common, with about 23 million miscarriages occurring worldwide per annum." Almost 15% of all identified pregnancies results in a miscarriage, explaining the 10.8% prevalence in the female population that have experienced one miscarriage (Quenby et al., 2021). The prevalence for women who have experienced more than one miscarriage was much lower (Mergl, et al., 2022).

Within research on miscarriages, there is no standard definition of miscarriage, leading to varying definitions (Mergl, et al., 2022). Within some studies, researchers have incorporated early still-births as miscarriages, but some studies do not include still-births in their definition. However, the most widely used definition of miscarriage includes, "the spontaneous death of an embryo or fetus within the first 20 weeks of gestations," (Mergl et al., 2022, p.2), whereas after 20 weeks of pregnancy, it would be considered a still-birth. Regardless of the specifics related to the loss associated with miscarriage, grief is frequently an overarching reaction.

Types of Grief

Grief oftentimes has been discussed in abstract language, but understanding the different types of grief allows for deeper understanding on this nuanced topic. There are many

different types of grief, and understanding the differences is critical to understanding grief further.

Normal grief has been defined as one's ability to continue to function in their daily life (Vock, 2019). Within this definition, it is often assumed that the grief corresponds with predictable reactions to a loss (Vock, 2019). The idea of normal grief brings the expectation that the individual will move towards acceptance of the loss, lessening the intensity of emotions

Anticipatory grief occurs when the loss relates to what an imagined (hoped) life would be (Vock, 2019). Anticipatory grief is often felt by caregivers as loved ones receive significant diagnoses or experience declining health. Anticipatory grief differs from other types of grief in that a death or physical loss has not yet occurred. For instance, preparing for a divorce or potential loss of a job could create anticipatory grief.

Chronic grief, on the other hand, is dynamic as is experienced in differing ways, often including feelings of hopelessness, a sense of disbelief that the loss is real, avoidance of reminders to the loss, and loss of meaning and value in an individual's belief system (Vock, 2019). Chronic grief may develop after an unexpected or violent death, a death of a child, or a close relationship to the deceased person. Chronic grief is pervasive to many individuals' lives and can lead to mental health concerns including depression, suicidal or self-harming thoughts, and substance abuse (Vock, 2019). Like all grief, individuals experiencing chronic grief need to be greatly supported through their journey.

Complicated grief, also referred to as traumatic or prolonged grief, is experienced when grief has developed in severity, indicated by longevity and significant impairment of function (Vock, 2019). For complicated grief, it is important to recognize the contributing factors of the loss including the relationship, severity, occurrence, and life experiences. (Vock, 2019). Symptoms of complicated grief may include self-destructive behavior, deep and persistent

feelings of guilt, low self-esteem, suicidal thoughts, violent outbursts, or extreme changes in lifestyle (Vock, 2019).

Delayed grief refers to a later response to a loss or death (Vock, 2019). When delayed grief occurs, an individual's reactions and emotional responses may come at a much later time in relation to the loss (Vock, 2019). The reaction may be initiated at a later time by a major event, anniversary, or unexpected reminder of the loss. In these cases, individuals are not always aware they are experiencing grief, as it has been delayed.

Disenfranchised grief has been widely defined as, "grief that is not socially recognized," (Doka, 1989 as cited in (Casarett et al., 2001). These losses may include loss of ex-spouse, loss of a job, loss of a pet, or a miscarriage. As this grief is socially unrecognized, individuals experiencing disenfranchised grief may minimize their experiences (Vock, 2019). With the minimization of the loss, the individual may not appropriately address or process this grief.

Criticisms of the Stages of Grief

The five stages of grief model has been popular among professionals and the general public in conceptualizing grief. Kubler-Ross's book, *On Death and Dying,* published in 1969, is where this model first appears. Kubler-Ross "detailed her observations from interviews she conducted with patients who were dying of a terminal illness," (Avis et al., 2021). Kubler-Ross's model identifies a dying individual experiencing five stages including denial, anger, bargaining, depression, and acceptance. Kubler-Ross later extended this model to include a sixth stage, meaning (Avis et al., 2021). Kubler-Ross is recognized for her contribution and meaningful work regarding death and dying by many, regardless of the criticisms to her model. Along with her model being popular among professionals and the general public, it has been widely accepted in educational and clinical settings (Avis et al., 2021)

In her book, Kubler-Ross recognizes the discourse around her stages of grief, saying “The stages have evolved since their introduction, and they have been very misunderstood over the past three decades. They were never meant to help tuck messy emotions into neat packages. They are responses to loss that many people have, but there is not a typical response to loss, as there is no typical loss. Our grief is as individual as our lives. Not everyone goes through all of them or goes in a prescribed order,” (Avis et al., 2021). Although Kubler-Ross recognizes this, Corr (2019) addresses the implication of the word “stages,” often leading to the belief that there is a linear progression of emotions within grief. Corr (2019) also mentions this implication of the word has led to the model being used as a “prescriptive guideline rather than a descriptive model,” (p. 2).

Avis et al. (2021), mentions that no study has supported the existence of the stages of grief as outlined by Kubler-Ross. Avis et al. (2021), additionally recognizes that grieving individuals are impacted the most by the implications of the model if their grief does not follow the emotional reactions of the model. Along with being presented as a resource for grieving people, this model has been presented in curriculums within medical schools and nursing programs, as Hall (2014) points out. Teaching this model of grief to individuals in the healthcare profession without explicit acknowledgement of the limits creates misunderstanding of grief and will impact the way healthcare professionals view grieving individuals (Avis et al., 2021).

Effects of Grief

As has been previously mentioned, grief is the process of reacting to a loss, while bereavement is the period after a loss in which grief occurs (Vock, 2019). In much of the literature, research focuses on the consequences of bereavement on health, with far fewer studies examining physical and mental health of individuals in severe grief (Thimm et al., 2020).

However, grieving individuals will often experience physical symptoms of their grief; thus this absence in literature is important when exploring the impacts of grief.

Thimm et al. (2020) present fatigue and sleep problems as the most common physical symptoms. Thimm et al. (2020) further explore associations between bereavement and increased risk for developing physical complications. Some of the health consequences that have been linked with bereavement include cardiovascular concerns, infections, and type I diabetes (Thimm et al., 2020).

Considerations for Grief Work in Counseling

As professional helpers, specifically counselors in training, it can be tempting to "rescue," "save," or "fix" a client in some of their deepest pain. It can be challenging to bear witness to deep grief. As counselors, grief will be commonplace in our rooms and knowing how to meet someone in their grief will be crucial in a client's journey.

Devine (2018) encapsulates this challenge as she writes, "We've got a psychological model that says anything other than a stable baseline of 'happy' is an aberration. Illness, sadness, pain, death, grief – they're all seen as problems in need of solutions. How can you possibly be expected to handle grief with any skill when all of our models show the wrong approach? Grief is not a problem to be fixed. It doesn't need solutions. Seeing grief as an experience that needs support, rather than solutions, changes everything" (pp. 198-199). If counselors approach grief with a solution-oriented focus, clients have the potential to feel isolated within their pain. Devine (2018) shares, "The griever is frustrated because they don't need solutions. They need support. Support to live what is happening. Support to carry what they are required to carry" (p.199). Supporting a client in their grief can look like affirmation, validation, space, and understanding. Offering space might look like allowing someone to be in their pain without attempting to resolve the pain (Devine, 2018). Affirmation might include

acknowledging their pain, and letting them know their pain has been seen and heard (Devine, 2018). Validation and understanding could include recognizing the reality of their situation as they experience this loss and devastation.

In the loss of an unborn baby specifically, Solomon (2016) identifies guilt as a common reaction for parents who mistakenly believe they are responsible for the death. This may come from the belief that the mother harmed the baby or that one or both parents should have sensed something was wrong (Solomon, 2016). Counselors may want to bring in self-compassion work with parents along with generally giving space to their grief. Self-compassion will allow for parents to understand this was not their fault and they were not responsible (Solomon, 2016).

In the midst of this loss, it is important for the parents to, "accept his or her life – existence as a person. No matter how brief a baby's life, parents have just as much right to grieve as any other bereaved parent. In fact, it is an integral part of the mourning and healing process," (Solomon, 2016, p.1). This acknowledgement of the baby's existence will be important work for counselor and parents to process. While parents must grieve the loss of their child, they will also be grieving the future, dreams, and expectations they may have had for years (Solomon, 2016). The journey these parents will be on will be life-long, and as counselors it will be crucial for us to recognize this and understand the myths we may still hold onto regarding grief.

Solomon (2016) and Devine (2018) address statements that should not be said to grieving individuals. Some of these phrases include, "Everything happens for a reason," "They are in a better place now," "You can handle this," or "It was meant to be." Specifically for pregnancy loss, Solomon (2016) included "Thank goodness you are young – you can still have more kids,"

as a phrase that would dismiss and minimize the loss and emotions a grieving individual may experience. As counselors, the aim should be to validate a grieving person's loss at all times.

Additionally, counselors need to address the discourse surrounding the potential for pathologizing grief. Currently, the American Psychiatric Association (APA, 2022) has included a diagnosis of prolonged grief disorder as described by, "a persistent and pervasive grief response characterized by longing for the deceased or persistent occupation with the deceased accompanied by intense emotional pain," (World Health Organization, 2018). Holmgren (2022) further points out this diagnosis can be given 6 months after a loss if the individual is experiencing disruptions to social, familial, or occupational relations. Holmgren (2022) additionally recognizes the debate regarding whether persistent grief should be a diagnosis, stating that the bereaved are rarely a part of this necessary conversation. His study invited bereaved individuals into the conversation surrounding diagnosing grief. One participant shared, "It's normal to grieve one's entire life. As bereaved, we should not be made to feel guilt or shame because we grieve. It is completely natural," (Holmgren, 2022, p. 416), thus describing grief as a natural part of life rather than a disorder. However, other participants were in support for a diagnosis, recognizing it may be the only way to receive the necessary support from family, friends, and occupations, as well as providing access to help (Holmgren, 2022). This is consistent with Kolf's 2015 study of parents who have lost an infant. Some parents would have appreciated the diagnosis, "as a kind of legitimization of their grief in relation to family and friends, as well as in relation to work," (p. 420). Counselors must remain aware of where their clients are in their reactions and invite them into the conversation around diagnosing. As grief is individualized to each client, so is their perception of this diagnosis.

Cultural Considerations

Rubine and Hines (2022) state, “pregnancy and motherhood are intensely embodied experiences, as is race,” (p. 4). Race needs to be at the forefront of conversations surrounding motherhood, loss, and grief. Counselors must be aware of race within this work, starting with the disparity in infant mortality rates between black and white mothers (Ramraj et al., 2019). Ramraj and colleagues explain the infant mortality rate (IMR) as, “the number of deaths in children less than 1 year of age per 1000 live births in the same year” (p. 282). The infant mortality rate has been found to be over twice as high for black women than their white counterparts in the United States (Ramraj et al., 2019). Ramraj et al. (2019) further explain that socioeconomic, behavioral, and genetic factors alone do not explain the gap in IMR, indicating something broader to be the cause. At the societal level, pay and job inequities, as well as differential access to education, decent housing, and medical care, are relevant to the IMR gap (Ramraj et al., 2019, p. 283). All of these may lead to race related stress, impacting the health of these minority groups (Ramraj et al., 2019). Rubin and Hines (2022) support this further, stating that “psychosocial stressors, such as those caused by deleterious neighborhood attributes, likely cause poor birth outcomes such as preterm birth and low birth weight,” (p. 3). Black mothers are a vulnerable population and are at greater risk of experiencing loss and grief. As counselors, it is necessary to remain aware of this and understand how to work with this population.

For this vulnerable population, it will be important to be cautious of the “Superstrong Black mother” stereotype that is so often expected of black mothers (Rubin & Hines, 2022). This stereotype often, “renders invisible their grief and struggles,” (p. 18) leading to limited support and access to help. Da´na-Ain Davis (as cited in Rubin & Hines, 2022) shares, “we constantly carry deceased children while simultaneously negotiating imagined futures,” highlighting the reality of black mothers. Understanding the realities of this population and remaining cautious of the stereotype are equally necessary. Black feminist theory in combination with a narrative

approach will allow the reality of the oppressed to be acknowledged, while creating space for the client to develop their own narrative for their life (Rubin & Hines, 2022). This population needs support and advocacy.

An additional piece to note surrounding advocacy is the recent politicization of female-bodied people. As Roe v. Wade was recently overturned, female-bodied people are witnessing varying societal and political responses to their bodies. Counselors must remain aware of this socio-political climate in working with this population.

Specific Interventions

There is very limited research on specific interventions for individuals who have suffered pregnancy loss (Gold et al., 2016). Knight and Gitterman (2014) further mention that although support groups have previously helped individuals cope in difficult situations, its benefits have been largely understudied for the bereaved population. A few studies have examined the use of support groups for those who have suffered pregnancy and infant loss, however, neither study found support groups to be of statistical significance regarding depressive symptoms (Gold et al., 2016; Gold et al., 2022). However, Gold et al. (2016) outlines the advantages of groups, including people often feel less alone, they may share their experiences and feelings, and they often learn from others in the group. As previously mentioned, studies of support groups for depression and bereavement have shown mixed results, yet they are still recommended for the bereaved population as a way to process their loss among those who have suffered similarly (Gold et al., 2016).

A process group may be most beneficial to recently bereaved women. Although there appears to be no current research related to the potential utility of process groups for grieving mothers, such a group could offer the conditions outlined above for validating, understanding, and allowing space for individuals to work through their own unique experiences in ways that

work for them. A support group develops when people with similar difficult circumstances come together through a sharing of experiences. This type of group allows for members to offer support, encouragement, and comfort as well as receive the same. Support groups aim to be a safe space for members to develop practical coping skills as they face similar experiences. Within this group experience, feelings of isolation lessen as members hear similar stories. Whereas a process group will typically be smaller, somewhere between eight to ten people, meeting weekly or bi-weekly. A process group will be led by one or two trained clinicians, with the intention of allowing members to explore their interaction and experiences with fellow members. A key component of a process group is as members interact with one another, they will begin to gain greater understanding of their inner world and their inter-personal relationships. Along with greater understanding of themselves, members will support one another in addressing identified goals. A process group would offer mothers the chance to explore their grief as it comes up in their inter-personal relationships.

Limitations

Within any topic, there are gaps in the research that must be recognized. In their review, Gold et al. (2016) point out that both groups included predominantly White, well-educated participants who had private insurance. The researchers acknowledged one of the biggest findings in the research for this study was the lack of diversity in participants. The lack of representation in participants, specifically black women, concerned Gold et al. (2016) due to the fact that black mothers are twice as likely to experience a still-birth. Black mothers need to be at the forefront of research on pregnancy and infant loss as well as approaches to support. Gold et al. (2016) mentions bereaved black mothers, “rarely describe support groups as part of their coping network, and African-American women who do attend a perinatal bereavement group may find few or no other African-Americans there,” (p. 1074). Additionally, individuals in

minority populations are less likely to seek formal mental health treatment leading to further isolation for this population (Gold et al., 2016). Black mothers are greatly understudied, especially within pre and perinatal loss. Researchers must work to continuously identify and close this gap.

An additional limitation that needs to be identified is the binary and gendered language in the research regarding pregnancy loss. The research on pregnancy loss excludes gender minority individuals, leading to studies based solely on female-identifying individuals. Along with this gap in the research, no studies identified this as a limitation. This gap in the research excludes a vulnerable population, further isolating them from the necessary support and help. In order to understand a topic in both depth and breadth, inclusion of all populations are necessary. Greater understanding leads to greater support.

Conclusion

Grief will impact us all at some point in our lives. However, the way it manifests will vary for every individual. Manifestations of grief are defined by an individual's reaction and the loss itself, and include normal, anticipatory, chronic, complicated, delayed, and disenfranchised grief (Vock, 2019). Naming the type of grief an individual is experiencing can allow for a more validating experience. Diagnosing grief may allow for a validating experience as well as an increased likelihood for support, however, some may find the diagnosis as pathologizing a very human experience (Holmgren, 2022).

The experience of varied grief reactions remains true for women who experience miscarriages. Within this loss, every woman will process and address their grief in differing ways. In order to appropriately serve this population and their needs, counselors must approach grief with the understanding that the client is the expert.

In serving this population, counselors must consider the insufficient research on approaches to support as well as mothers who are gender and racial minorities. Specifically, black mothers are twice as likely to experience a still-birth as their white counterparts (Ramraj et al., 2019). The experience of black mothers is understudied and underserved. Additionally, individuals who do not identify as female have not been identified in current studies, but this does not mean they do not experience pregnancy loss. The experiences of minoritized mothers needs to be researched in order to appropriately serve their needs as they move through their grief. As research on this population continues to grow, so will advocacy, support, and service to this population.

References

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

Arslan, S., & Buldokğ, K. (2019). Grief support programs implemented to reduce the effects of grief on family. Psikiyatride Güncel Yaklaşımlar, 11(3), 402–417.

Avis, K., Stroebe, M., & Schut, H. (2021). Stages of grief portrayed on the internet: A systematic analysis and critical appraisal. *Frontiers in Psychology,* 12. https://doi.org/10.3389/fpsyg.2021.772696

Casarett D, Kutner J, & Abrahm J. (2001) Life after death: a practical approach to grief and bereavement. Ann Intern Med, 134(3), 208-15.

Corr, C. (2019). The 'five stages' in coping with dying and bereavement: strengths, weaknesses and some alternatives. *Mortality* 24, 1–13. doi: 10.1080/ 13576275.2018.1527826

Devine, M. (2018). *It's Ok that you're Not Ok: Meeting grief and loss in a culture that doesn't understand*. Sounds True.

Garrod, T., & Pascal, J. (2019). Women's lived experience of embodies disenfranchised grief: Loss, betrayal, and the double jeopardy. *Illness, Crisis, & Loss*, 27(1), 6-8. https://doi.org/10.1177/1054137318780582

Germain, A., Shear, K., Monk, T. H., Houck, P. R., Reynolds, C. F., III, Frank, E., & Buysse, D. J. (2006). Treating Complicated Grief: Effects on Sleep Quality. Behavioral Sleep Medicine, 4(3), 152–163. https://doi.org/10.1207/s15402010bsm0403_2

Gold, K. J., Boggs, M. E., Plegue, M. A., & Andalibi, N. (2022). Online support groups for perinatal loss: A pilot feasibility study for women of color. Cyberpsychology, Behavior, and Social Networking. https://doi.org/10.1089/cyber.2021.0304

Gold, K. J., Normandin, M. M., & Boggs, M. E. (2016). Are participants in face-to-face and internet support groups the same? Comparison of demographics and depression levels among women bereaved by stillbirth. Archives of Women's Mental Health, 19(6), 1073–1078. https://doi.org/10.1007/s00737-016-0657-x

Hall, C. (2014). Bereavement theory: recent developments in our understanding of grief and bereavement. *Bereave. Care* 33, 7–12. doi: 10.1080/02682621.2014. 902610

Holmgren, H. (2022). Defining normal: What widowed parents make of diagnosing grief. Illness, Crisis, & Loss, 30(3), 410–426. https://doi.org/10.1177/1054137320966261

Knight C, Gitterman A (2014) Group work with bereaved individuals: the power of mutual aid. Soc Work 59, 5–12.

Mergl, R., Quaatz, S. Edeler, L-M., & Allgaier, A. (2022). Grief in women with previous miscarriage or stillbirth: A systemic review of cross-sectional and longitudinal prospective studies. *European Journal of Psychotraumatology,* 13(2). https://doi.org/10.1080/20008066.2022.2108578

Oreg, A., (2020). The grief ritual of extracting and donating human milk after perinatal loss. *Social Science & Medicine,* 265. https://doi.org/10.1016/j.socscimed.2020.113312

Quenby, S., Gallos, I. D., Dhillon-Smith, R. K., Podesek, M., Stephenson, M. D., Fisher, J., Brosens, J. J., Brewin, J., Ramhorst, R., Lucas, E. S, McCoy, R. C, Anderson, R., Daher, S., Regan, L., Al-Memar, M., Bourne, T., MacIntyre, D. A, Rai, R., Christiansen, O. B, Coomarasamy, A. (2021). Miscarriage matters: The epide- miological, physical, psychological, and economic costs of early pregnancy loss. The Lancet, 397(10285), 1658–1667. https://doi.org/10.1016/S0140-6736(21)00682-6

Ramraj, C., Siddiqi, A., El-Amin, S., & Hamilton, D. (2019). What matters more, maternal characteristics or differential returns for having them? Using decomposition analysis to

explain black-white racial disparities in infant mortality in the United States. Race and Social Problems, 11(4), 282–289. https://doi.org/10.1007/s12552-019-09268-x

Rubin, S. E., & Hines, J. (2022). “As long as I got a breath in my body”: Risk and resistance in black maternal embodiment. Culture, Medicine, and Psychiatry: An International Journal of Cross-Cultural Health Research. https://doi.org/10.1007/s11013-022-09780-7

Solomon, F. (2016). *Coping with pregnancy loss and infant death*. HealGrief. https://healgrief.org/coping-pregnancy-loss-infant-death/

Thimm, J. C., Kristoffersen, A. E., & Ringberg, U. (2020). The prevalence of severe grief reactions after bereavement and their associations with mental health, physical health, and health service utilization: A population-based study. European Journal of Psychotraumatology, 11(1). https://doi.org/10.1080/20008198.2020.1844440

Vock, J. (2019). *Types of grief and loss*. Elizz. Retrieved December 1, 2022, from https://www.elizz.com/caregiver-resources/palliative-care/types-of-grief-and-loss/

World Health Organization. (2018). 6B42 Prolonged grief disorder. In *The International Classification of Diseases, ICD-11*. https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/1183832314