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Management of Sudden Unexpected Infant Deaths in the Emergency Department:

A Family-Centered Care Protocol

Stephanie Anne Deutsch, MD, MS, FAAP; Jennifer L. Macaulay, MSW; Nadine Smith, DO, FAAP; Allan De Jong, MD, FAAP

Nemours Children's Health, Delaware

Abstract

Objective: To establish a standardized, trauma informed and family-centered emergency department (ED) sudden and unexpected infant death (SUID) management protocol at Nemours Children's Health, Delaware for medical professionals and multidisciplinary team (MDT) collaborators, informed by national clinical practice guidance, and respective of both family and investigative needs. SUID are emotionally distressing for involved family members, often precipitated by profound grief and confusion as the family interacts with many mandated public agencies during the course of a medicolegal death investigation. Although SUID necessitates consideration of child abuse and neglect as a contributory factor, and accurate determination of death cause may have critical implications for other family members and public health, prioritizing family needs in a trauma informed manner is paramount. Collaboration between MDT partners to provide optimal care to families following SUID involves transparent family communication, attending to medical and mental health needs of surviving family (especially siblings), and respecting medicolegal investigative constraints. Many institutions lack standardized approaches to SUID cases, which may precipitate increased family distress and delay initiation of necessary medicolegal death procedures. **Methods:** An MDT expert panel consisting of medical, legal, law enforcement, and child welfare professionals was convened at Nemours Children's Health, Delaware in 2018 over a 3-month period to analyze and implement an enhanced, family-centered, trauma informed hospital protocol. **Results:** Using exploratory inquiry and dialogue to elicit important protocol goals, a family-centered protocol with revised, coordinated roles for MDT members was developed with enhanced focus on communication, family-, and team-oriented care. **Conclusions:** Implementation of a family-centered, ED-based protocol standardizing the approach to SUID effectively supports medicolegal death investigative procedures while prioritizing trauma informed, supportive, sensitive ED care for grieving families. **Policy implications:** Health care institutions serving children and their families should develop and implement trauma informed, family-centered protocols to ensure sensitivity during medicolegal death investigations.

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Background

The sudden and unexpected death (SUID) of an infant or child is highly emotionally distressing for all involved. This traumatic experience is further complicated as family members or direct

caregivers are frequently the first to discover or provide aid to an unresponsive loved one, often overwhelmed by near-immediate feelings of loss, difficulty regulating emotions or thoughts, and shock at the inexplicable, incomprehensible nature of the loss.[1] First responders and emergency medical personnel may be recruited to provide emergent resuscitative care and/or transportation to an emergency department (ED) hospital setting, where eventual death pronouncement may involve interaction and communication with multiple professionals from a variety of disciplines.[1] Interactions and events between professionals and grieving family members during this crisis period and immediately after death can positively or negatively impact bereavement and adjustment to life without the person, becoming an intimate part of the family's history of the experience, and are therefore of critical significance.[2]

What follows SUID is a publicly mandated process of medicolegal death investigation, typically involving multiple public agencies (law enforcement, child protective services, medical examiner or coroner) to ascertain accurate cause of death.[1] Of paramount importance, analysis of death cause has potential health- and safety-related implications not only for other immediate family members, but also for the general public, such as when death is attributed to an underlying or heritable medical condition, infectious cause, consumer product, or even child maltreatment-related etiology. Failure to accurately identify death cause may impact the future safety of surviving children in the home or result in errors in prosecution when deaths are not accurately attributed to maltreatment.[1,3,4] In-depth exploration of maltreatment is warranted, as national statistics suggest infants are most vulnerable to fatality from abuse or neglect; nearly half of abuse-related deaths nationally involve infants less than one year of age.[5]

Distinguishing a natural infant death from those due to accidental, abusive, or neglectful causes may be difficult in the ED setting,[3] particularly when obvious external physical exam or radiologic findings supportive of maltreatment are absent. These SUID cases therefore involve comprehensive, multidisciplinary team (MDT) collaboration across medical, social, and child protective services (CPS), law enforcement (LE), the medical examiner (ME), legal and other sectors to accurately identify death cause through thorough medical and radiologic assessment, forensic autopsy, evidence collection, scene investigation, and clinical history review.[1,3] However, families thrust into immediate interactions with a multitude of cross-sector professionals while in crisis may naturally perceive the medicolegal process as highly distressing, confusing, intrusive, or even overwhelming, and may lack understanding of or agreement with the importance of the investigative process.[1,6–9] Distress may additionally permeate the experience of involved hospital ED staff, tasked with notifying multiple MDT partners while sharing worries that investigative involvement, such as by LE or CPS, may potentially increase family trauma after the death experience.

Families involved with SUID therefore deserve compassionate, non-accusatory, trauma-informed and family-centered interactions with involved MDT members; it has been suggested that "parents and other caregivers deserve an investigation that is sensitive to their grieving state and not one that is accusatory or insensitive to the emotions they are feeling."[10] The 2014 joint policy statement by the American Academy of Pediatrics Committee on Pediatric Emergency Medicine, the American College of Emergency Physicians Pediatric Emergency Medicine Committee, and the Emergency Nurses Association Pediatric Committee identified key principles and practices for addressing child deaths in the ED setting, prioritizing delivery of "patient centered, family focused, and team oriented care."[4] Development of written protocols, such as those addressing whether family member presence is permitted at resuscitation or after death to reduce distress in

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immediate crisis periods, was recommended.[11] Despite this and other clinical guidance,[1,3] many health care institutions lack standardized, family-centered approaches to SUID cases.

The following case example typifies challenges facing medical professionals involved in SUID cases. Three-week-old JM was found unresponsive in his crib, resuscitative efforts upon arrival to the ED were futile, and he was pronounced deceased. His parents were at his bedside in the ED, multiple other family members arrived, and hospital staff including Pastoral Care and Child Life were gathered for support. However, the unexpected infant death scene became chaotic, with voiced confusion by ED staff over the need to involve the ME, CPS, and LE even though the circumstances around his death were unclear. Confusion delayed initiation of medicolegal death procedures, primarily out of concern that involvement of investigators would further stress the grieving family. Ultimately, the ME was contacted and declared jurisdiction, abruptly restricting all contact of family members with JM and causing his family to feel stigmatized and express sentiments around a "crime scene." JM's case highlights the need to establish local protocols to ensure medicolegal death investigative partners are expeditiously engaged while maintaining a compassionate, family-centered, and trauma-informed approach to minimize family and MDT collaborator distress and optimize accurate ascertainment of death cause.

Because responding to SUID cases in the ED setting is extremely complex, the purpose of this study was to develop and implement a trauma-informed, family-centered ED-based protocol to support medicolegal death investigative procedures after SUID in a compassionate and sensitive manner, prioritizing family needs and preferences.

Methods

In 2018, a panel of MDT experts was convened from jurisdictional medical, judicial, CPS, LE, and legal arenas within the jurisdiction of Delaware's level 1 pediatric trauma center, Nemours Children's Health (Figure 1). The taskforce met twice over the course of approximately 3 months to collaborate and information-share regarding the roles and responsibilities of each agency involved in an SUID case. Panel members were selected based on their interest in the subject matter and role in the SUID process.

Figure 1. Multidisciplinary Team Expert Panel

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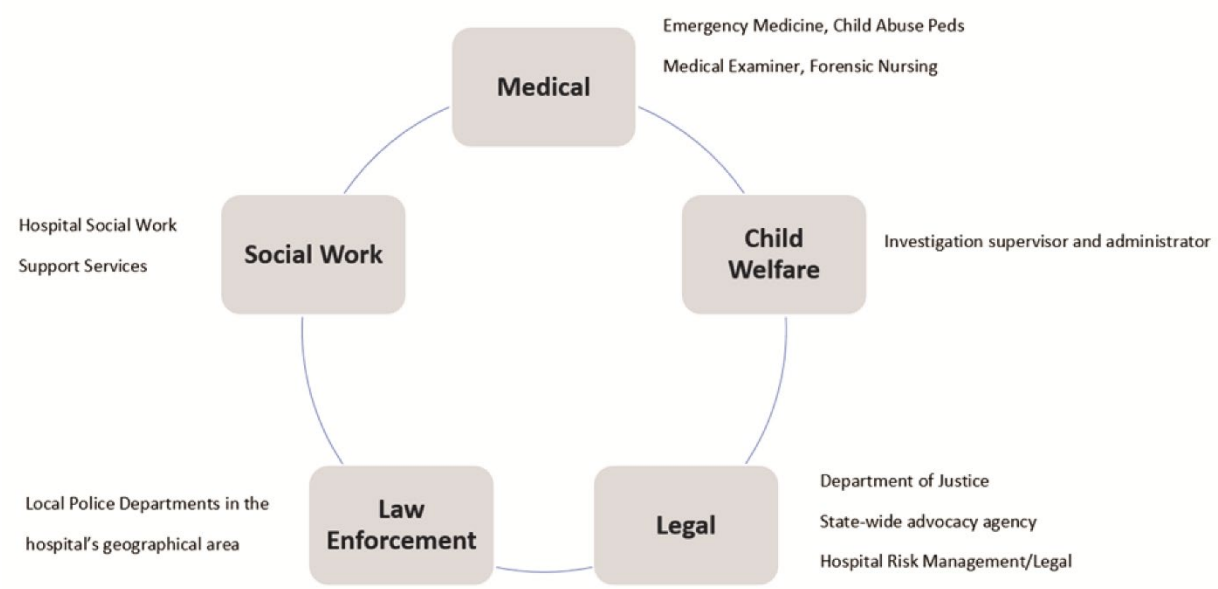

The expert panel used informal, exploratory inquiry and dialogue to explore barriers to family-centered care, and identified strengths/weaknesses associated with the existing ED-based response to SUID cases. Using themes and ideas that emerged from this dialogue, the MDT developed through consensus agreement an enhanced ED-based protocol with revised and coordinated roles for MDT members premised on communication, family-, and team-oriented care.

Results

Geography & Placement

Through exploratory inquiry and dialogue facilitated by ED-based medical experts, the first identified barrier in the SUID case management process was the physical geography and placement situation of family members during the resuscitation event in the ED setting. The MDT panel reviewed that unique to local state protocol, a 9-1-1 notification to emergency medical services automatically generates an LE response. Therefore, when an infant arrives at the ED setting, LE personnel from the jurisdiction where 9-1-1 was called typically present in tandem with the infant and family. If the infant is critically ill, has a suspicious history that is concerning for abuse or neglect, if cardiopulmonary resuscitation is in progress, or if the child is visibly injured, LE personnel frequently remain in the ED throughout the assessment.

Often, a family member may be permitted to travel in an ambulance with the child; however, sometimes family members are held at the scene by LE personnel, impacting the family's ability to participate in end of life bedside medical care. Explicit safety concerns may also prevent families from entry into the ED, a determination typically made by LE personnel prior to hospital arrival. If the family travels with the infant or child, they are welcomed to the bedside to be observers of attempted resuscitation, with the support of an identified health care staff member, and LE personnel will generally position themselves inside or outside of the room. If the family are not permitted to travel with the infant and held at the scene, and the infant was already pronounced deceased upon family arrival, family are typically not be allowed to enter the infant's room until the ME or LE personnel granted permission.

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Geographical space constraints in the ED also pose a challenge to accommodate additional visitors. Relatives or other family supports arriving at the hospital are typically supported in a designated waiting area or choose to return home. Reviewing the possible geographic or situational placements of family members in the ED setting was a priority area of exploration for the MDT panel, as ED-based medical experts highlighted literature that supported family/caregiver presence at the bedside improved emotional and psychological outcomes for surviving family members when they are observers of the resuscitation of their family member.[12]

ME Involvement

A second identified barrier was time to involvement of the ME. The ME was typically contacted by the ED medical team or unit supervisor, and during the initial call, the ME was often asked what restrictions must exist at the bedside, exploring inquiries such as *can family be present, can they touch the decedent's body, can memory making be completed,* etc. The ME often restricted family contact following death pronouncement and limited viewing of the body, touching, and memory making until his or her arrival. Response time was variable, and frequently perceived as delayed. The ME sometimes granted medical staff permission to complete photo documentation before his or her arrival, which might contribute to familial perceptions of the ED setting as a "crime scene" and criminalization of the SUID. Once the ME arrived to the bedside, there was typically limited time before the infant was transported off premises to the ME's office, and most families were instructed to meet with investigators at either the ME's office, local police station, or CPS agency.

Investigative partners, including CPS and LE, were variably contacted by ED medical staff. The MDT panel discussed that families might be offered the opportunity to engage in supervised contact with their deceased loved one,[1] and that members of the ED and other hospital staff should be educated around appropriate anticipatory guidance reflecting such parameters and other bereavement supports, while LE personnel remain present to enforce any restrictions around bodily contact that have been established by the investigators. Any physical contact with the deceased's body (either by family members or MDT professionals) requires direct consent from the ME in the hospital's jurisdiction.

Strengths

A notable identified strength was the involvement of Hospital Pastoral Care, Child Life, and volunteers, who are often contacted by medical ED staff to offer support to family members or engage in legacy building activities such as handprints/molds or hair clippings, after ME consent. The Child Life professional was also consulted to provide interventions around informing surviving siblings or other family members about the death at the request of the primary caregivers, as well as provide books and educational materials related to coping with grief and loss. If legacy building activities were prohibited by the ME, the family would be informed that handprints, molds, and other activities could be explored in conjunction with the ME's office or local funeral home following the medicolegal death investigation. The act of legacy building and religious rituals has been recognized as an important detail by all members of the working group, with the noted commitment to support both within the context of the SUID investigation.

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Themes

Key themes emerging from panel dialogue included enhanced need for family participation and communication, dynamic reassessment of family's needs and wants during ED management, transparency (clearly defining for family members expectations of the medicolegal death investigation process), rapport building and support (including offering support for termination of breast feeding, notification of the primary care pediatrician or next of kin), and anticipatory guidance post-hospital discharge (meaning, discussion of autopsy, funeral arrangements, and scene investigations, etc.).

Process refinement was discussed by MDT think tank experts and through consensus opinion, the following steps were developed:

Step 1. Rapid, efficient mobilization of the MDT (Table 1). The panel established that assessment for immediate safety of all parties, followed by a clear definition of roles and responsibilities based on the needs of the case, was necessary. Orienting the grieving family to the resuscitation and postmortem process and providing clear communication around the necessity of a medicolegal SUID investigation were prioritized as necessary action steps. The panel identified that LE personnel and the hospital social workers were often best positioned to provide information to the family regarding SUID medicolegal investigation within the context of their professional roles, as this dyad could support legal expectations/procedures.

Table 1. Mobilization of Multidisciplinary Team Response to Sudden and Unexpected Infant Death

Action	Responsible Party
Contact Child Welfare Agency (assess safety of household contacts, coordinate medical evaluations)	Hospital Social Worker/hospital staff
Contact Law Enforcement (LE) if not initiated by a 9-1-1 call	Hospital Social Worker/Child Welfare
Contact Medical Examiner (ME) Office	Hospital staff/Social Worker
Contact Pastoral Care (address initial religious needs of family, provide support)	Hospital staff

The panel clarified that parents/legal guardians or an identified support person should be accommodated in the ED patient care area if no active threats to physical safety were identified. Scenarios that involved a known violent incident (such as a firearm related incident) may raise concern for imminent safety and impact caregiver participation in the resuscitation. Physical space constraints in the ED may also impact family presence.

If the infant arrives to the ED via emergency medical services, the medical team should anticipate the simultaneous arrival of family members, permitting a member of the medical team to greet the caregiver and support their presence at the bedside during the resuscitation and medical care.

There may also be instances in which an infant will arrive unaccompanied by a family member/caregiver. If the child dies prior to the caregiver's arrival, the caregiver should be supported in a hospital waiting room that can provide privacy until further guidance is provided by LE personnel and the ME regarding family presence with the deceased. Once death is

declared, LE personnel are responsible for securing the body of the deceased and the scene for ME jurisdiction.

Step 2. Establishing the jurisdiction of the ME in the SUID case. *Does the death of the person meet criteria for ME involvement, and if so, to what extent*? If the ME accepted the death for further investigation, several parameters require clarification, such as postmortem photo documentation, radiologic imaging, and physical care of the body. It is recommended that all intravenous lines and tubing remain in place on the body, and communication regarding organ donation should be facilitated by the organ procurement organization with the ME, following consent for donation by the family; an SUID investigation does not preclude organ donation.[13]

Upon death and jurisdiction declaration by the ME, he or she should identify stipulations and parameters regarding family presence at the bedside and the movement of the infant's body for postmortem imaging or procedures. Any interaction and observation of the body by family or other MDT members should be discussed with the ME (Table 2). This includes continued physical care of the body in the ED setting. The MDT recognized that religious needs may require physical handling or touching of the body, and prioritized discussion of these elements with the ME so that they can be accommodated within the context of the family's religious preferences.

Table 2. Hospital-Based MDT Response to Sudden and Unexpected Infant Death

Action	**Responsible Party**
Photo documentation, evidence collection (clothing, bottles, diapers, blankets)	Medical Examiner, Nurse Examiner team
Chain of custody protocols for evidence	Law Enforcement
Enforcement of restrictions. No one is permitted contact with decedent (including family members) unless for postmortem imaging. All tubes/lines/bandages should remain intact from pronouncement until otherwise directed by the Medical Examiner	Hospital staff/Law Enforcement
Recommend/Perform postmortem imaging	Medical Examiner, Hospital staff

Step 3. Assessment of the medical and mental health needs of surviving family members, with specific attention to siblings and other minor children in the household. An age-appropriate physical examination with occult trauma screening is recommended for all children in the household, given that immediate cause of death is unknown and could include acute illness, underlying health or genetic conditions, toxic exposure, abusive or accidental trauma, and sleep-related injury.[14] Prompt intervention with a medical professional in the ED setting could potentially be lifesaving. Emotional health should also be assessed in the context of the medical crisis. Children may need help processing experiences like hearing and seeing first responders in their home, or understanding why their parent/caregiver is crying. The emotional health of the children should be repeatedly assessed, and appropriate services should be available and accessible (bereavement counseling, ongoing therapeutic interventions for complex psychological and emotional needs that may arise in the future, etc.). Assessment of surviving children for suicidal and/or homicidal ideations to ensure immediate personal safety should be prioritized.

Engagement with the ED setting was viewed by MDT panel members as useful to assess for immediate psychosocial needs of the family, including identification of religious/cultural needs,

assisting family with logistics of funeral/burial arrangements, and mobilization of extended family members and friends to help the parent/caregiver navigate this crisis period. Legacy building or memory making activities should also be facilitated during this step if possible, as well as provision of guidance and strategies to disclose or talk about the death of the infant to other surviving children and family members, at the explicit direction of the family.

Step 4. Directives around comprehensive medical record documentation. What the infant was wearing on arrival to the ED, the names/relationships of those present, and events that occurred either pre-hospital or during medical care delivery (i.e.: reported events that lead to the current state of health, the attempt to insert an intravenous line, or give a medication during resuscitation) should be documented (Table 3).

Table 3. Hospital-Based Comprehensive Documentation in Sudden and Unexpected Infant Death Assessments

Action	Responsible Party
Dislodgement/movement of lines/equipment during evidence collection/imaging	Hospital staff
History provided by family, siblings/household contacts	Pastoral Care, Child Life, Hospital staff
Communication with Gift of Life	Hospital staff
Disposition of body determination (transferred to hospital morgue, Medical Examiner's office, or funeral home)	Hospital Social Worker, Law Enforcement

Step 5. Debriefing forum. An informal process for MDT debriefing was recommended to occur before the MDT leaves the ED, involving clear and transparent information-sharing about available medical history, radiologic results, and history gathered. A debrief was also recommended for ED staff and involved medical providers to discuss medical care delivery, elements of any resuscitation performed, and patient outcomes.

Most importantly, following this MDT debriefing, a purposeful conclusion of care or transition time for the family/caregivers was recommended. The MDT members should outline what to expect next from the medicolegal, investigative perspective, timelines for results of outstanding medical or investigative procedures, and identification of an MDT partner families could contact with questions or needs that may arise in the future. These needs may be related to ongoing bereavement support, funeral arrangements, school/employment absences, and any other self-identified concern that requires supportive intervention.

Discussion

The majority of SUID occur at home, frequently after the infant was placed to sleep, and the specific manner and cause of death are often unknown at the time of medical professional assessment in the ED.[1,3] Because of possible contribution of underlying health issues, infectious disease, or abuse or neglect to the SUID presentation, and a need to ensure the ongoing health and safety of surviving siblings and other family members in the home and larger community, a conservative, collaborative, trauma informed approach that expeditiously involves MDT partners to facilitate a comprehensive medicolegal death investigation is warranted. Procedural guidance and key considerations for hospitals involve establishment of protocols to coordinate communication with families and investigating agencies, education of medical staff and other relevant hospital personnel about the jurisdiction's medicolegal death investigation approach,

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state statutes and local regulations regarding notification of deaths, hospital-related policies and procedures, and establishment of local protocols at the discretion of the ME and hospital that provide the family the opportunity to interact with their loved one, while respecting medicolegal investigative constraints, following death pronouncement.[1]

Section 906 of Title 16 of the Delaware Code[15] requires the use of a multidisciplinary team response for any child abuse or neglect report involving death, serious physical injury, physical injury, human trafficking of a child, torture, or sexual abuse. The statute requires a CPS investigation for the death of a child three years of age or younger that appears to be sudden, unexpected, and unexplained. The state is also required to implement a memorandum of understanding among agencies and entities to ensure that the state conducts a multidisciplinary response to such cases. In 2017, the Memorandum of Understanding for the Multidisciplinary Response to Child Abuse and Neglect was implemented.[16]

The following language is in the Memorandum of Understanding:

- In nearly all child death cases, the body will be transported to the hospital. In cases where the death is suspicious and the child is pronounced at the hospital, parents and caregivers will not be permitted to touch the body. However, parents and caregivers may be permitted to touch the body with supervision by LE, in consultation with ME, in cases where there is a sudden unexpected infant death (i.e., sudden infant death syndrome (SIDS), unknown cause, and accidental suffocation in bed). For cases in which the child is pronounced and remains on scene, LE will preserve the body and maintain the scene, not allowing anyone to touch the body until the ME assumes responsibility.
- Photographs must be taken to document the number and size of the injuries to the child; scale of injury should be documented in photograph. These photographs will be taken as part of the medical examination process if the child has been transported to a medical facility. This does not preclude LE and ME from taking photographs as needed for investigative purposes.
- If life supporting mechanisms were utilized, then LE will consider video documentation of these efforts to include the explanation by the medical provider.
- The ME will conduct a post-mortem examination of the child in all unexpected and unexplained death cases. LE and DOJ will be contacted prior to the post-mortem examination to allow for observation. A post-mortem computed tomography (CT) scan at designated children's hospitals may occur prior to the post-mortem examination. In cases where there are surviving siblings or other children in the household, the ME will request an expedited CT scan…will discuss findings from imaging, the post-mortem examination, SUIDI Form, doll re-enactment, and relevant information obtained from the interviews to ensure that team members are fully aware of all relevant case information.[15]

The Nemours ED setting must approach SUID cases in adherence with relevant state statutes and MDT protocols. Revisions to the existing SUID response process in the Nemours ED setting highlighted the following key lessons. First, the expert panel identified critical MDT collaborators for SUID cases involving ME, CPS, LE, and ED medical professionals including the attending physician, social worker, and forensic nurse examiner. Second, it was understood

that the ME had the authority to restrict contact with the deceased infant and must be consulted to understand these parameters before any postmortem care or preparations could take place. Third, delivery of postmortem health care must be comprehensively documented in the medical record. Development of the protocol also allowed exploration of more challenging issues, including need for standardized referrals to investigative agencies for medicolegal death investigation initiation and/or tension around more restrictive parameters sometimes established by the ME after death pronouncement. Additionally, the panel identified and debunked perceptions by participating MDT members that families would feel unduly emotionally burdened by involvement in the resuscitative process; rather, medical literature suggests otherwise.[12] Investigating agencies had incorrectly perceived that observing the resuscitation or death of an infant would result in negative emotional outcomes and increased trauma for the caregiver/family member. Finally, also explored was confusion around consent for various medical and postmortem interventions (like radiologic imaging or lab testing) and organ donation, with strong recommendation for continued collaborative decision-making across sectors in partnership with involved family members.[13]

Although the above protocol was structured as a step-wise approach, the MDT panel acknowledged that each component operates across a continuum of care delivery in the ED setting and may occur simultaneously or in a varied approach that is unique to the needs of the child and family, harnessing a trauma informed, family-centered approach. The MDT identified a need to balance investigative needs with family needs, which rarely provoke conflict but may potentiate stress in an inherently stressful circumstance. The MDT panel determined this was best accomplished through collaborative communication among MDT members and with involved family members, engaging in purposeful efforts to keep the family at the forefront of the process through trauma-informed participation.

Public Health Implications

Family needs after SUID are extremely complex, and facilitating a family-centered approach that is compassionate and trauma informed, while respecting investigative standards, provides the best opportunity for improved outcomes for families suffering profound losses.[1] Collaboration among necessary MDT partners is best accomplished when preexisting protocols are in place that have been developed and implemented with multi-stakeholder input, and health care institutions should explore and refine policies and procedures to ensure medicolegal death investigations involving SUID are approached with sensitivity, compassion, and minimal family distress.

Limitations

At the local level at Nemours Children's Health, Delaware, impact of the revised process on families grieving SUID is unknown, as the family experience pre- and post-process implementation was not specifically assessed. Consideration should also be given to assessing MDT experience with the implementation of such protocols in future study.

Conclusion

Implementation of a family-centered, ED-based protocol standardizing the approach to SUID can effectively support medicolegal death investigative procedures while prioritizing trauma informed, supportive, sensitive ED care for grieving families.

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Dr. Deutsch may be contacted at Stephanie.deutsch@nemours.org

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