Sudden Unexpected Infant Death and Its Impact on Families: A Primer for Professionals

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The Massachusetts Center for Unexpected Infant and Child Death* presented *Responding to Sudden Unexpected Infant Death: Strategies for the Professional* to perinatal social workers at the NAPSW 2019 annual conference. We provide an overview of the theoretical and practical approaches offered by the Center for compassionately supporting bereaved families and self-care.

The death of a loved one can be difficult for everyone, but the death of an infant or young child presents an especially extraordinary, shocking and devastating crisis for families and the communities that surround them. Parents liken their feelings and thoughts to King David's cry upon the death of his son, *Would I had died instead of you.* In events such as these, particularly when the death is sudden or unexpected and followed by immeasurable sadness, anger, guilt, blame and agony, it is vital that professionals involved in a bereaved family's life be equipped to offer competent, individualized and compassionate support. Specialized training, including information about common misconceptions, terminology, processes and grief responses, can prepare professionals to offer anticipatory guidance and support to affected families.

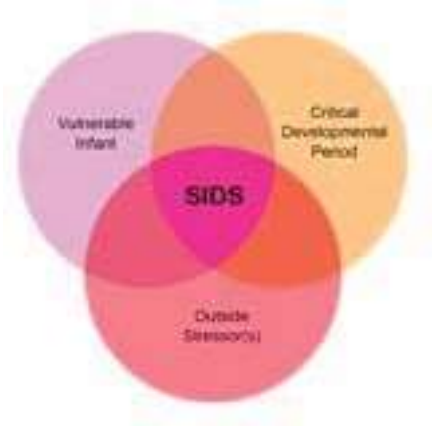
Child Fatality Diagnoses

Acronyms and definitions surrounding child fatality can be confusing. In the case of infant deaths, there are two central terms: Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Infant Death (SUID). SIDS is the more familiar term to most, but more often than not, SUID is the accurate term (see Figure 1). Clinically, SIDS and SUID (sometimes referred to as Sudden Unexpected Death in Infancy [SUDI]) have different meanings and there are important implications for families if the terms are confused or used interchangeably.

SUID, SIDS, Accidental Suffocation and Strangulation in Bed, and Undetermined Cause

SUID is a term used to describe the sudden and unexpected death of a child less than one year of age in which the cause was not obvious before investigation. These deaths often occur during sleep or in the infant's sleep area (CDC, 2018).

Figure 2. The Triple Risk Model of SIDS



(Filiano & Kinney, 1994)

SIDS *is a type of SUID*, and is defined as a death in a seemingly healthy infant under one year of age whose death remains unexplained even after a thorough case investigation, including a complete autopsy, review of medical and clinical history, and death scene investigation (Hymel et al., 2006). SIDS is therefore considered a "diagnosis of exclusion" (National Sleep Foundation, n.d.), meaning that all other possible causes of death have been ruled out. While

Figure 1. Types of SUID

much remains unknown about SIDS, the "triple risk model" can help us understand factors that may contribute to these unexplained deaths (see Figure 2). This model postulates that there is a "complex interplay between intrinsic vulnerability, a critical period of homeostatic development, and exogenous stressors" (Filiano and Kinney, 1994; Kinney and Thach, 2009). In other words, risk is heightened when there is a collision of a critical developmental period (child less than one year of age, particularly between two to four months), an external stressor environmental factor, such as cluttered sleep setting or co-sleeping), and an inherent vulnerability (biological underpinning or genetic susceptibility).

Researchers have enumerated the risk factors associated with "unsafe" sleep, including a prone sleep position, cluttered bedding, use of blankets while sleeping, and co-sleeping (Trachtenberg et. al., 2012). There is also considerable ongoing research (Subbotina et. al., 2019; Gando et. al., 2019; Mage et. al., 2016; Moon and Hauck, 2016) which strives to understand the unknown biological underpinnings and to identify external stressors and intrinsic vulnerabilities, especially as they relate to an identified critical time period.

Although it is not uncommon for some health care providers to label a death as SIDS immediately after an infant's demise, it is inaccurate to do so, as it takes significant time and a thorough review of systems and circumstances surrounding the death for practitioners to arrive at that conclusion. In fact, determining SIDS as the official cause of death on a final autopsy report can be a lengthy process that can take months or even years to complete.

Accidental Suffocation and Strangulation in Bed (ASSB) and Undetermined Cause are two other types of SUID. ***ASSB*** occurs when something limits an infant's breathing, such as soft bedding or blankets, or when there is an entrapment between two objects, such as a mattress and wall. Eliminating risk factors present in an infant's sleep space reduces the risk of ASSB.

The ***Undetermined Cause*** category of SUIDs are similar to SIDS in that there is no known, definitive cause of death upon conclusion of the autopsy, investigations and review of histories. However, the finding of Undetermined SUID may be used in the case of deaths with an incomplete investigation, those that are highly suspicious or those that present inconsistent medical findings (Crandall et. al., 2017). Practitioners may rely on a diagnosis of SIDS for cases in which full investigative due diligence has been met, and a cause of death is still unknown despite consistent findings.

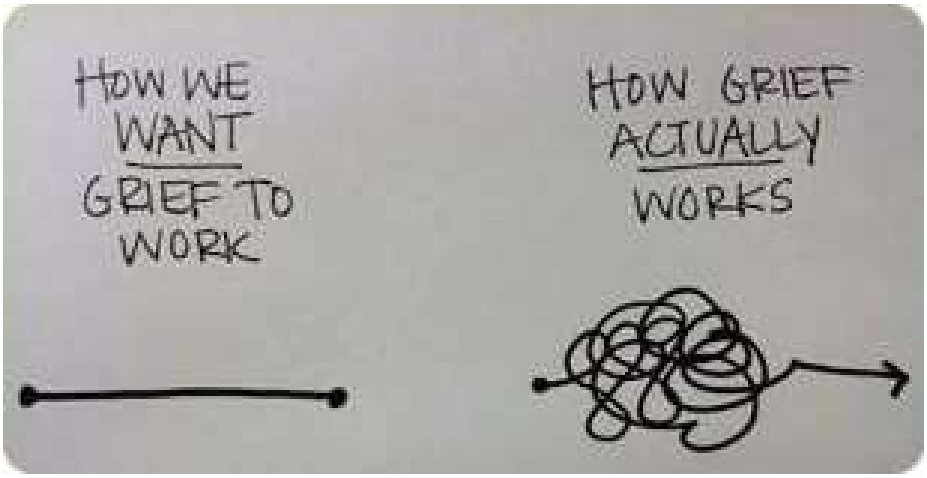
To complicate things further around the classification of SUID and SIDS, there is a high degree of variability in how these terms are utilized among different jurisdictions, and even between different practitioners within the same setting. SUID investigations are not always conducted in a standardized manner, nor are there universally accepted definitions or biological markers to differentiate SIDS from SUIDs of Undetermined Causes (Shapiro-Mendoza et al., 2014). This lack of uniformity can complicate epidemiological analysis, making it difficult to ascertain SUID/SIDS trends over time (Shapiro-Mendoza et al., 2018). Regardless, it is important to understand how these terms differ from one another so that professionals can use them accurately when discussing a death with a family. Explaining a death as "SIDS" implies that there is no known cause and would be inaccurate if the death were attributed to strangulation or suffocation from co-sleeping. How this is explained to families must be conducted with extreme consideration, caution and compassion, especially when there is an indication of wrongdoing.

A determination of SIDS/SUID often carries enormous weight for families. Some families feel a sense of closure after receiving a diagnosis of SIDS because it implies there was nothing they could have knowingly done to prevent the death. Others may feel anxiety or alarm at receiving that diagnosis for fear that it may occur in subsequent children or that surviving siblings may be carrying inherent risk factors that increase their likelihood of dying. It is important to listen intently to how each family makes sense of the diagnosis and to their feelings and perceptions, while validating and normalizing their response.

Processes following the death of a child

The bureaucratic processes that occur following the death of a child vary significantly among states, but typically include legally-mandated investigations spearheaded by district attorney offices with involvement from law enforcement agencies, child welfare offices, and the medical examiner or coroner office responsible for that municipality. It is often the case that families are subjected to similar inquiries and repetitious questions by personnel from different agencies, which heightens the probability of re-traumatization with each retelling of this painful story. The implications of being "under investigation" can create a climate of fear, judgment, and guilt, leaving families to fear potential outcomes, such as having other children removed from the home, facing criminal charges, and long-term ramification affecting one's public record. This despair is further amplified by what may be a lack of transparency on the part of investigatory authorities, such as lack of follow-through with regard to case closure or general ambiguity in terms of process.

It is imperative that investigators understand the complexity of SUID when drawing any conclusions about fault or actions during these circumstances. It can be helpful for those tasked with investigating cases of SUID to acknowledge the devastating tragedy that has befallen the family and to conduct investigations with sensitivity. It is necessary that investigators clearly explain their agency's processes and protocols, and to ensure that loops are closed when investigations are finished.



The Autopsy

The autopsy process presents unique challenges for families and the professionals that support them. In the U.S. most cases of SUID are required by law to include an autopsy. Typically, a medical examiner or coroner will take possession of the decedent's body once a declaration of death has been made and will retain custody of the body for several days to collect needed specimens and samples. At that point, the body will be released to the family or funeral home, so that acts of commemoration can occur. The medical examiner will complete a final autopsy report, which according to National Association of Medical Examiners guidelines, is "a process which should be completed within 90 days" (NAME, 2013). However, this is not always possible, particularly in cases of SIDS, which involve a lengthy process to rule out other possible diagnoses.

The final autopsy report is often a highly technical document that can be difficult for a lay person to understand. The portions of the report that a family understand can trigger strong feelings, as they may reference how certain samples were collected, discuss the appearance of organ systems, or include graphic descriptions of a child's body. Families may request the assistance of a trusted healthcare professional to interpret the autopsy report, but need to be aware that not all healthcare professionals may be able to thoroughly understand the document. In some states, families may have the right to request a meeting with the medical examiner who performed the autopsy to have their questions answered.

It is important for professionals involved with these cases to become familiar with the relevant protocols surrounding autopsies in their jurisdiction, which may include family's rights to request additional copies of the report and establish proxies to speak or receive communication on their behalf. It is also important for professionals to recognize that, oftentimes, the autopsy report may not necessarily provide the sense of closure that a family is seeking. This may be particularly the case with SIDS or SUIDs of Undetermined Cause, where so much is ultimately unknown. For this and many other reasons, professionals should be armed with resources. These can include reading materials, referrals to skilled behavioral health providers, information about online or local support groups, or peer-to-peer connections with those who have experienced similar losses. The Massachusetts Center for Unexpected Infant and Child Death has a website (magriefcenter.org) with much of this information.

Experiencing grief and providing support

How individuals experience grief is as unique as their DNA, and engenders many different emotions: anger, blame, guilt, and sadness often among them. Although there are established "models" or "stages" of grief that attempt to define how people "progress" through grief, we know that grief manifests differently for each person, is unpredictable and non-linear in its course and is a lifelong journey. Triggers can happen at any time of year or day. They can be subtle and difficult to anticipate and can occur unexpectedly, such as when a song plays on the radio or when a certain meal is prepared. Major life milestones such as graduations, weddings or birthdays are often times of renewed strong feelings. In one case, a parent who was simply cleaning her house collapsed on the floor and could barely breathe when she found the paraphernalia she had used to breastfeed her baby.

Supporting families in their grief

The loss of a child profoundly affects a parent's view of the world and how they make meaning of it. Pillars of daily life such as work, religious practice, friendships and family relationships can simultaneously be sources of strength and uniquely complicated. When supporting a family whose child has died, it is important to recognize that feelings of grief are experienced with greater intensity than other losses. It is paramount that professionals partner with families, allowing them to take the lead in expressing their own grief experience, personal story and needs while empathetically supporting them in their quest to make meaning of the loss and forming a new normal. For do's and don'ts of what to do and say, see Figure 3 below.

It's important to keep in mind that when professionals support grieving families, they may experience feelings of guilt, helplessness, and self-blame. Professionals need colleagues and supervisors with whom they can speak openly about difficult cases and how they are affected by them. It can be additionally important to practice self-care in ways that are personal, impactful, and ongoing.

The death of an infant or young child is one of the most painful experiences that can befall someone, but having the support of compassionate, empathetic and knowledgeable pro-

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Figure 3. Helping the Bereaved: Do's & Don'ts*

DO...	DON'T...
• Be a good listener; offer silent support as needed	• Compare your loss with theirs
• Remember that you can't take away the pain, but you can let them know that they are not alone	• Wait for them to contact you for help, just help
• Continue to call and understand that calls may not be returned right away, if at all	• Tell them what they should do
• Accept and be sensitive to all moods	• Be afraid to talk about the child who died and share memories
• Allow them to talk about their child as much and as often as they need to	• Think the age of the deceased determines the importance or impact
• Use the name of the child who died	• Change the subject when they want to talk about their child
• Cry if you feel like crying	• Offer unsolicited adviceMinimize the death
• Understand that there is no timeline or stages of grief	• Compliment them on their strength or bravery
• Use touch sensitively (hugs, hand-holding, etc.)	• Ask how they are doing if you aren't willing to listen
	• Assume when they laugh that they are "over it"
	• Avoid those who are grieving because you are uncomfortable
	• Worry about reaching out if you have not done so already

DO SAY...	DON'T SAY ...
• I am so sorry.	• It could have been worse.
• My thoughts are with you and your family.	• It's really a blessing in disguise.
• I can't imagine how you are feeling.	• Be brave for your family.
• You're not alone, I am here for you.	• Don't cry.
• How are you doing today? and listen to the answer	• This isn't the end of the world.
	• You're doing so well.
	• You'll get over it.
	• Your loved one wouldn't want you to be sad.
	• You'll be okay.
	• Things will be back to normal soon.
	• The first year is always the hardest.
	• It was God's will.
	• Aren't you over it yet?
	• Be happy that you even had them in your life.
	• You will have other children.It was meant to be.
	• Time will heal everything.
	• You can try again.
	• Good thing you are young so you can try again.
	• God only gives us what we can handle.

*Adapted from: Loss of Loved Ones to Sudden Tragedy (LLOST)

fessionals can help to make a family feel heard, validated and supported. Professionals need not be "experts" in child loss in order to make an impact on the lives of a grieving family. *At the end of the day, people may not remember what you said, but they will remember how you made them feel.*

*The Massachusetts Center for Unexpected Infant and Child Death, housed within Boston Medical Center, supports families, communities and professionals after an unexpected death during pregnancy, infancy or early childhood. For inquiries or consultations, please contact magriefcenter@bmc.org.

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COMMENTS FROM MEMBERS

Already this morning I've met with two families and don't think the conversations did much to alleviate their distress. The common themes seem to be loss of control, further isolation from support and increased grief over loss of newborn experience they had anticipated. I'm able to validate they are not alone in these feelings. Basically, I'm feeling like my clinical skills are inadequate. Is anyone having luck in directing these conversations in a way that they find more beneficial to the families? I would take any and all suggestions.

Jenny Duffy