Your child is dead

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Abstract

***Objective*—To determine parents' views on how death of their children should have been handled.**

***Design*—Retrospective questionnaire survey of parents who had experienced death of their child.**

***Setting*—Charitable organisation of bereaved parents.**

***Subjects*—150 bereaved parents, all members of the organisation, of whom 120 (80%) participated voluntarily in the study.**

***Main outcome measures*—Child's age; date and cause of death; details of person breaking the news and handling of the interview; time parents spent with dead child, their attitude to requests for organ donation, and follow up support received.**

***Results*—122 children's deaths were described; the largest single group was due to road traffic accidents, 16 were suicides, and eight were murders. Twice as many interviews were rated as sympathetically or reasonably handled as badly or offensively handled (68 *v* 34). The interview ratings depended on the sensitivity and personal skills of the interviewers rather than on their previous contact or professional position; police were rated as more sympathetic than doctors and nurses. Of 109 respondents, 81 had seen their child's body, 44 of whom thought that sufficient time had been denied. Of the 28 parents who did not see the body, 17 subsequently stated their regret. In 82 parents organ donation had not been discussed. Only 16 parents recorded any follow up support from hospital staff and very few support at the time.**

***Conclusions*—The consistency of the responses suggests a serious need to revise the in service training and education of the police and health professionals in their approach to informing of death; organ donation should be discussed sensitively and parents allowed time with their dead child with fewer restrictions.**

Introduction

The Compassionate Friends is a charitable organisation of bereaved parents, which aims at providing befriending support to other bereaved parents. Distress is commonly reported by bereaved parents about the way they were informed of their child's death.[1] Through the organisation we conducted a questionnaire survey of bereaved parents to collate information about how they thought the death of a child should be handled.

Methods

The survey was performed for 120 (80%) parents, who described 122 children's deaths; two parents had each lost two children. The questionnaire asked about the child's age; the date and cause of death; and details of the people who broke the news, including their profession, seniority, and attitude to the parent. Parents awarded a global rating to the interview (offensive, badly handled, reasonably handled, sympathetically handled), which was collated with details of the interview. Parents were also asked about the time spent with their dead child, their attitude to a request for organ donation, and the support they received in their bereavement. Further comments were also invited.

Results

The largest single group of deaths was in road traffic accidents (table 1); 25 died of non-neoplastic medical causes, eight of whom had a known congenital defect but in whom death was completely unexpected by the parents. Two suicides reported seemed to be closely linked with the previous death of a sibling. Eight children had been murdered, and their parents' replies seemed desperately hopeless, as if they too felt tainted by the terrible crime. Only two of the replies received did not contain additional comments. Many parents wrote about their own experience, three mothers also sent written or taped descriptions of other bereaved parents' experiences.

TABLE I—*Causes of death in 122 children*

Cause	No
Road traffic accident	54
Other accident	4
Drowning	2
Fall	2
Neoplasm	14
Congenital problem	8
Sudden death from natural causes	7
Cardiac arrhythmia	1
Asthma	1
Suddent infant death syndrome	2
Heart failure	1
Cardiomyopathy	1
Subarachnoid haemorrhage	1
Medical disorder (death in hospital)	10
Suicide	16
Murder	8
Drug overdose (accidental)	1

As this survey was done with voluntary respondents the sample may be unrepresentative of bereaved parents. The responses in only four of the questionnaires, however, suggested an ongoing abnormal grief reaction; 43 of the respondents are known to us and none of them have evidence of a pathological grief process.[2] Although each parent's story was individual, some common patterns emerged; these patterns have been reinforced by subsequent contacts with other bereaved parents.

BREAKING THE NEWS

Almost twice as many parents reported the interview as sympathetically or reasonably handled than as badly handled or offensive (68 *v* 34) (table II). The police were rated as being more sympathetic than nurses or doctors, possibly because they have some formal training in breaking bad news during both their basic and in-service promotional training. Public expectation of the police may also be lower than of "caring professions." There was no time relation to suggest that recently occurring deaths had been handled any better than those occurring 10 years ago or more.

INTERVIEW CHARACTERISTICS

Interviews reported as reasonably or sympathetically handled had specific features: they were unhurried and conducted in private; the parents felt respected and the

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TABLE II—*Parents' overall assessment of handling of interview. Figures are numbers (percentages)**

Informant	Offensive	Badly handled	Reasonably handled	Sympathetically handled	Question not answered
Police (n=44)	1 (2)	9 (20)	13 (30)	20 (45)	1 (2)
Doctors and nurses (n=58)	6 (10)	18 (31)	11 (19)	22 (38)	1 (2)
Doctors (n=48)	5 (10)	14 (29)	10 (21)	18 (38)	1 (2)
Nurses (n=10)	1 (10)	4 (40)	1 (10)	4 (40)	

*Other informants not included in table: chaplains (2), friends (6), parents who found the body after suicide (4), spouse (6), child's employer (1), unidentified (1).

informant had an understanding and caring attitude, and they felt unhurried and had sufficient time to ask questions as the news sank in, with the interviewer checking that they had understood the news. These parents had a designated person from whom they could subsequently ask for help or information about the death. By contrast, those parents whose questions remained unanswered or evaded felt that a cover-up had occurred; some even suggested that litigation seemed their only recourse to obtain information.

Parents gained great support from being aware that the informant was also upset—for example, "he cared so much he had tears in his eyes" whereas the colder, businesslike informant tended to cause great offence. Many parents criticised poor communication between their general practitioner and the hospital or police.

Overall, the way the interview was handled seemed to depend on the informant's sensitivity and interpersonal skills rather than on prior contact with the parents or on professional rank. It is worth noting that no parents felt adequately prepared for their child's death, even when it had been preceded by a period of severe illness.

PARENTS' WISH TO STAY WITH CHILD

Nearly all parents wished to spend time with their child after death, even when the body was mutilated. Of 109 respondents, 81 had seen the body after death, and this was regretted by only one mother, whose daughter had been murdered; 49 felt that they had been denied enough time with the body, particularly when a road traffic accident was the cause of death. Twenty eight parents had not seen their child's body, 17 of whom subsequently deeply regretted this. Three parents reported that it had been difficult to believe that the child had actually died, and two parents subsequently remained angry that they had been actively dissuaded from seeing the body. Several parents expressed deep regret that they were not allowed to hold, to wash and lay out, or even to touch their child's body. Some parents thought that the process of identification was insensitively and harshly handled; some commented on the callous attitude of the mortuary attendants.

ORGAN DONATION

Eighty two (68%) parents stated that they had not been approached about organ transplantation, of whom 48 (59%) wished that they had been: four parents deeply regretted not having been approached and thought that their child's organs were wasted by not being used. Ten parents had discussed organ donation at the time of death and none regretted their decision. This suggests that the option of organ donation may help rather than hinder bereaved parents.

BEREAVEMENT

After the death the child's personal items—for example, a pair of shoes, a dress, or a loved toy—are tremendously important. Parents appreciated care being taken to return all items, however trivial, to them. The process of asking bereaved parents to sign for receipt of belongings may cause great offence when insensitively handled. The most helpful support after the death came from follow up contact by a professional present at the time. One policeman who visited parents a few times after the day of an accident was subsequently recommended by them for an award for his kindness. A doctor who subsequently contacted the bereaved parents was also singled out for praise.

FOLLOW UP

Only 16 parents had contact from anyone at the hospital in a caring capacity after the death; three from the transplant coordinator alone, who was supportive. Few parents thought that they were shown any care at hospital immediately after their child's death, commonly being left to find their way home alone. In casualty departments parents often felt inadequately informed of events. Some parents were left for up to three and a half hours without being given information on their child's progress during resusitation attempts.

Discussion

Many replies disclosed distress about how bad news was broken. The consistency of some responses suggests a serious need to improve the training of police, doctors, and nurses to improve communication.[3] The current medical undergraduate curriculum seems to need urgent revision to enable training in breaking bad news and informing of death. In-service and postgraduate training programmes for doctors, nurses, and paramedical staff (including mortuary attendants) should incorporate such training as a core curriculum topic. The value of expressing care needs to be actively taught.

Senior staff must recognise the need to spend time with bereaved parents explaining the events surrounding a child's death. Health authorities should ensure this occurs,[4,5] as our respondents suggested that several complaints, including considered litigation, might be avoided if their questions had been answered. The value of giving all available information to the child's parents should not be underestimated.

The impact on parents and siblings of the devastating tragedy of the death of a child must be fully recognised by all. Supporting parents to stay with their child during treatment, even including resuscitation attempts, may be valuable. False reassurances should never be given. Organ donation can be discussed sensitively, and when organs are unsuitable, the reason for not requesting them should be explained to the parents. All parents should be given as much time as they wish to stay with and touch their dead child, irrespective of the cause of death, and those who wish to lay out the child's body after death should be helped to do so. Mortuary viewing rooms should have no physical barriers between parent and child. Parents may wish time alone to sit and hold their child's body; they must not feel hurried.

Lastly, we hope that the experiences of these bereaved parents may help to provide guidelines to prevent unnecessary distress and offence being caused to others in similar circumstances.

1 Awoonor-Renner, S. I desperately needed to see my son. *BMJ* 1991;**302**:356.
2 Warden W. *Grief counselling and grief therapy.* London: Tavistock Publications, 1983.
3 Hossack A. How a family's confidence in the health service was shattered. Glasgow Herald 1991 Jan 14 :7.
4 Geffen T. The complaints procedure. *Health Trends* 1990;2:87-9.
5 Hughes S, Henley A. *Dealing with death in hospital: procedures for managers and staff.* London: King Edward's Hospital Fund, 1990.

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