DOES THE CAUSE OF DEATH INFLUENCE HOW PHYSICIANS INFORM PARENTS OF THEIR CHILDREN'S DEATHS?

Daniel H. Grossoehme, Jeffrey Kempf

Abstract: An uncontrolled prospective observational study was conducted to record the interaction of Emergency Department physicians in cases of trauma and possible Sudden Infant Death Syndrome (SIDS) deaths, to determine whether the manner of death influences whether physicians immediately deliver news of a child's death to the parents or whether the physician first asks questions of the parents. Physicians immediately delivered news of the child's death in three-quarters of the cases at our centre. The presence of other professionals appeared to influence physician behaviour. The sample size limits the conclusions to be drawn, but room for improvement is noted. Chaplains are in a position to teach other staff.

Key Words: Death, SIDS., Children, Physician Behavior

Introduction

Children who die unexpectedly are normally brought to the Emergency Department (ED). They may be transported by emergency medical services (EMS), or brought in directly by the parents. In the experience at this centre, the most frequent causes of death in children who arrive at the ED and are dead on arrival are accidents (trauma) and Sudden Infant Death Syndrome (SIDS). The emergency physician is most often responsible for officially informing the parents that their child has died. This is a difficult situation for the physician, particularly when the cause of death is not clearly understood, as may be the case with SIDS deaths.

ED staff interactions can have significant impact on survivor's grief (Wolfram 1998). Dubin & Sarnoff (Dubin & Sarnoff 1986) emphasise the importance of the initial contact with the family which will have a significant impact on the survivors, and that "inadvertent inhibition" of the family grief response "can result in a pathological response with an increased risk of morbidity and/or mortality" Taking seriously what occurs during the initial physician and family encounter, this study was developed to determine whether the presumptive cause of death is an influence on whether or not a physician immediately informs parents of their child's death. Chaplains are normally called upon at such times to provide both spiritual and emotional support to survivors. To a degree, the care provided by a chaplain is influenced by physician behaviours.

Method

An uncontrolled prospective observational study was conducted on the emergency department Attending and Fellow physicians at our hospital. This emergency department had between 10 and 15 attending physicians and fellows during this time. Approximately 44,000 patients were triaged each year; 5% were admitted to the hospital. The hospital serves a 17 county area in the state. The study and data collection instrument was approved by the hospital Institutional Review Board, which required the investigators to inform the emergency department physicians that an investigation about communication skills was underway; although the physicians were given no further details. Those who were uncomfortable being part of this study without further information were given the opportunity to decline participation; none of the physicians chose to withdraw. In all cases, a Resident physician works together with either an Attending or Fellow. The Attending or Fellow is responsible for communicating with the parents, and subsequent references to "physician" refer to the Attending or Fellow present. The physician-investigator was excluded from the study.

The data was collected on an observational tool with 12 questions in a check-box format with a place for open-ended comments. A copy of the survey instrument is appended to this article. The survey instrument was completed by a hospital chaplain for convenience, as they are normally present when such news is delivered. The eight chaplains were trained on the use of the data collection tool, and a trial was conducted on fictitious patients to assure consistent use of the survey instrument. The Director of Pastoral Care is a board-certified chaplain; the Adjunct chaplains have a minimum of one unit of Clinical Pastoral Education with experience in paediatric pastoral care. In five cases, the chaplain was not present when the parents were informed. In these cases, the necessary information to complete the form was collected by the chaplain investigator interviewing the physician involved within twenty-four hours of the event.

The ICD-9 (International Classification of Diseases) classification was recorded on each survey at the conclusion of the study period after reviewing the autopsy report. ICD-9 data was used to separate the patients into the arms of the study group (SIDS, Trauma, and Medical causes of death). The data from the survey instrument was entered into EpiInfo 6.02, obtained from the Centre for Disease Control, from which correlations between the survey items were sought. A p-value of 0.05 or less was considered statistically significant.

Results

During the observation period, twenty children presented to the emergency department who met the criteria for data to be collected. The demographic data is presented in Table 1.

Table 1

Demographic Data

Patient No.	Age months	Gender	Classification	ICD-9 Coce
1	5	M	Medical	746.9
2	3	M	SIDS	798.0
3	2	M	SIDS	427.5
4	3	M	SIDS	427.5
5	21	M	Medical	746.9
6	22	F	SIDS	798.0
7	155	F	Trauma	959.8
8	0	F	Medical	761.8
9	34	M	Trauma	959.8
10	3	M	SIDS	427.5
11	65	M	Trauma	994.1
12	22 days	M	SIDS	798.0
13	6	F	SIDS	798.0
14	2	F	SIDS	798.0
15	3	F	SIDS	798.0
16	33	M	Medical	038.9
17	8	M	SIDS	798.0
18	4	M	SIDS	798.0
19	191	M	Medical	427.5, 359.1
20	4	M	Medical	275.0, 516.1

The data that were obtained indicate that in the case of suspected SIDS, physicians asked questions of family members before delivering the news of death 25% of the time. In the cases of traumatic death, physicians delivered news of death prior to asking questions 100% of the time. Table 2 summarises physician behaviour and causes of death. When the physician's initial actions (delivery of news or asking questions) was compared to the cause of death, all of the p-values were greater than 0.05, and are not statistically significant to draw conclusions from. Thus, we are not able to use this test to definitively answer the fundamental question of whether physician behaviour is influenced by the presumptive manner of death due to the small number of patients in the sample. It is also worth noting that in four cases, the physicians did not begin either by asking questions or delivering the news (in one case, the parent looked at the physician and said, "Oh no ! He's dead, isn't he?" to which the physician responded by nodding affirmatively).

Table 2

Physician Behaviour and Cause of Death

	SIDS	Trauma	Medical
Physician initially asked questions	4	0	1
Physician initially delivered news of death	4	2	5
Other	3	1	0

The presence of certain types of people when the news was delivered was significant. When a nurse was present while the physician met with the family,

the physician was somewhat more likely to ask questions before delivering the news of the child's death (27% of the cases). When a nurse was not present, the physician asked questions initially in 20% of the cases ($p = 0.045$). Although outside the usual limit of statistical significance, the results indicate that the physician immediately delivered the news of a child's death 82% of the time. When the chaplain was not present, the news was delivered immediately only 50% of the time ($p = 0.08$).

Also of interest was whether or not physician behaviours influenced parental behaviours. Specifically, did the physician's initial message influence whether parents asked questions of the physician ? No such correlation was found between the physician's initial behaviour and whether or not the parents asked questions of the physician ($p = 0.045$).

Discussion and limitations

The risk factors for complicated parental mourning cited by Oliver and Fallat (Oliver & Fallat 1995) are primarily beyond the control of hospital personnel. However, they note that how physicians interact with parents can impact how parents heal from the wound of having their child die. This led to the current study to determine whether the cause of a child's death affects physician behaviour, which in turn may influence the parent's healing. Chaplains' training in interpersonal skills, and generally accepted presence in an emergency department make them excellent candidates to guide, model, and teach healing behaviours and interactions to other professionals. The results of this study show room for improvement, and there is no reason to believe that the experience of our centre is unique.

In situations when the cause of death is not immediately clear, it has been noted empirically that the physician may delay informing the parents of their child's death in order to ask questions about the situation and events which occurred prior to the death. The practice of questioning the parents at this time may be unnecessary, and may only serve to increase the parent's sense of guilt concerning the death. The American Academy of Paediatrics' Committee on Child Abuse and Neglect noted that, "The appropriate professional response to any child death is compassionate, empathic, supportive and non-accusatory...Inadvertent comments as well as questioning by medical personnel and investigators are likely to cause additional stress..." (Committee on Child Abuse and Neglect, 1994).

The death of a child is devastating. Often parents are subjected to it without any previous knowledge or experience from which to draw strength or resources for coping. Parental bereavement after the loss of a child has been said to be more intense than any other loss (Rando 1984). Parents in this situation deserve to be given every special effort possible. The majority of studies involving parental grief at the loss of a child have involved characterising the grief response and long-term coping skills of the parents. In a study about parental coping following the traumatic death of a child, Oliver and Fallat noted that "Parents reported that their experience with physicians during critical times significantly shaped their memory of the death..." and, "In acute situations where bad news is expected, parents typically were more interested in the 'bottom line' than the process of treatment..." They suggest that, after the news has been delivered and the family allowed some time to be with the child and adjust to the child's death, physicians make a return visit to the parents to ask and answer their questions.

The concept of promptly informing parents of their child's death is not new. Hamilton's paper is one example of how, despite empirical evidence that prompt communication is beneficial to parents, such practice is not necessarily standard (Hamilton 1988). Yet, as Wolfram et al. note, "Survivors of children dying despite resuscitation efforts are likely to benefit when HPs (healthcare providers) are skilled in the compassionate management of patient death and are able to provide anticipatory guidance" (Wolfram 1998). It could be argued that prompt delivery of news of death is a bias of the authors; however, a literature search of MedLine and PsychInfo from 1990 to present failed to produce any citations which advocate gathering data before delivery of bad news as an approach to be taken with parents. If it is a bias, it is a bias uncontested in the literature.

The chief limitation is the relatively small number of patients included in this study. Another limiting factor is the effect of random chance determining which physician was on duty when the child presented to the emergency department. Of the ten to fifteen Attending and Fellow physicians in the emergency department during this time, only seven were involved with these twenty patients.

Additionally, two of those seven physicians were involved with eleven of the twenty patients. Thus, the effects of individual biases may be magnified in our results. Future replication of this study in a multiple-site setting, including possibly multi-cultural settings, would be desirable.

Conclusion

It is clear that in 25% of the cases, the physicians did not deliver the news of the child's death immediately after introducing themselves to the parents, in spite of literature which strongly supports this practice. However, our study shows room for improvement in how one group of physicians interacted with parents immediately after the deaths of their children. For the sake of parental healing, we encourage education of emergency department personnel to adopt this practice unless there is a significant reason to do otherwise. Chaplains are in a prime position to take the initiative in providing such education services as they can speak both a medical and emotional language, and assist other care providers in finding more healing ways to interact with grieving parents and other family members.

News of a child's death, while the responsibility of the physician, is best delivered in the presence of other clinical staff. These persons can remain with the family to provide needed spiritual and psychosocial support to the family and to accompany them to view the child's body. The role for chaplains and social workers is to help parents clarify what they have heard from the physician, and to help parents verbalise questions they may be unsure how to ask. This also allows support personnel to corroborate what occurred when the physician delivered the news.

The possible effect of the chaplain's presence upon the physician's behaviour is intriguing. Although normally a small proportion of how a chaplain's time is spent, the aura of being the "angel of death" is sometimes projected onto chaplains. This leads us to wonder if having a chaplain present sharpened the focus of the meeting's purpose in the mind of the physician. This heightened awareness of the focus meant that they physicians were more likely to focus on immediately delivering the news of a child's death, rather than their roles as scientists or investigators. It may also be that the chaplain's presence makes prompt delivery of bad news easier because the physician can inform the parents of the child's death and then "hand them off" to the chaplain for care, knowing that the chaplain is someone who is capable of providing a spiritual grounding for the family. Physicians are not typically trained to provide that sort of presence or care. The anecdote provided by one ED physician (Haughey, 2000) makes clear the awkwardness and struggle a physician feels when entering a room to give parents the news of a child's death. This study suggests that being able to leave the family in the hands of someone trained to help others through chaos -- the chaplain -- prompts physicians to deliver the news early in the conversation, and permit the grieving process to begin immediately. This is a question that it would be desirable to explore further in the future.

The presence of a chaplain when difficult news is delivered can also be helpful when there is moderate to severe dysfunction in families. Family members may become agitated or threatening towards physicians or any member of the staff perceived as not fighting to keep their child alive. Chaplains, by their training, are frequently able to respond in ways that de-escalate such situations. Empathetic listening is one way chaplains can do this. They may also be among the first to recognise potentially volatile situations and discuss with physicians beforehand how the news might be most helpfully delivered. Chaplain's knowledge of family dynamics, when they have such information before a child is pronounced dead, may help the physician in choosing whether to include extended family members or others (such as family clergy) in this conversation.

Although the physicians who were observed in this study generally delivered news of a child's death promptly, there were cases where this did not occur. Those cases always involved suspected SIDS. Chaplains are in a position to assist physicians in the prompt and gentle delivery of devastating news, which will support parents in their healing.

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Acknowledgment

The authors gratefully acknowledge the assistance of Adjunct Chaplains Don Kuntz, Karen Kapes, Timothy Crouch OSL, and Bill Tompkin with the collection of data for this research project.

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