

# Death scene investigation: parents' experiences

Unni Heltne<sup>1</sup>, Atle Dyregrov<sup>1,2</sup>, Kari Dyregrov<sup>1,3</sup>

<sup>1</sup>Center for Crisis Psychology, Bergen, Norway

<sup>2</sup>Department of Clinical Psychology, Faculty of Psychology, University of Bergen

<sup>3</sup>Faculty of Health and Social Sciences, Western Norway University of Applied Sciences, Norway

E-mail: ugulla@online.no

## Abstract:

This article presents the results of a study undertaken to evaluate how parents experience voluntary Death Scene Investigation (DSI) in their homes. In total, 35 parents were interviewed using semi-structured qualitative interview guidelines developed for this project. These focused on the parents': 1) appraisal of information provided prior to the DSI and motivation for participating in the study, 2) experience of, and reactions to the DSI, and 3) thoughts and reactions following the DSI. The evaluation shows that performing a DSI is an important part of providing good care for bereaved parents following Sudden Infant Death Syndrome. If such an investigation is undertaken by professionals with extensive professional knowledge and experience in meeting bereaved parents in an empathic and caring manner, it can be a positive experience for parents, and help support them in coping with the painful death of their infant.

## Keywords:

Death scene investigation, autopsy, parents' experience

## INTRODUCTION

Routine examination of the death scene following a sudden infant death has been a controversial subject in Norway for several years. Although a Death Scene Investigation (DSI) is viewed as very important to decide on the cause of death and to gather new knowledge about Sudden Infant Death Syndrome (SIDS) [1], this kind of investigation was stopped for a long period of time. This decision was based on reactions from parent associations and media reports where parents reported such investigations to be stigmatizing and an added stressor in an already difficult situation. Before the 1990s, these investigations were conducted by local police officers, sometimes uniformed and/or using marked police cars. The Director of Public Prosecutions advised against compulsory DSIs following SIDS in a circular sent to police stations across Norway in 1991 (Circular of 21 November 1991). After a trial period of four years [2] the routine officially became voluntary in 2010.

For many years, there has been a lack of systematic information about parental reactions to DSI. A literature search of both MEDLINE and PsycINFO provides no exact hits, and despite the extensive international network of the present authors in the field of SIDS, they have come across no research that has systematically evaluated parents' experiences of post-mortem investigations after SIDS. However, somewhat related topics can be found, for example how parents view autopsy and organ donation [3-5] and how bereaved people receive death notifications in general.

Studies of how bereaved people experience autopsy conclude that information gained from the autopsy results can reduce rumination, confirm the cause of death, and reduce the feelings of the bereaved that they could have done something to prevent the death [6-8].

In a study of bereaved family members' reactions to establishing the cause of sudden deaths in the home (not through SIDS), Criz [9] found that family members expressed both relief and sadness at the arrival of police and health professionals. A few felt angry, reacting to sirens and blue lights, or exhibited disrespectful behaviour towards those carrying out the work. Criz concluded that it was important to use personnel experienced

in meeting people in difficult circumstances, and that more training should be provided for those undertaking such work in order to make them more sensitive to the families' needs.

Concerning medical information, early and understandable information is viewed as especially important, as well as having caring, knowledgeable health professionals available over time to repeat or provide more information [6,7]. Other studies have confirmed parents' need for early preliminary information on causes of death, and for information on further processes regarding the results of biopsies and other tests of organs [10,11].

The Institute of Forensic Medicine (IFM) at the University of Oslo argued for several years that omitting the DSI after SIDS would prevent vital information coming to light [1,2]. Finally, IFM was granted the permission to conduct DSIs on condition that it was followed by an evaluation [12]. As a context for the evaluation study we will explain the content of the DSI:

The DSI was undertaken one or two days following the sudden death of a child (and after the autopsy had taken place) by three different pathologists and a tactical investigator (project director) on leave from the National Criminal Investigation Service in Norway (Kripos). The following routine was observed: 1) After confirmation of the death of the child, information about the DSI as well as an invitation to participate in an evaluation of the project was provided by the local doctor at the receiving hospital. A mandatory autopsy of the child was then conducted, and the DSI was conducted for parents who had consented to it. 2) The DSI consisted of the communication of preliminary results from the autopsy and a thorough interview with the parents about the events surrounding the death of their infant. In the interview, the condition of the infant prior to the death was established, and risk factors for SIDS were mapped. 3) In addition, a detailed and practical reconstruction of how the infant was placed in the bed and how he/she was found was undertaken and videotaped. For the reconstruction, a specially designed doll was used, which came in two sizes, one small, and one big, similar in weight and size to a real infant. The DSI team also devoted time to answering questions from the parents. For a more detailed description of the DSI, see Rognum et al. [12].

The evaluation study was conducted from the autumn of 2002 until the autumn of 2003 to learn about how parents experienced the voluntary DSIs in their homes. Thus, the main aim of the study was to evaluate whether the risk of burdening parents would outweigh positive experiences by a DSI or not. In order to generate a phenomenologically based understanding of how parents experience the DSI, in-depth interviews were considered the most appropriate method (refr. Kvale, 1996/no 15). In line with this, the following explorative research questions were posed:

- What was the parents' motivation for participating in the DSI?
- What was the parents' evaluation of information given prior to the DSI?
- How did parents who lost a child to SIDS experience the investigation by the forensic team in the voluntary DSI
- What factors contributed to a negative versus a positive experience by the parents?

## MATERIAL AND METHODS

### Procedure

The evaluation study was conducted by the Center for Crisis Psychology (CCP) in Bergen, Norway, an institution with no connection to the IFM in Oslo. The parents provided written consent to participate in the DSI, and at the same time consented to being contacted for participation in the evaluation. The families were contacted by telephone by the project leader of the evaluation study, and the study was described in detail. They were asked if they still consented to participate, and a time for the interview was arranged. Several studies undertaken at the CCP investigating the stress involved in research participation have shown, with similar procedures to the one utilized in this study, that such participation is viewed as very positive; although it can be stressful at the same time [13,14].

### Sample

Of the 21 consecutive families, two declined to participate at the start due to the difficult situation in their lives at the time of the study. One family asked for a follow-up conversation to obtain more information about reactions following the loss of a child, as they had not received any psychosocial follow-up previously. During this conversation, they spontaneously talked about their experience of the DSI and described it as positive. The other family, represented by a single mother, declined participation because she was exhausted. However, she emphasized that this had nothing to do with the DSI, which had been a positive experience.

In total, 35 parents were interviewed in 19 interviews. These included 16 mothers and 16 fathers interviewed together as couples. One mother, one father, and one care-giver (a woman who was caring for the child at the time of death) were interviewed alone.

The mothers were between 19 and 39 years of age (mean age = 29.2; SD = 4.37), while the fathers were between 22 and 42 years of age (mean age = 29.4; SD = 3.76). One mother and one father had completed primary school, 11 mothers and six fathers had completed secondary school, and seven mothers and 10 fathers had undergone higher education. Fifteen of the families resided in a city/urban area, while four lived in rural areas.

One family had experienced prior loss of a child from a hereditary disease, and seven families had other children, all below 15 years of age.

### Interviews

An interview guide was developed for the qualitative interviews focusing on the parents': 1) memories of their child and experience of the death, 2) motivation for participating in the DSI and evaluation study, 3) appraisal of information given prior to the DSI, 4) experience of, and reactions to the DSI, and 5) thoughts and reactions following the DSI. Whereas the first open questions acted as a context for the research questions, the following questions provided answers to them. As important for qualitative interviews and phenomenology, the interviewer went back and forth between the themes following the elaborations of the parents.

All the interviews were conducted by a clinical psychologist (first author). The duration of the interviews was between 1½ to 2½ hours, and they were conducted in the homes of the bereaved parents. Except for two interviews, all were conducted two months following the death (and the DSI). One interview was conducted six months after the death because the parents changed their minds after initially having decided not to participate. One couple were interviewed three months later due to a summer vacation.

The interviews were tape-recorded and transcribed. Key utterances and descriptions (meaning units) were condensed and thereafter categorized based on dimensions in line with the tradition of the quantification of facts in the social sciences [15].

### Questionnaires

All 35 participants filled in a brief questionnaire with open and closed questions developed for the study. They were asked about their contact with the DCI team members, and whether certain reactions had been triggered or made worse because of the DSI. The parents also considered statements regarding the trust they felt towards the DSI team members and whether they were treated with warmth and respect, received good information about the study, and had sufficient opportunity to ask questions, and whether the DSI members were easy to talk to, whether the contact was good, and whether the officials made a professional impression. The categories used were: "quite correct", "somewhat correct", "somewhat incorrect", and "quite incorrect".

The parents also put a tick next to questions concerning reactions of sadness, guilt, sleep difficulties, intrusive images, emptiness or anxiety, and whether such reactions had been triggered or made worse by the DSI. The categories for these questions were: "not at all", "somewhat", "to some extent", and "to a large extent".

Finally, the parents were asked to give an overall evaluation of the DSI as either "very positive", "positive", "neutral", "negative", or "very negative".

### Ethical considerations

The Medical Ethical Research Committee, Eastern Norway, approved the study on the basis that it would be undertaken by a professional with solid experience in meeting bereaved people. Participants' verbal and written information was secured; they were informed that they had the right to withdraw from the study at any time, to refuse to answer questions, and to have the tape-recorder turned off whenever they wanted. The researcher also offered to undertake the interviews in the homes of the bereaved, with no pressure on the length of time taken. A debriefing session, in order to let the bereaved ask questions and to allow the researcher to ask about their

experience of being interviewed, followed the interviews. If any participant revealed a need for help during this session, the researcher was free to offer it or to ask the appropriate parties for assistance.

## RESULTS

The results from the interviews are organized as answers and comments relating to the main subjects that came up in the interviews. The themes spontaneously raised by the parents were strikingly similar from interview to interview, but sometimes additional questions were raised by the interviewer, as described above. The number of informants is noted in parentheses. Representative quotes are chosen to illustrate the content of the parents' answers. The results from the questionnaires are presented in Tables 1 to 3.

### Parents had multiple motivations for participation in the DSI

The motives for participating were categorized as opportunities to: 1) contribute in order to help reduce the incidence of SIDS: "We thought that the investigation could contribute to prevent new deaths"; 2) receive information and answers to their own questions about the death and SIDS: "We had never heard about SIDS before", "We wanted to know if we had done something which had caused the death"; and 3) support the work of the Norwegian SIDS and Stillbirth Society: "We wanted to support the Norwegian SIDS Foundation and their work".

Three couples and a single care-giver said they did not have any expectations before the DSI. Two fathers and a mother were a little nervous about what they would be told by the "experts", that is, they were worried it would be confirmed that they had done something wrong. One couple wondered what it would be like to talk to strangers in such a difficult situation. However, the majority seemed to experience this similarly to the father who said: "Everything was already so painful that nothing could do much one way or the other".

### Parents valued the information given prior to the DSI

The interview data showed that several parents (n=7) had problems recalling the information they had received before the DSI. They also had problems remembering what had been said and whether they had received both verbal and written information. Although they had been informed both verbally and in writing, some parents (n=4) stated that they did not know the DSI would be videotaped and that it would be followed by an evaluation from the CCP. Especially the mothers had problems recalling this information, while in these instances the fathers were able to remember. Despite this lack of recall, most parents stated that it was acceptable and important that the DSI was videotaped.

Although several participants had problems recalling the content of the information received prior to being contacted by the IFM, they were able to remember most information provided by the project director when she called and set the time for the DSI. This conversation was evaluated as informative and important. Some parents had several telephone conversations with the project director before the DSI took place, and they felt that this made it easier to take part in the investigation, as they had the opportunity to have some contact with the DSI team before they arrived.

All parents viewed the information provided by the DSI team as clear and concise at all times. The majority saw it as unproblematic to refrain from parts of the study if they did not wish to participate. Two parents stated that they viewed the evaluation project as part of the overall DSI package.

### The parents experienced the contact with the DSI team mainly very positive

The positive contact with the DSI team was often the first thing commented on by the parents when they were asked to describe their experiences. Thirty-four of the 35 interviewees (97%) experienced the DSI as positive or very positive. They emphasized that they had felt understood and looked after in a difficult situation, and their contact with the team was described as safe and positive. The parents experienced the team as compassionate, understanding, and easy to talk to. They gave them "a choice all the time", so that they felt no pressure. Furthermore, they felt that they could ask questions about anything they wanted to. It was important that the team allowed ample time, so that the parents could talk at their own pace. The parents perceived the team to have "both feet on the ground", so that they felt relaxed with them, and it was "nice" and "OK" to have them in their homes. A typical comment from a parent was: "Very nice people, pleasant to talk to, easy to ask, the chemistry was right".

The parents felt that those responsible for the investigation were professionally competent, with separate, but clear, roles and tasks. Often, they claimed, it is unclear who can be asked what questions in the context of such tragedies. Nevertheless, when the DSI team came, it was clear which questions could be posed to the investigator or the medical doctor. The parents appreciated that the team had a clear task to perform: to investigate the scene of death, and not to give psychosocial aid. In particular, they appreciated that the medical doctor had lots of experience and knowledge concerning the situation at hand, i.e., the sudden death of a child. They felt taken very seriously, since one of Norway's most well-known experts in the field was visiting them and helping to answer all the questions they had. They felt that their child's death was also being taken seriously. This is illustrated by the following comment of one of the parents: "What I felt was essential was that they were experts, that they were some of the best professionals in their field, and they came here and spent time with us and gave all this attention to what had happened to our baby".

The parents reported that the DSI team talked about medical issues in a way they as parents could understand, and that it was easy to pose questions and ask for explanations. The parents expressed the importance of the clear and precise answers from the professionals and particularly the importance of the team's ability to explain emotional and difficult issues in an understandable way.

Almost all parents pointed to the opportunity to gain information through the DSI as especially important. They received new information that they had not previously had any knowledge of, such as:

- General information about SIDS and possible other causes of the death of their child.
- Information invalidating their sense of having caused the death in some way, or that they could have done something to prevent it.
- An explanation of why the baby looked as it did when it was found.
- Confirmation of their own suspicions about the cause of death.

Therefore, most parents emphasized that the contact and interaction between them and the DSI team made the DSI a positive experience.

### The DSI temporarily worsened some reactions

The results from the questionnaire showed that especially sadness (n=12), intrusive memories of the death (n=12), and rumination about the death (n=7) were triggered or increased by the DSI. However, no parents ticked the category "very much" in response to the question whether the investigation triggered or worsened reactions. The majority of parents reported "little" or "no increase" in the reactions mentioned above because of the DSI. No gender or age differences were observed. The parents described increases in reactions as mild and temporary.

Three mothers were unprepared for the reconstruction and videotaping of their putting their infant to bed and later finding it dead. They were especially unprepared for the use of the doll. These three mothers found it unpleasant both to see and to hold this doll. One jumped at the sight of the doll, which had been brought into the room whilst the mother was outside for a short time. It came as a total surprise to her. Three others commented on the doll without describing it as unpleasant; they found it strange to look at, and were unsettled by its similarity to a real child. Those who did not react were those who saw no similarity between their own child and the doll. Even those who found it unpleasant emphasized that they understood that the doll was important for the reconstruction, and that it should continue to be part of the investigation.

Four of the mothers could not bear to take part in the reconstruction, with or without the doll. In these cases, the fathers participated. The fathers found this hard and painful, but felt more at ease after having gone through the reconstruction. For some of the parents, the reconstruction meant that they

had to enter the room where the death took place for the first time since the event – something they had not managed to do before the reconstruction. The DSI in this respect helped them cross a barrier, as described by this father: "It was very tough, but good. We had not entered this room since the death, and I know now that I will be able to go in there any time I want to".

One couple later changed their minds about taking part in the DSI, and undertook the procedure several months following the death. They experienced it as agonizing to have to put back things that had been cleared from the room in order to undertake the reconstruction. This couple did not experience the same reduction of guilt and rumination reported by the majority of the parents.

### The DSI was generally a positive experience

Parents described a reduction of guilt and rumination over the cause of death as a positive outcome of participating in the DSI. This is quantified in Table 2.

In the interviews, the parents elaborated on the positive outcome of the autopsy. It was a great relief for parents to have it ruled out that they had done anything wrong, i.e., that the death was somehow their fault. Thus, the reduction of guilt at an early stage was essential. The importance of early guilt reduction is expressed by this parent: "They took away much of what we had been ruminating about, weakened suspicions, and dampened guilt feelings".

The parents' answers also confirmed that it had a calming, relieving effect to go through the chain of events during the DSI. They felt the reconstruction of the death scene to be like a "cleansing process". Going through it in a detailed manner helped the parents to understand what had happened, because they had been in shock at the time.

**Table 1.** Parents reporting that the DSI triggered or worsened reactions N = 35 (Mothers/female care-giver: n = 17; fathers: n = 17).

| Reactions                              | Mother     | Father | Mother   | Father | Mother | Father | Mother    | Father |
|--|------------|--------|----------|--------|--------|--------|-----------|--------|
|  | Not at all |        | A little |        | Much   |        | Very much |        |
| Sadness                                | 11         | 12     | 6        | 4      | 1      | 1      | -         | -      |
| Guilt/self-reproach                    | 17         | 14     | 1        | 3      | -      | -      | -         | -      |
| Sleep disturbances, nightmares         | 16         | 17     | 2        | -      | -      | -      | -         | -      |
| Ruminations about aspects of the death | 13         | 14     | 4        | 3      | 1      | -      | -         | -      |
| Intrusive memories                     | 16         | 15     | 1        | 1      | -      | -      | -         | -      |
| Emptiness, lack of energy              | 16         | 15     | 1        | 1      | -      | -      | -         | -      |
| Anxiety/restlessness                   | 17         | 15     | 1        | 2      | -      | -      | -         | -      |

**Table 2.** Parents' assessment of positive outcomes as a result of the DSI (N = 35)

| Positive outcome             | N*        |
|------------------------------|-----------|
| Reduced guilt                | 12        |
| Reduced rumination           | 10        |
| Reduced restlessness         | 4         |
| Better overview of the facts | 4         |
| <b>Reduced guilt</b>         | <b>12</b> |

\* N here refers to the number of statements and answers to direct questions during the interviews. The oral statements have been counted during the analyses of the interviews and categorized.

Talking through the events with the DSI team also helped the spouses exchange information about their reactions in a way they had not done until then. As explained by this parent, such sharing of information enabled them to form a common narrative about the death of their child:

"I felt it got a bit better. We had a chance to go through what happened, and we could give each other information about what happened when the baby was found, about resuscitation and what happened when the ambulance arrived. We had focused on different things".

The interviews also showed that something viewed as especially positive was the chance to talk to the pathologist who had performed the autopsy on the child, both because he/she could provide first-hand information, and because it was important to meet this person and see what kind of person he/she was. Many parents expressed their appreciation of the DSI professionals, whom they described as "very caring and nice people". Furthermore, the professionals were able to answer the questions parents had about the way their child looked when they found it. One parent summarized what she considered as especially positive about the DSI investigation:

"It was very good that the people who came to our home were those who had performed the autopsy. They had seen our baby, and could give answers based on this. It was important that they could say things like they thought our baby was beautiful, and they were such nice people, we felt sure that they had treated our child with respect".

For some parents, the DSI helped to create meaning in the meaningless void that had followed the loss of their infant: "The DSI made it easier. It gave a sort of meaning to the loss".

The parents' overall assessment of the DSI is summarized in Table 3.

**Table 3.** Parents' total evaluation of the Death Scene Investigation (N = 35)

| Total assessment | N  | %  |
|------------------|----|----|
| Very positive    | 31 | 89 |
| Positive         | 3  | 9  |
| Neutral          | 1  | 2  |
| Negative         | 0  | -  |
| Very negative    | 0  | -  |

As seen from the table, no parents viewed the DSI as "negative" or "very negative", and the large majority viewed it as a "very positive" experience.

## DISCUSSION

The results of this study show that it is possible to conduct a thorough DSI and at the same time look after parents who are in a difficult and vulnerable situation. Thirty-four out of 35 parents (97%) experienced the DSI as "positive"

or "very positive". The majority found that participation in the investigation helped them reduce guilt and rumination, and provided an opportunity to review what had happened.

### What are the aspects contributing to the DSI becoming a positive, and sometimes a relieving experience?

#### *The investigation helped quick provision of facts and information*

One of the most important needs of people who have suddenly lost somebody close without an obvious cause of death is to have the opportunity to ask questions and receive answers to their confusing thoughts [16,17]. When they are allowed to obtain this information from knowledgeable professionals, it is experienced as reliable and satisfactory. The possibility to talk to experts on SIDS was emphasized as "very positive" by the participants in the study. In many cases, the information the pathologist was able to impart reduced parents' guilt feelings, because the expert was able to confirm clearly that they had in no way caused the death.

Several investigations and clinical experiences have uncovered the importance of receiving early information and access to facts in a crisis. Information can reduce unnecessary guilt and rumination [6,17].

#### *Information was tailor-made to the parents*

The lack of information, or information which is complicated or confusing, might lead to misconceptions and increase anxiousness and guilt. Inaccurate statements can add to rumination of the type "What did she mean by...?". It takes a good professional to be able to talk about a subject in a way that everyone understands and to be attentive and sensitive about the information the receiver needs and can absorb. The participants valued this aspect very highly. They reported that those who were responsible for the DSI had expressed themselves in a clear manner, and that it was easy to ask questions without feeling ignorant or helpless. This way of communicating seemed to be just what the parents needed.

It is hard to provide information to people in an acute crisis. Concentration and memory can be reduced and attention can be selective [7,17]. Repeating the information and being clear and distinct in the provision of information along the way compensated for this in the DSI.

#### *The DSI was undertaken soon after the death*

Most of the DSIs were conducted one or two days following the death. Some parents thought this was early, at a time when they had to make many choices concerning the funeral. Still, many parents stated that it was important that the investigation be conducted early. They were unsure about how successfully the information would have reduced guilt feelings and rumination if more time had elapsed. In crisis intervention, the principles of immediacy and proximity are evaluated as very important [18,19]. The DSI fulfils both of these. In modern trauma theory [20,21], maladaptive interpretations of the event, or one's reactions and thoughts to it, are found to be predictive of later problems. The DSI, with its emphasis on providing correct, direct, and important facts about SIDS to the parents, can reduce misunderstandings and misconceptions.

### *Those who conducted the investigation were able to create a good relationship with the parents*

Many parents pointed to the contact established with the DSI team as the most positive aspect of the investigation. They felt looked after, respected, and taken seriously. They perceived that their experiences and views were important, and some found the DSI helped them to attribute a form of meaning to their terrible loss. Social and professional competence is essential in creating such a relationship [10,22]. The parents found the DSI team possessed such competence. This contributed to the parents' experience of the situation as emotionally and socially supportive. In addition, they valued that the investigation took place in a safe atmosphere.

### *The DSI gave the parents an opportunity to go through what had happened and fill in important information for one another*

Clinically, it is our experience that reviewing dramatic events provides a better overview of what has happened, and helps those involved to put the event in a comprehensible frame and reduce unnecessary distress [19]. This seemed to be true for most of those involved in this investigation. They described the reconstruction as painful, but said that it made them more at ease afterwards. Several partners had exchanged experiences and filled in gaps in their respective experiences to create a common narrative about what had happened, a process referred to as "family meaning making" [23,21]. These are factors known to be important in crisis intervention. As suggested by Brewin [21], giving words to their experiences helped them transport or "code" the emotional and sensory experience into words in a helpful manner. In many ways, this is similar to the effects of the cognitive elaboration described by Pennebaker [24], where people put their thoughts and reactions in relation to various traumatic experiences into writing.

### *For some participants, reactions were triggered or increased*

A small part of the sample found that reactions were triggered or increased by the DSI, in particular reactions such as restlessness, sadness, rumination, and guilt, which are usual reactions following stressful situations. Talking about the traumatic events in the DSI was associated with a temporary increase in distress, followed by a later reduction. This resembles the finding of Pennebaker regarding the positive effect of writing about difficult experiences [24]. There was little evidence that the DSI caused any permanent deterioration of the parents' situation.

### **What explains the perception of the DSI as a positive experience**

The factors that contributed to a positive experience of the DSI are similar to the principles of good crisis intervention and the needs of bereaved people [17,19]. These principles are also included in newer guidelines on how to look after bereaved parents after sudden infant death [22]. However, crisis intervention was not the intention of the DSI. The main purpose was to gather information to decide on the cause of the child's death, and to illuminate the causes of SIDS in general.

Does the positive experience of the DSI reflect that parents lack other psychosocial follow-up opportunities? Even though this was not the focus of this evaluation, most parents spoke about the follow-up they experienced in

their local community. Although this varied a lot, it was not our impression that this affected the evaluation of the DSI. It seems evident that in the manner this investigation was conducted and experienced, it also served an important function as good crisis intervention [18,19].

It can be inferred that because the investigation was experienced so positively by the parents it is very important to be thorough and explicit in describing the purpose of the investigation. It is also important to explain what the consequences can be if the investigators find that parents have contributed to the infant's death. Parents who participated found that both the pathologist and the project director were clear about their roles, and that the overall purpose of the investigation was clear. This is important if such investigations become part of regular routines, or if other studies are undertaken.

The DSI team was the most important factor in creating the positive experience. Therefore, only personnel with solid experience in dealing with traumatized people should undertake such investigations. Adequate professional and personal competence is the best guarantee that such procedures are not experienced as adding stress or as being offensive for the parents participating.

### **Generalizability, validity and reliability**

All of the 21 families and the single care-giver who participated in the DSI were asked to participate in the evaluation study. The two who declined to participate informally gave the same positive evaluation as those who took part in the DSI. The answers to the main questions in this study, and the spontaneous comments from parents are the same, regardless of their background and life situation in general. We believe that by following a similar procedure with the same attention to looking after parents, the results can be generalized to a wider population. However, it cannot be predicted how changes to the procedure or level of interaction will affect the experience of participation.

It was emphasized both verbally and in writing that the project leader from the CCP had an independent role in relation to the IFM. There was no evidence that the participants answered in a desired way or in fear of hurting the DSI team members. Many started to describe their experience already at the time of arranging the interview. The individual families had no knowledge of what others in the investigation had answered, and thus could not be influenced in any particular direction.

Concerning the questionnaire, it is possible that some respondents answered the questions not in relation to the DSI, but to their reactions to the loss in general. Since the questionnaire was answered with the project leader present, the respondents had the opportunity to ask questions, and in some instances it was apparent that they had misunderstood. It is thus a possibility that the reaction scores are somewhat inflated, which has implications for the reliability of the results.

### **CONCLUSION**

The evaluation of voluntary DSI showed that performing a DSI, in addition to providing essential information, also represented an intervention providing important psychosocial care for bereaved parents following SIDS. If such an investigation is undertaken by professionals with a high level of professional knowledge and experience in meeting bereaved parents in an empathic and

caring manner, it generates a positive experience for parents, and supports them in coping with the painful death of their infant. However, it is important

to ensure that the information given beforehand is clear regarding the purpose of the investigation.

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