

When a Baby Dies: Ambiguity and Stillbirth

Joanne Cacciatore, John DeFrain, and Kara L. C. Jones

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ABSTRACT. Stillbirth, or sudden intrauterine death, is in many ways an invisible death. A stillborn infant is one mature enough developmentally to have lived outside the womb but for some reason, or perhaps multiple reasons, was born dead. Stillborn infants are often

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demarcated from other types of child death and are rarely legitimized as a real loss. When a baby is stillborn, mothers, fathers, surviving siblings, and grandparents may struggle for years to find answers to a series of complex and inherently unanswerable questions. The family members' profound feelings of grief and ambiguity loss are borne in a social environment that denies this reality because the child's death was invisible to most of the world. Boss's framework for understanding ambiguous loss proves quite helpful in thinking about stillbirth.

KEYWORDS. Ambiguous loss, bereavement, boundary ambiguity, infant death, stillbirth

INTRODUCTION

When a baby dies in a family, the surviving family members begin a journey toward healing that continues, realistically speaking, through the rest of their lives. They struggle together and as individuals to find answers to countless critical questions that, in many profound ways, probably defy answers. In our own experience working with bereaved families who have lost a baby and as researchers, we found ambiguity to be a dominant theme. The pioneering work of Pauline Boss (1977, 1987, 1988, 1999, 2001, 2002) on ambiguous loss, boundary ambiguity, and subsequent stress in families can be used to better understand the nature of this tragedy.

Yet, literature searches in two prominent computerized databases yield no studies linking infant death, in general, or sudden intrauterine infant death, in particular, and ambiguous loss. The American Psychological Association's *PsycINFO* catalogues more than 2,000,000 research-based and clinically based sources with none making the connection. Similarly, Family and Society Studies Worldwide database, a joint project of the National Information Services Corporation and the National Council on Family Relations (2004), lists more than 600,000 sources: however, none recognizes the utility of Boss's ambiguous loss framework for understanding the emotional crisis in the wake of the death of an infant.

Boss identified ambiguous loss as an element of the process and underscored the difficulty of the challenges we face in life. The subtitle, *Learning to Live with Unresolved Grief*, to her book, *Ambiguous Loss* (1999), illuminates this challenge. She is telling us in no

uncertain terms that we can learn to live with the tragedies life brings us, but resolution is less likely to be attained (Boss, 1999, p. 140):

The dilemma for all of us is to bring clarity to an ambiguous situation. Failing that, and we will in most cases, the critical question is how to live with ambiguous loss. For each of us, the answer will be different. But the answers are less critical than the questions. 50

Her definition of family coping complements her thinking on ambiguous loss (Boss, 2002, p. 79):

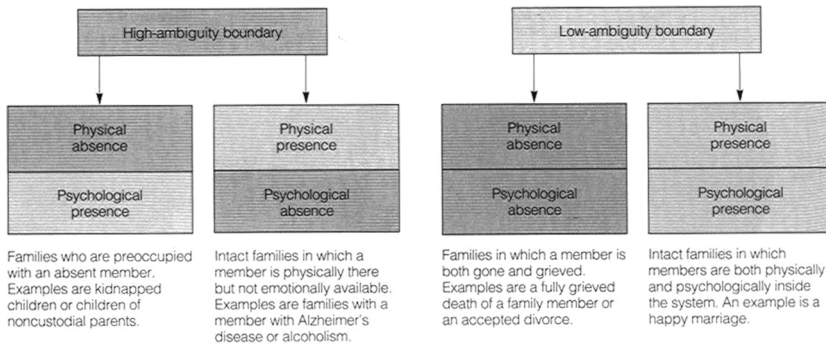
I therefore define family coping as the process of managing a stressful event or situation by the family as a unit with no detrimental effects on any individual in that family. Family coping is a cognitive, affective, and behavioral process by which individuals and their family system as a whole manage, rather than eradicate, stressful events or situations. 55
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In sum, the bereaved *live with loss and manage loss*, but loss remains a part of grieving parents forever—for both better and for worse. Loss, particularly death in a sense, can change people. And specifically, the death of a child changes the makeup of any family to some degree. 65

Boss explains that when there is ambiguity regarding a family member's presence or absence in the family, the situation can be called ambiguous loss. The family's interpretation or perception of the situation of ambiguous loss can be called boundary ambiguity and as such is a risk factor or barrier to the family's management of stress, increasing feelings of disenfranchisement (Boss, 2001, pp. 94–95). The relationship between boundary ambiguity and family stress is relatively easy to grasp by looking at Figure 1. 70

Boss (2001) argues that low levels of boundary ambiguity (congruence between physical and psychological presence or absence) are related to low levels of stress. As an illustration, in the long expected death of an elderly parent, the middle-aged children and grandchildren of the deceased loved one are likely to grieve and then move on with their lives. Or, in the case of an amicable divorce, the marriage over the years has lost its vitality, the spark is gone, and the individuals are relatively free to begin new lives because of the 75
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Figure 1. Boundary Ambiguity and Family Stress. (From Boss, P. (2001). *Family stress management* (2nd ed.). Thousand Oaks, CA: Sage. Copyright © 2001 by Sage Publications. Reprinted by permission of Sage Publications.)



congruence between physical absence and psychological absence. The most debilitating aspects of grief are likely to end and the level of stress for both ex-partners is low. Similarly, in situations in which there is both physical and psychological presence there is also low stress. A happy marriage is a good example of an intact family in which the partners are physically and psychologically together inside the system. 85

On the other hand, high-ambiguity situations, in which there is physical absence and psychological presence or physical presence and psychological absence, tend to be highly stressful. Physical presence coupled with psychological absence can be illustrated by families with a member with Alzheimer's disease or alcoholism. 90

Physical absence and psychological presence are critical elements of families whose baby has died. Using Boss's framework, we would argue that the death of a baby is a highly ambiguous event and thus highly stressful for family members: Although the baby is physically absent after death, for many bereaved parents the baby's psychological presence continues for the rest of the family members' lives in a multitude of ways. 95

STILLBIRTH, OR SUDDEN INTRAUTERINE DEATH

Stillbirth, or sudden intrauterine death, is in many ways an invisible death. A stillborn baby is one mature enough developmentally 100

to have lived outside the womb but for some reason was born dead. Gestational age distinguishes a stillborn baby from a miscarriage. A miscarriage is defined as the spontaneous termination of a pregnancy resulting from natural causes before the fetus is viable outside the mother, generally before 20 weeks' gestation. A stillbirth is defined as the death of an unborn baby weighing more than 500 grams after at least 20 completed weeks of gestation but before birth (DeFrain, Millspaugh, & Xie, 1996; Institute of Medicine, 2002).

The number of deaths reported from stillbirth is equal to that of all infant deaths combined (Ananth, Shiliang, Kinzler, & Kramer, 2005; MacDorman, Hoyert, Martin, Munson, & Hamilton, 2007; National Institutes of Health, 2003; Silver, 2007). Each year, more than 26,000 American women experience a stillbirth, compared with 2,500 infant deaths each year attributed to sudden infant death syndrome (National Institute of Child Health and Human Development, 2005; National Institutes of Health, 2003). Many stillbirths occur at or near full term. Upon postmortem examination, between one-fourth and one-half of stillborn infants are found to have died from indeterminable causes (Faye-Peterson, Guinn, & Wenstrom, 1999; Frøen, Gardosi, Thurmann, Francis, & Stray-Pedersen, 2004; Saller, Lesser, Harrel, Rogers, & Oyer, 1995; Silver, 2007). In essence, a perfectly formed baby is born . . . dead.

Medical examiners and perinatal pathologists are unable to isolate and identify the biological mechanisms for the death. Mothers are left searching for answers, for any explanation to the questions surrounding the child's death, and often in the turmoil of irrational self-blame (DeFrain, Martens, Stork, & Stork, 1986, 1990). Although the clinical aspects of stillbirth are cloaked in obscurities, the psychosocial dimensions of grief responses to stillbirth, as well as child death in general, are even more elusive and sometimes disregarded by researchers (Cacciatore, 2007).

For the woman, a baby's death may incite an existential crisis. Particularly in the case of stillbirth, a baby's death is often demarcated from other types of child death and is rarely legitimized as a real loss. Thus it may be difficult for a mother to reconcile her profound feelings of grief and loss. This pervasive sense of invisibility after a baby's death may exacerbate the boundary ambiguity related stress, heightening the emotional tumult and social isolation.

And for both parents in the case of stillbirth, their status as "parents" becomes complicated because there are no tangible signs of

parenthood to affirm their roles. Even if they have older living children, the full scope of their parenthood is ambiguous because most people will not acknowledge the child who died at birth as a member of the family. 145

Collectively, the family—mothers, fathers, surviving siblings, grandmothers, and grandfathers—struggles through the years to find answers to a series of complex and inherently unanswerable questions (DeFrain, 1991; DeFrain, Jakub, & Mendoza, 1992; DeFrain et al., 1986, 1990): 150

- Why did our baby die?
- Did I contribute to the death of our baby?
- How can I love my spouse when my baby is dead?
- Have I killed my sister?
- Am I still a brother/sister? 155
- What can others say that would make things better?
- What can I do to help myself and others?
- Should we have another baby? Will this happen again? Could I endure it?
- Who will continue to be my friend now that my child is dead? 160
- Can good be found in the midst of such tragedy?

We do not answer these questions definitively in this article, because they are essentially among the most elusive and complicated aspects of infant death. But we use examples from our research, clinical work, commentary from support groups with whom we work, and personal experiences to show how both individuals and family members struggle with the ambiguities of the loss of their baby and how some are able to embrace the discordant and find peace even through the uncertainty and unpredictability of ambiguous loss. 165

METHODS

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This was a retrospective analysis of anonymous data collected by two nonprofit organizations that provide care and support to grieving families after child death: MISS Foundation and KotaPress. MISS Foundation is an international organization based in Arizona that offers aid to families experiencing the death of a child at any age and from any cause. They hold an annual international conference 175

for bereaved families and professionals and have 27 online support groups with thousands of members. KotaPress is a local group near Seattle, Washington that mentors grieving families through the arts. Quotations from bereaved family members cited in response to the questions presented below in the Results section were compiled with permission from 74 people, including grieving mothers, fathers, sisters, brothers, grandmothers, grandfathers, and an aunt. The questions were targeted to families who had experienced stillbirth only. Locations of data collection included a discussion group with 55 participants at a bereavement conference in Phoenix, Arizona and an online discussion group with 19 participants. The questions posed by the nonprofit organizations were informed by empiric research led by John DeFrain on infant death over the past 30 years across nine distinct studies and involving more than one thousand participants.

RESULTS

Why Did Our Baby Die?

There may or may not be a clinical answer as to why a baby died, but the larger question of *why* is often more elusive. Many individuals pose this question after the death of a baby, and some endure a genuine crisis of faith after the death of their child. These parents not only end up searching for ways to endure the death, they may also lose faith or seriously question their belief system. Some of them eventually find resolution, whereas others do not. For many, the death of their baby precipitates its own type of ambiguous relationship with their faith:

I thought God was testing me like he tested Job in the *Bible* ...but... there is no answer to WHY.

Does [G]od really care that my baby died? Maybe if I would have been more faithful...[G]od wouldn't have had to take my daughter to teach me things....

It sounds selfish, but why did ours have to die? Were we picked for a reason?

Some mothers told us that God was punishing them because they had not wanted the baby and had considered an abortion. Consistent with past research, others said they were being punished for an extramarital affair (DeFrain et al., 1986, 1990). 210

Did I Contribute To the Death of Our Baby?

Both mothers and fathers seem to grapple with issues of self-confidence after the child dies. Some focus on the failure of their bodies to bring forth life. Others question their work ethic before the death. This can result, for mothers in particular, in an ambiguous relationship with their own bodies. Again, some resolve this for themselves and some do not: 215

I felt quite guilty about the stress-level I endured/ignored that was generated by my job throughout my pregnancy. 220

What did I do wrong?...I've reverted back to "family of blamers" tendency.

I was her connection to life and my body failed, therefore I am at fault. 225

I will always think I did something... I got sick with the flu. I tried really hard to take care of myself but I still got sick.

...It was my fault that he died—I carry the gene that killed my son. 230

How Can I Love My Spouse When My Baby Is Dead?

Boss's ambiguous loss model asserts that high levels of boundary ambiguity (incongruence between physical and psychological presence or absence) are also related to high stress. Tension in the couple relationship is common, but couples may also be drawn closer together by the death. An earlier study of stillbirth among 304 mothers and fathers (80% mothers, 20% fathers) asked about divorce: "Have you ever seriously considered divorce because of the still-birth?" Only 9% of the mothers and 7% of the fathers said yes. Some couples find comfort from each other, and the immediacy of grief 235

seems to bond partners together. It is clear that partnerships are being recreated, redefined on many levels:

We entered a new place as a couple as a result of this tragedy . . . there is a sense of invincibility there now that was not there before.

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Sometimes I get mad . . . because he doesn't seem to show emotions . . . but . . . he is grieving in a different way.

I feel so far from him at times, and so close at others. I have to love him because he is the only other person in the world who lost as much as I did . . .

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Profound grief has the ability to make people cling together for dear life, forcing them to become closer than ever before. It also has the ability to tear deeply caring and close people apart . . . The fact is that, no matter what else happens, only he knows what I've been through . . . [but] our love from one another has been forever changed . . .

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Am I Still a Brother/Sister?

The handful of siblings who responded to the questions seemed very confident in their role as a brother or a sister. All respondents were older siblings, born before the baby's death. It is difficult to say what ambiguities would exist for a subsequently born sibling wherein the family is predominantly silent about the loss, and this warrants further study. In many of the responses by siblings, the theme of a psychological presence/physical absence is palpable, as they continue to recognize their brother or sister as part of their family system:

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Yes, I am still a sister, a big sister . . . I am happy to be a big sister. I can be her big sister by visiting her at the grave, putting pictures in her cabinet, drawing pictures of her in our family, and when I grow up I am going to write books for her.

Yes I am because [she] is still in my heart and she always will be. When people say she is not my sister and she is dead . . . it makes

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me feel angry and I say that she still is my sister, whether she is on earth or not When someone dies, it doesn't mean they are not a part of our family anymore

I feel that I am still [his] brother despite the fact that I have never heard his voice I find myself thinking about him often. Most people tend to not think of [him] as my brother. My sister recognizes him as our sibling, but she tends to be the only one who brings this subject up My parents never shy away from letting people know that they love [him] and wear his memory proudly for all to see. Because of this fact, I have never felt uncomfortable or unsure about where I stand with them either I feel that I have a stronger bond with my parents . . . while I shared my strength with my family, they were simultaneously sharing their strength with me. It is a powerful feeling

What Can Others Say That Would Make Things Better?

Responses from the discussion and support group members varied, but everyone seemed resolved to let it be known quite clearly that clichés simply do not work. Most believed there was nothing that really could be said, but there were ways to share something so the newly bereaved do not feel so isolated in grief.

The most helpful things . . . people shared with me were their own experiences I hope I've learned to never utter a cliché again in my entire life.

You can be there for someone to hold their hand but you can never make it better.

I can help others . . . by sharing my own [story] . . . it's almost as if I have the ability to lend normalcy to a very abnormal situation. Sometimes, it's enough just to know that you are not alone

What Can I Do To Help Myself and Others?

Those whose children died more recently seemed unable to identify helping behaviors. Those who have had more time since the death

seem to have found many ways to help themselves and others. Again, the idea of a psychological presence/physical absence was observed in their responses as they engage in immersive grieving styles that help them remain connected to their child in meaningful ways: 305

For me, I journal, write poetry and work on the memorial website... [for others] send e-cards, snail-mail cards... let the person know that someone cares... not forget them... knowing that the grief lasts a lifetime. 310

Simply speak the names of the dead to those who loved them.

You can first of all talk... the more I was able to talk... the less alone I felt. I also found that I was able to help others over time as my need to talk became less I was able to listen.

I find crafting to be very deeply therapeutic, so I put my sewing skills to use by making quilts for families who have recently lost a child. 315

Should We Have Another Baby? Will This Happen Again? Could I Endure It?

Stillbirth is not just about the child who died and the grief parents endure. There is a certain ambiguity and uncertainty that follows the death of a baby before birth. This experience also extends into future pregnancies, redefines decisions about how many children people have, and can bring new stresses as issues such as secondary infertility come up and must be addressed: 320

What followed was... years of secondary infertility, diagnosed with PCOS... finally... put on Metformin... I conceived... Sadly, that pregnancy ended at 7 weeks in miscarriage. So, it DID happen again to us, and yes we endured... 325

Part of what I lost was the innocence I previously had... I will never again be unabashedly excited over a pregnancy... 330

My sub [subsequently born child] is absolutely the best thing I can ever imagine... [but] that [subsequent] pregnancy was the

scariest time of my life. Too scary and horrible to endure again even for the huge payoff.

This question hurts. I cannot have another baby . . . [we] are both carriers of the genetic disorder that took our son, which would also cause 50% of our children to die . . . Even so much as I loved—and continue still to love—our son, that is not a fate I am willing to risk. 335

Who Will Continue To Be My Friend Now That My Child Is Dead? 340

There is a saying among members of bereavement groups that “friends become strangers and strangers become friends.” Each case is different, but there is little doubt that death changes people. These changes can be difficult on relationships, even family relationships, and can sometimes become stressors that seem insurmountable. For some, the agony of watching their friend suffer becomes too difficult and they try to offer quick fixes that, instead, alienate the bereaved parent. Sometimes bereaved parents themselves report a feeling of not fitting in with their usual group of friends. Some friends move on in life to focus on their own children and in the flow of their lives often forget special days in the lives of the bereaved friend, such as the deceased child’s birth or death day and Mother’s or Father’s Day. A bereaved parent loses much more than their child in death. They often lose their sense of purpose, roles, future orientation, and even their friends. All these unique features of stillbirth can add to the ambiguity of their very intimate losses: 345 350 355

My little address book completely changed after my child died . . . I have a whole new set of friends.

Can Good Be Found in the Midst of Such Tragedy?

If any question borders on cliché, it is this one. And the polarization of answers to it reveals how vulnerable the bereaved parent can feel: 360

Yes, I believe so. So many people have come to me . . . with our loss, they are finally freed to talk about [their losses], and that talking is so healing.

I think that in order to survive in this world, for me, the answer to this has to be yes. I may not be able to articulate what it is . . . but I believe it is there. I believe we can create it. 365

No. I hate that phrase. Even though I have learned so much . . . I would give it all back to have her back.

Boy, this is a tough one. I still have a hard time finding any good that has come from our loss. But I guess . . . I have learned a lot about myself . . . my family . . . how much we really do love each other . . . how blind and selfish I was to the people who had lost a child before us. 370

Certainly good can be found. My [surviving] children have developed a sense of compassion and strength . . . Of course I would have rather them grow up innocent, but . . . [her] death made me realize who I am . . . who my real friends are . . . what is important and what is just the junk of life . . . 375

[Can any good come from this?] No. 380

DISCUSSION

Boss's ambiguous loss model is highly relevant for families experiencing stillbirth, and the experience of the baby's *physical absence and psychological presence* is apparent in these findings. Thus stillbirth appears to be a highly ambiguous event, resulting in high stress for family members. The stress arises on deeply personal levels. From questioning their faith and their partner to questioning themselves, some of these issues linger in ambiguity and are simply unanswerable. 385

For example, parents of children who have died often ask, *Why me? Why my child?* Those questions can haunt parents despite the age of the child or the cause of death. Sometimes, a seemingly simple question can only be answered with ambiguity. For some couples, physical closeness is an integral part of healing. For other couples or individuals, even the thought of intimacy may be overwhelming, and partners may not understand these feelings. Reasons for failing relational intimacy after a child's death may include exhaustion; lack 395

of interest; physical recovery time; feelings of guilt, shame, or blame; fear; and psychic distraction. Mothers, in particular, who participated in these discussions expressed a sense of shame—self-betrayal—over their body’s failure to produce a living, healthy baby. She may no longer trust her own body and may wonder if her partner feels the same. This emotional burden may impede a woman’s desire for intimate contact. 400

Siblings, too, are affected by the baby’s death. Often, their grief can result in somatic distress and may include a parade of physical symptoms ranging from insomnia or hypersomnia, lack of appetite or over-eating, regression in development, anxiety, irritability, anger, hostility, apathy, nervous tics, muscle tension, emotional outbursts, rage-like episodes, and tearfulness. These may last for months or years after the sibling’s death (Opie et al., 1992). 405

Q3 As demonstrated in the findings of this study, bereaved parents have similarities during the process of mourning the death of a baby, and they also have differences. Parents who were earlier in grief-seemed to struggle more to find meaning in their losses. Still, for all the respondents, there seems to be an interminability to grief. Grief often does not keep to a schedule. It is a timeless, nonlinear procession of emotions that rises and falls. The reality of the child’s death includes the grief over the possibilities and potential loss, the endless wondering over what it would be like if the baby were still alive day-by-day: “What would she be doing right now? What would he look like?” Each day represents a new loss. Each new loss brings an awakened grief. It will surely always hurt, though parents often get more skilled at managing the hurt and navigating the journey through grief. Though the baby is physically absent after death, for many bereaved parents their psychological presence continues for the rest of the family members’ lives in a multitude of ways. 410 415 420 425

CONCLUSION

When we read Pauline Boss on ambiguous loss, we are drawn to her words because they ring true with our experiences in trying to understand the meaning of the loss of a child in the life of a family. The beauty of Boss’s writings on ambiguous loss is that it is a theory for grown-ups: It does not patronize us, it does not hold out false hopes and pat answers. 430

The death of a baby is a horrendous event that generates an endless cascade of profound and essentially impossible questions, and Boss makes it very clear that life will always pose questions for us that we will not, in the final analysis, be able to answer. Rather than give us a false sense of security by throwing out a 6-fold path to healing or a 10-point program for overcoming the tragedy inherent in living, she reminds us that our lives still can be worthwhile and meaningful even if we really don't have a solid understanding of the what, where, how, or why.

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