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Bereaved Parents Experiences of Hospital Practices and Staff Reactions after the Sudden Unexpected Death of a Child

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ABSTRACT: *The purpose of this study was to examine the experiences of bereaved parents and caregivers, who experienced a sudden unexpected infant or child death, an infant death attributed to Sudden Infant Death Syndrome (SIDS) or a child death attributed to Sudden Unexplained Death in Childhood (SUDC), with hospital practices and staff upon the child's arrival at the emergency department. A convenience sample of 139 parents, caregivers and guardians responded. Data collected were descriptive and narrative. Narrative data was analyzed using phenomenological qualitative analyses. The study addressed the parents' experience with: the ambulance service, contact with professionals, information received about procedures, access to or holding the child, extended family's access to the child, perceived respect and support of the hospital staff, obtaining keepsakes or the child's belongings and the parent's aftercare instructions upon leaving the hospital. Implications to improve or revise current hospital procedures are discussed.*

KEYWORDS: *Sudden infant death syndrome, Hospital policies, Bereaved parents, Staff reaction*

INTRODUCTION

Each year in the United States roughly 3,500 children reportedly die a sudden and unexpected death classified under Sudden Infant Death Syndrome (SIDS) or other ill-defined and unspecified causes of mortality (ICD R99) (Centers for Disease Control, 2018). SIDS and Sudden Unexpected Infant Death (SUID) are diagnoses of exclusion and considered when an infant, under the age of 1 year, has died suddenly and unexpectedly and the autopsy, examination of the death scene and a review of the clinical history provide little explanation to the cause of death leaving the death ultimately unexplained (Centers for Disease Control, 2018). There remains another subset of sudden and unexpected deaths in childhood, referred to as Sudden Unexplained Death in Childhood (SUDC), that typically occur in children over the age of 1 year old, and much like SUID and SIDS deaths, the cause of death goes unexplained after a thorough case investigation. The rate of deaths is approximately 1.5 deaths per 100,000 children, with most of these deaths occurring in children ages 1 to 4 years old. In 2016, there were 236 toddler deaths in the United States classified as ill-defined or unknown causes of mortality (Sudden Unexplained Death in Childhood, 2018).

In many sudden and unexpected child death cases, the child is brought to the emergency department by way of caregiver or ambulance, whereas a much smaller number of children are pronounced and remained at the scene (Rudd, Capizzi-Marain & Crandall, 2014). Unlike more common reasons for sudden child deaths, such as drowning or accidents, children later identified as SIDS, SUID or SUDC come to the emergency department with no easily identifable cause for the presenting symptoms. Therefore, hospital personnel are tasked with not only providing life-saving measures to the child, but balancing the caregiver's grief and ensuing requests that can include requesting to be with or hold the child, and the local medicolegal death investigative practices.

Hospital practices regarding the family's access to the child or honoring the family's requests are often informed by, or completed in conjunction withJo.27hl2eng lr -.2eng lr -.2eng lrd

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support resources. Furthermore, in 2016 the U.S. Department of Justice's National Committee on Forensic Science released their view regarding the medico-legal death investigative practices. They suggest investigators should make or allow all reasonable attempts to provide caregivers time with their child, information on the investigative process, and a timeline for procedures including the autopsy and other measures. However, families experience of the death investigation practices continues to be widely varied across the United States depending on the emergency department, agency and jurisdiction (Drake, Cron, Giardino, Trevino, & Nolte, 2015; Posey & Neuilly, 2017).

Regardless of the cause of death, hospital personnel are tasked with the supporting bereaved families, many without clear guidelines for best-practices (Field & Behrman, 2003; Rudd, Capizzi-Marain & Crandall, 2014). Additionally, due to the unexpected nature of these deaths, hospitals must also comply with the county's corner and local law enforcements death investigative protocols which in some cases may conflict with the family's wishes (Department of Health and Human Services, 2007). Therefore, the responsibility is relegated to emergency room staff to meet the conflicting requirements of all involved after the sudden and unexpected death of a child. The purpose of this study was to examine the experiences of caregivers with hospital procedures and staff after the sudden and unexpected death of their child.

METHODS

Design and Collection

This study was specifically interested in the experiences, opinions and frequencies of events for parents bereaved by a sudden unexplained death and whose child was taken to the emergency room. A survey research design was chosen. A convenience sample of parents, grandparents or guardians who lost a child under the age of 18 due to a sudden and unexpected death was obtained through three organizations: Sudden Unexplained Death in Childhood (SUDC) Foundation, The CJ Foundation for SIDS and First Candle. Participants were asked to complete a 20-minute multiple choice and narrative fill-in survey created in an online survey software program. The survey was developed to identify the experiences of participants with hospital personnel and procedures including the policies of the medicolegal death investigative process while at the hospital, the experiences with medical staff, access to their child and their child's belongings and opinion of perceived support from those involved. The invitation to participate in the survey was made via e-mail communications from the three major support organizations. The data was collected over a three-month period. Inclusion criteria were restricted to a parent, grandparent or guardian whose child was taken into the emergency room and pronounced dead. These individuals are referred to as caregiver in this article. Also, the child's death was ultimately ruled undetermined, unexplained or lacked evidence to substantiate the final cause of death. This study protocol was

staff. The most frequent contacts with staff members were nurses 85% (96) and ER Physicians 85% (96). 66.1% (n=72) of caregivers were asked if they wanted a spiritual or religious advisor called (i.e., Clergy, chaplain or rabbi), and only 56.6% (n=64) of the total number of participants received that service. A lower number of caregivers reported contact with a hospital social worker (35.4%, n=40) and only 33% (n=36) had a social worker assigned to their family. Additionally, families had the lowest amount of contact with hospital physicians (31%, n=35). However, a few caregivers reported no contact with hospital staff or doctors (f=4). One parent shared “Our experience was terrible. We were left alone, no one explained anything. No one offered to get a social worker or chaplain.” Regardless of the contact-types with hospital staff, overwhelmingly caregivers were provided the death notification

infant." The majority of participants, believed the care shown to their child by professionals was "very respectful" (Figure 3).

Child's Belongings and Keepsakes

Upon leaving the hospital it is not uncommon for caregivers to want his or her child's belongings such as clothes or other items that may have traveled with the child to the hospital. When caregivers were asked if items were returned the majority of caregivers noted the items were collected by the police and/or investigators (35.7%, n=41). A total of 31.3% (36) of caregivers did not receive the child's belongings and 30.4% (35) of caregivers did. Of those caregivers who were asked by hospital staff if they wanted to take the child's belongings 1.7% (2) of caregivers did not. Furthermore, 1 (0.9%) caregiver was able to take the items home but had to initiate the request. In addition to the child's belongings only 40.4% (n=44) of caregivers were provided a memorial keepsake box (i.e., footprints, handprints, locket of hair). Two parents stated they were thankful

their child at the hospital. However, the quality and nature of this time varied greatly among our participants. Some caregivers were able to hold their child unsupervised while others were only allowed to touch their child with supervision present. Caregivers and family members expressed appreciation for the invitation to not only be with their child after death, but to be given a private space with ample time to be with their child. Hospital and death investigative staff should weigh the family's desire and wishes to hold the child with the death investigative process. The opportunity to spend time holding and being with the child appears to have a lasting meaningful and memorable impact for these parents and should be strongly considered.

Participants of this study were overwhelmingly pleased with the level of perceived respect, compassion, and attention their child received in the emergency department and overall felt positively supported by hospital staff. This suggests that current patient-centered or family-centered care practices are making a big impact on these families.

Many hospitals with maternal wards have policies and procedures in place to support parents after the death of a fetus such as keepsake boxes which include footprints, handprints or lockets of hair. Emergency departments may consider offering this service to these caregivers especially if the materials and policies are in place. When caregivers become bereaved suddenly and unexpectedly they do not often think to request keepsakes or even know such options exist. Hospital staff can create a memorable and priceless memento for these caregivers to take with them when they leave.

Understandably, the emergency department is focused on patient care and saving lives and is not intended provide long-term aftercare to grieving families-or in these cases, even providing discharge instructions. However, caregivers may benefit from receiving aftercare instructions to include: contact information for the coroner or medical examiner's office, the purpose of the autopsy and suggested timeline for procedures and results, grief