Int J Legal Med (2006) 120: 352–354
DOI 10.1007/s00414-006-0100-3

ORIGINAL ARTICLE

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Are autopsies of help to the parents of SIDS victims?

A follow-up on SIDS families

Received: 8 December 2005 / Accepted: 18 April 2006 / Published online: 10 May 2006

Abstract Little is known about what bereaved parents feel about the autopsy performed on their child. A multi-centre case control study of sudden infant death syndrome (SIDS) victims was carried out in Germany between 1998 and 2001, in which all infants had been autopsied. We performed a follow-up study 4–7 years after the parents had lost their child. A total of 141 parents filled in the questionnaire, which were sent to them by the study centre. Of these, 71% had had another child after the SIDS/sudden unexpected death in infancy. The majority (83%) of the participating parents found the autopsy helped them to cope better with the death. A large proportion (46%) did not want any professional help after the death, and 55% did not wish to have any contact with a self-help group. We conclude that the autopsy is helpful to the majority of bereaved parents. Professional help and self-help groups should be offered to the parents even if the majority in our study did not want to use either.

Keywords SIDS · Autopsy · Parental follow-up

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A number of studies were undertaken on the acute reactions of parents after the loss of their infants due to sudden infant death syndrome (SIDS) [1]. However, few studies were conducted into how parents of SIDS victims cope several years after the sudden death of their infants [2, 3]. Moreover, little is known about the feelings of the parents with hindsight regarding the autopsy.

Materials and methods

We conducted a case control study on SIDS in Germany between 1998 and 2001. The study area was half of Germany, comprising 11 states in the vicinity of 18 institutes of legal medicine. Data was collected from October 1998 to September 2001. The study comprised 455 infants who had died suddenly and unexpectedly. Of the 455 parents, 373 (82%) agreed to an interview shortly after the death. All cases were autopsied by a forensic pathologist in accordance with a standardised autopsy protocol. The methods and results are described in detail elsewhere. After all the information regarding the infants had been collected, the cases were classified by a multi-disciplinary panel into one of four categories, whereby categories 1–3 are SIDS and borderline SIDS cases and category 4 comprised death due to explained causes, mainly infection (sudden unexpected death in infancy, SUDI) [4, 5].

In January 2005, we contacted all the 373 parents previously interviewed. A letter was sent to them thanking them again for their participation in the study and presenting the most important findings of the study. A short questionnaire was included, consisting of 11 questions, which asked if they had subsequently had any children, how important the autopsy was to them with hindsight, and whether they had had any professional help or contact with self-help groups after the death of their baby. If no response was received within 4 weeks, we sent a reminder. The data collected in the first interviews was used to assess their socioeconomic status.

Table 1 Parental socioeconomic status (SES) and maternal age of the original parents and the follow-up parents

Parental SES	Cases *n*=373 *N* (%)	Follow-up *n*=141 *n* (%)
Lower SES	181 (48.79)	48 (34.04)
Middle SES	148 (39.89)	66 (46.81)
Upper SES	42 (11.32)	27 (19.15)
Maternal age <25 years	158 (47.45)	37 (27.21)

Table 2 Characteristics of the original cases and the follow-up parents

Characteristics	Cases *n*=373 *n* (%)	Follow-up *n*=141 *n* (%)
Gender		
Male	221 (59.25)	87 (61.70)
Female	152 (40.75)	54 (38.30)
p-cat		
p-cat1	30 (8.04)	9 (6.38)
p-cat2	225 (60.32)	89 (63.12)
p-cat3	78 (20.91)	28 (19.86)
p-cat4	40 (10.72)	15 (10.64)

p-cat1–3 SIDS, *p-cat4* explained death

Table 3 Percentage of parents with a live birth after the SIDS/SUDI

Did you have another baby	Number (percentage)
Yes	100 (70.92)
No	41 (29.08)

Results

Of the 373 parents previously interviewed, 141 (38%) responded, 83 letters were returned undelivered, and 148 did not respond at all. One refused expressly.

Comparing this group of respondents with the original group of parents, the former has a slightly better socio-economic background (socioeconomic status, SES) (Table 1). No differences were noted between respondents and non-respondents with regard to the sex of the deceased baby nor the disease classification (SIDS and non-SIDS) (Table 2).

One hundred families (71%) had one or more children after the death of the index case, 18 (13%) didn't not want any more children and 16% wanted more children but were unable to attain pregnancy (Table 3).

Responding to the question concerning the autopsy, 66% (93) said the autopsy had been helpful in the bereavement period. Twenty-four parents (17%) stated that they thought the autopsy was wrong at the time of the death but they now think it was right. Four (3%) parents thought it was right at the time of the death but think it was wrong now. And for 9% (13), the autopsy was and is still wrong (Table 4).

Fifty-one parents (36%) had consulted a psychologist or psychiatrist after the death, and seven were admitted to a therapeutic facility. Seventeen talked with their family doctor about the death and the biggest group, 46% (65), did not want any professional help. Twelve of the parents wanted help but could not find anybody to consult (Table 5). Twenty-three (16%) parents had been in contact with the GEPS (Gemeinsame Elterninitiative Plötzlicher Säuglingstod), a German SIDS self-help group, whilst 13% had contacted the other major parental self-help group in Germany, Verwaiste Eltern ('orphaned parents'). Ten (7%) parents had been in contact with other self-help groups, 15% wanted contact but couldn't find any and 55% did not want contact with any self-help groups (Table 6).

Table 4 Assessment of the parents about the autopsy

How did you judge the autopsy after that time?	Number (percentage)
Autopsy was beneficial for the bereavement.	93 (65.96)
I found the autopsy right at the time, but not anymore.	4 (2.84)
I found the autopsy wrong at the time, but right today.	24 (17.02)
The autopsy was wrong for me at the time and still is.	13 (9.22)

Table 5 Percentage of parents using professional help after the death

Did you use professional help after the death of your baby?	Number (percentage)
Yes. I talked to a psychologist/psychiatrist.	51 (36.17)
Yes. I visited a therapeutic/medical facility.	7 (4.96)
Yes. I talked several times with my family doctor.	17 (12.06)
No. I didn't use professional help because I couldn't find any.	12 (8.51)
No. I didn't use professional help because I didn't want to.	65 (46.10)

Multiple answers were possible

Table 6 Percentage of parents using self-help groups after the death

Did you contact a self-help group after the death of your baby?	Number (percentage)
Yes. I was in contact with GEPS.	23 (16.31)
Yes. I had contact with "verwaiste Eltern" (orphaned parents).	18 (12.77)
Yes. I had contact with other self-help groups.	10 (7.09)
No. I didn't have any contact, because I didn't find anybody.	21 (14.89)
No. I didn't have contact because I didn't want to.	77 (54.61)

Multiple answers were possible

Discussion

In our original study, which was carried out in 1998–2001, the study centre in Münster maintained intensive contact with those parents who wished it. We telephoned each family, often several times over a period of weeks, and organised local meetings with them if there was a demand.

However, after some weeks, parents mostly talked with family and friends about their grief, and we only had contact with a few families for a period of more than 6 months. Sometimes they called us for information, when they were expecting another child and needed addresses of specialist paediatricians.

The questionnaire we sent out was short enough to be completed within 5–10 min. The response rate of 38% is high considering that these are young and mobile families. In 22% of cases, we were unable to locate the new address, 40% did not respond and one refused to participate. We can only speculate why parents did not respond to our questionnaire. The non-respondents come from lower social classes and the mothers are younger. It is known that the response rate is better amongst those from a better socioeconomic background, so the group with older parents and better education are more likely to answer questionnaires [6].

In our study between 1998 and 2001, we attempted to communicate the autopsy results to all the parents. In the first instance, this was done by the forensic pathologist, and if wished for, a more detailed explanation was provided by one of the doctors from the study centre.

The role of the autopsy in the bereavement process was judged positively by the majority of the parents (83%) who responded to our questionnaire. Seventy-nine percent of them had the opinion that it was the right thing to do after the death, and they had not changed their minds subsequently, whilst the other 21% needed time to realise that the autopsy was the right instrument for finding out what it was that caused the death of the baby. Only 11% considered the autopsy not right for them. This is a high approval rate and shows that it is important for parents to know about the cause of death. We think that one reason for the high consent rate of the parents is that, during the study period, the parents were given the results of the autopsy. Not only did parents often feel guilty that their infant had died in their care, but also friends and family questioned their ability to be good parents [7]. Helmerich and Saternus [8] reported about defamation of some bereaved parents by family and neighbours, which is consistent with our experience in our cot death study. Therefore, the results of the autopsy prove not only to the parents, but also to their environment, that they are not guilty for the death of their child.

The high rate of agreement amongst parents regarding the autopsy is also reassuring for criminal investigators and forensic pathologists. A lot of parents fear that they have overlooked an illness in their child and therefore need proof that this was not the case. All major self-help groups in the world approve explicitly of the autopsy in cases of sudden and unexpected child deaths, also because it relieves the parents of their guilt. In Germany, only about half of the children who die suddenly and unexpectedly are autopsied, but 70% of those parents whose children were not investigated regretted it afterwards [9]. Therefore, it is not only necessary to investigate sudden infant deaths to detect infanticides, but also to help parents in their bereavement.

A high proportion (36%) of the parents in our study talked to a psychologist or psychiatrist, so there is obviously a need for professional care after the death of an infant. However, nearly half of the parents did not want to talk to any healthcare professional about their deceased child. When asked about self-help groups, the percentage of parents not wanting any contact was even higher.

In conclusion, the majority of parents in our study viewed the autopsy favourably. Some of them needed the help of health professionals or self-help groups. Such services should be made available to them, but the majority coped with their bereavement with their own family and friends.

Acknowledgements We thank all the parents for their assistance, for without them, there would have been no study. We would like to thank Professors Brinkmann, Jorch and Köpcke for their cooperation.

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