

4 Telling Stories About SIDS - Mothers' Accounts of Loss

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This chapter explores the way in which mothers talk about their infants and their experience of grief following the loss of an infant in Sudden Infant Death Syndrome (SIDS). Mothers tell stories about their infant and in defining their relationship to the dead infant they maintain their own status as mothers. They recount their experiences of loss following SIDS which indicate the way they felt about themselves as mothers. They describe the ways in which they maintain a mothering role following the death of the infant. Mothers include a variety of objects, people, words and sites in a network that facilitates the telling of particular stories about the infant. Accounts of the infant and subsequent sudden death in turn become part of the story of the 'self' as mother. This chapter addresses the importance of remembering the dead in everyday conversation and how the unique characteristics of SIDS influence the formation of particular maternal narratives.

Introduction

This chapter is the result of an ongoing research study in which mothers were interviewed whose infants had died of SIDS within the preceding year. For reasons of brevity the interview data is not directly utilised, but instead reference is made to the themes relating to maternal narratives which occurred in the interviews. Talking about the dead and telling stories about the deceased is an important part of defining one's own identity following bereavement (Walter, 1999). The telling of stories about the dead infant by mothers following SIDS is important as it enables the continued definition of the self as a 'mother'. Various maternal accounts of loss are offered following the experience of SIDS. Some of these maternal accounts are given in response to questioning and enquiry from professionals such as clinicians and police investigating the cause of death.

Mothers describe these stories as originally beginning with an incoherent description of the circumstances of death and ultimately developing into a story which is repeatedly told, becoming refined and edited in the retelling. My focus is on the personal, sometimes spontaneous stories which mothers tell following SIDS, these accounts being more detailed than the stories mothers recount giving to doctors and the police. These personal accounts are more

fluid and unscripted, and intertwine stories of the mother and infant. Mothers are aware of the audience when they begin to share their story and take care not to disclose information which they feel would not be well received, or which may have implications for the way in which they are viewed by others. Grief following SIDS is a particular and specific experience in terms of the characteristics of SIDS, and loss of a child at the beginning of life. These characteristics are important in that they shape the story which is subsequently told.

Characteristics of SIDS

Sudden Infant Death Syndrome is defined as the ‘unexpected death of an apparently healthy infant’ and for which subsequently the cause of death is ‘unascertained’ (CESDI, 2000). The implications of this are, that following an unexpected infant death, strenuous efforts are made to uncover the cause of death. This process involves the investigation of the circumstances of death by police and pathological investigation which involves a post mortem. These investigations mean that a period of time elapses between the death and the classification of the death as SIDS. It is important to note that SIDS is a classification of death and not a diagnosis of the cause of death. It is the category which is applied when all other avenues have been explored and a cause of death has not been found. Should new ‘evidence’ come to light then the classification can be revisited and revised at a future date. SIDS is therefore an ‘unstable’ category. This has implications for maternal narratives in that mothers express a need to justify their mothering practices, a process which begins in the investigation phase when such practices are examined and scrutinized, but is maintained beyond this. One feature of maternal narratives is the way in which the mothers describe their adherence to risk reduction advice, the ‘Back to Sleep’ guidelines, which are widely disseminated by health professionals and advocate particular infant sleep positions. The description of these practices is seen as an indication of ‘good’ mothering.

Particularities of Death at the Beginning of Life

SIDS occurs within the first two years of life, is more common in the first year and incidence peaks between the ages of 4 and 6 months of age. This means that in the majority of cases of SIDS birth and death are in close proximity. This represents for the mothers involved significant shifts in identity between ‘non-mother’, ‘mother’ and ‘bereaved mother’ within a short space of time. Furthermore the mother may have developed a peer group of other mothers for which she has now come to represent ‘the worst thing that can happen’.

Mothers have to negotiate their position and tell a story of bereavement and SIDS which allows them to assert themselves as good mothers and is acceptable to those around them. This is difficult as the narrative of the good mother in turn emphasises the random and non-preventable aspects of SIDS, which are an uncomfortable reminder of the fragility of infant life for other mothers in the peer group. Infant death is relatively uncommon in the Western world and there is a tendency for bereavement following death at the beginning of life to be minimised by others in the social context (Lovell in Field et al., 1997). The mothers interviewed in this study expressed a need to represent their infant to others not just for reminiscence but in order to acknowledge and recognise the importance of the infant's life within the wider family.

Narratives and the Expression of Maternal Needs Following SIDS

The conditions in which infant death occurs and the characteristics of SIDS leads to the production of a narrative of grief which is unique in that it responds to elements of this specific experience. The narrative of grief is intertwined with associated aspects of experiencing SIDS and public understandings of SIDS. The mothers interviewed in this study expressed particular and specific maternal needs following the death of an infant from SIDS. These included (see Table 1) the need to regain control following the investigation and scrutiny of their mothering practices. Mothers expressed the need to establish and assert that they were a 'good' mother to the deceased infant. They sought to maintain their own identity as mothers and to represent the infant to others, particularly other siblings. Mothers also identified a need to resist the medicalisation of grief and to challenge assumptions about maternal grief. It is useful to explore the way in which narrative maternal accounts of SIDS reflect these specific needs. Hence telling stories about their grief is intertwined with the telling of stories about SIDS.

Table 1: The Relationship Between Maternal Narratives, Expressed Maternal Needs and Maternal Behaviour

Expressed need via maternal narrative	Example of data from interview transcripts	Example of linked activity described by mother
To regain control following investigation and scrutiny.	“I just need to be able to keep some things private again.”	Centralising objects in the household which relate to the infant and removing these from general view.
To assert themselves as ‘good’ mothers	“All the documents show that he was well looked after - I was always taking him to clinic.”	Using Health records and other documents to illustrate acceptable or ‘good’ levels of care.
To maintain their identity as mothers.	“ I go up to the grave every week and tidy it - I feel that I am still looking after her.”	Visits to graves, making reference to the infant in conversation.
To (re)present the infant to others - particularly siblings.	“I need them to know about their sister - she is part of the family.”	Using photographs and other objects as props to facilitate shared memories and story telling.
To resist the medicalisation of grief.	“You tell the doctor what he wants to hear - otherwise they will sedate you.”	Concealing feelings of depression and anxiety. Accepting prescriptions but not collecting the medication.
To challenge assumptions about maternal grief.	“People avoid talking about her - but I long to hear her name.”	Confronting information they disagree with relating to SIDS. Initiating conversations about the infant.

Relationship Between Maternal Needs and Maternal Stories Following SIDS

Firstly, mothers expressed a need to regain control following the investigation and scrutiny of their mothering practices. During these investigations mothers have been required to respond to enquiries about the circumstances of the infant's death. One of the recommendations of the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI, 2000) is that the behaviour and care levels of mothers should be subjected to increased scrutiny in cases of unexplained death. Mothers respond to these enquiries by formulating a set of responses that conveys the necessary information which is frequently requested. This account begins as a reflection of what happened, but mothers recount how, over time this becomes a synopsis of events - the version which is requested by officials. Mothers described how initially this co-exists with a narrative of maternal feelings, but over time this version becomes edited to become a factual account of parenting practices and events. This allows mothers to regain control of their private narrative of grief in which they describe their feelings about the death and subsequent investigation. Mothers keep objects for reminiscence and representation of the infant. The mothers I interviewed kept a cluster of objects in a centralised collection. Some of these were link objects (Wheeler, 1998) which clearly provoked memories of the infant, but others, such as documents, photographs and toys, were essentially 'props' used as tools to tell a particular story about the infant and their relationship as mothers with that infant. These objects were not on general display but were brought out by the mothers and discussed with the interviewer. Hence narrative is seen as important by the mothers, objects are mediated and explained and not left in visible places to 'speak for themselves'. Mothers managed the exposure of the objects associated with the infant to create a space between 'public' and 'private' stories of their grief.

Furthermore, mothers recounted how they chose appropriate people and places for telling their private story. Stories of grief were shared on occasions with complete strangers in public places, allowing for total anonymity in expressing feelings; at other times mothers related how they felt able to talk to family, friends, befrienders or other parents who had shared similar experiences. Mothers also described how they reverted to the more scripted account of events with people who initiated conversation but whom the mothers felt 'would not really understand'. Conversations were rendered 'private' not by the location in which they took place, but by the content of the conversation.

Secondly mothers expressed a need to assert themselves as 'good' mothers in order to counter the aspects of suspicion and blame which accompany investigation of the death. They sought to re-establish control of the narrative, emphasising particular versions of SIDS, such as the lack of preventability of

SIDS, and minimising other narratives which focus on associations with poor parenting (CESDI, 2000) or with criminal behaviour and instances where mothers are implicated in the deaths of their infants. This was linked to a debate in the public domain between paediatricians as to whether SIDS as a category masks some cases of infanticide or criminal behaviour (Emery, 2000; Green, 1999; Meadows, 1999). Summaries of these papers representing differing perspectives on the categorisation of deaths as SIDS were reported in the press. These reports shaped the narratives of mothers interviewed in that they offered a personal response to these perspectives.

The mothers I interviewed drew on a range of resources, including documents and comments from health professionals, comments from peers and family, to illustrate their competence as mothers. Their narrative of being a caring mother was accompanied by 'evidence' in the form of corroboration of their position by others. Hence Health Visiting records were used to show that the infant was healthy and cared for in a satisfactory way, comments on sympathy cards were used to show that other people regarded them as good mothers. One mother emphasised the cost of the funeral and flowers to indicate an aspect of her mothering in that she spared no expense in arranging the funeral of her child. These diverse materials were used to offer evidence to support the stories told by mothers. This is similar in part to a process outlined by Latour (1990) in which he describes the process by which scientists use documents and information to 'muster allies' to support their perspective. There are parallels here in the way in which mothers use documents such as health records to illustrate their level of care. Mothers personally use laboratory reports in ways unintended by the authors; the pathologists use the reports to reflect the state of the body after death, but mothers used these documents to indicate that their care was adequate and that there is no evidence to suggest that the infant was unhealthy prior to death.

Mothers expressed a need to maintain their own identity as mothers and one of the sites for achieving this was the infant grave. The grave becomes a visible site of continued care and mothers described the way in which the graves of the infants were often adorned with toys and other childhood memorabilia. Bradbury (2001) describes the way in which this is becoming a characteristic of children's graves. The mothers describe their visits to the infants' grave and the way in which they keep the grave tidy making regular routine visits often with other family members and siblings. They also describe how visiting the grave with siblings becomes an opportunity to share their stories of the deceased infant. Lupton (1998) in her work on the emotional self, describes the way in which individuals establish 'territory of the self' in which they use possessions to represent aspects of the 'self'. She uses the example of the mother who takes children's artwork to work to represent the self as a mother in a childfree space. Mothers who have experienced SIDS similarly use objects at the graveside and in the home to establish verbal and visual

assertions of self as a mother. Wheeler (1998) also describes the use of link objects and link possessions in the experience of grief to focus recollections of the deceased. Objects, along with family photographs become the location for asserting the infant's place in the family and to reinforce 'self' as a mother. Mothers describe the importance of the infants' name and the need to talk about the dead in conversation. Infant death is the subject of social taboo and yet mothers use objects and the grave to facilitate descriptions of their relationship with the infant.

Another feature of maternal narratives is the need to resist the medicalisation of their grief, in particular the desire to resist being prescribed medication in order to cope with their bereavement. This leads to a situation in which mothers are aware of the narratives and accounts of grief which are anticipated by professionals and which fit within the accepted framework of a normal response to grief. Mothers describe how they tailor their accounts to 'play by the rules' and give partial information in order to resist further interventions and scrutiny. An interesting feature of these maternal accounts is the way in which mothers demonstrated an awareness of bereavement models and challenged some of the assumptions which health care professionals make regarding the process of bereavement. This is in sharp contrast with the way in which mothers described the interventions and support of befrienders who were seen as allowing stories to be told which were without endings, permitting the telling of stories which fluctuate in focus and content. This is a long way removed from the stories told to professionals which appear to be more stable in content. It is interesting to note that mothers also felt that self help groups often represent a set of unified accounts of an experience and in doing so, overlook the distinctiveness of individual stories. This may be due to the fact that groups focus on shared experiences as a way of consolidating support.

Implications for Supporting Mothers in Cases of SIDS

It is clear from the stories which mothers tell about grief following SIDS that particular stories emerge from a distinctive experience. Although certain facets of that experience may be shared, mothers also have highly individual stories to tell. Interviews suggest that mothers develop different versions of their experience with the emphasis on different aspects of bereavement, the appropriate story is selected depending on audience and location. Professionals encourage mothers to talk about their grief experience but this is generally shaped by the information which they need to elicit in order to offer support. Mothers offer an account of their experience which conveys the required information and which reinforces their compliance with professional guidelines and frameworks. In responding to professional expectations mothers draw on

models of bereavement and grief, and tend to give an account of grief which fits with understandings of what constitutes 'normal' grief. Mothers may challenge existing versions of maternal grief and in particular maternal grief following SIDS, but this may be viewed as a 'risky' strategy in that it makes certain aspects of their grief visible in turn this may result in receiving treatment.

Mothers recount that talking to those who share their experiences is helpful, but also that talking to strangers is also beneficial in that both of these scenarios are ones in which mothers are permitted to offer their own version of maternal grief. Maternal stories which are shared with professionals become edited over time as the mothers become acquainted with what the professionals concerned require from the interaction and also familiarise themselves with what is considered to be acceptable. However the original versions of their stories are not lost and can be mobilised by the mothers to support their identity as mothers. In doing so they utilise objects and sites to represent their infant and to emphasise their care of the infant and their mothering skills. Mothers use a range of resources to assist with managing the representation of their infant and of themselves as mothers, shaping and reviewing information as necessary. This is due in part to the specific characteristics of SIDS in which the mother is initially the object at the centre of an investigation and as such may view herself as an object of suspicion and blame. The importance of these activities as a reflection of the maternal need to regain control and to minimise guilt and suspicion cannot be overlooked. The stories mothers tell centre on their own feelings of loss and preserving the memory of the infant. In telling these stories of maternal grief the infant and the maternal biography ultimately become intertwined and the stories of motherhood become in part accounts of SIDS.

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