THE QUALITY OF HEALTH CARE AFTER SUDDEN INFANT DEATH IN IRELAND — THE REALITY AND THE IDEAL —

Katharina Ungruh, William Shannon, Owen Hegarty, Hannah McGee

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Katharina Ungruh.
**List of Abbreviations:**

This report is based on material gathered during interviews. The speakers in each quote are identified in terms of the following categories:

- **M** = Mother
- **F** = Father
- **I** = Interviewer
- **D** = General Practitioner
- **PHN** = Public Health Nurse
- **HS** = Hospital Staff
1. Introduction: Aims and Method

This report was commissioned by the Irish Sudden Infant Death Association (ISIDA) in early 1990. The overall aim of the research project was to answer the following question:

What is the quality of health care experienced by families bereaved by cot death in Ireland at present?

This area of study arose from expressions of dissatisfaction with care voiced by some cot death families to the ISIDA. Over the past decade only a relatively small number of publications deal with the effects of cot death and the benefit of health care to parents. One Irish study (Ward et. al., 1986) found that only 57% of 87 parents considered that they had received support from doctors. Another smaller Irish study (Matthews, 1982) involving 17 infants showed that while 82% of the parents interviewed expressed satisfaction with their general practitioner care, an important minority (18%) expressed great dissatisfaction. Other publications, such as Limerick (1983), report that the general practitioner or other doctor of first contact such as a paediatrician appear to have a key role and constitute one of the essential elements of professional care required by grieving parents. Good communication appears to be an integral part of the doctor's skills in dealing with the bereaved, especially in the case of cot death where a counselling approach should be coupled with the sharing of accurate information (Limerick, 1979). In addition, an Australian study (Cornwell, 1977) found that at least half of the medical practitioners involved did not see the plight of the bereaved parents as within their sphere of professional activity.

In completing the research task, the researcher drew on the qualitative method of unstructured interviewing. In contrast with the often criticised tool of the questionnaire which produces at best only a very partial understanding of social processes, this qualitative approach has become an increasingly important tool in the research process (Silverman, 1985). In social psychological research, the use of qualitative methods is also becoming more widespread. Griffin (1986) discussed how these methods have often been dismissed as 'subjective' or 'unrepresentative' or have been viewed as 'rich' anecdotal material and thus as less valuable than quantitative methods. In contrast to quantitative techniques, qualitative methods generate quite different information and are less amenable to the research designs and statistical analyses of experimental social psychology. However, the two methods are best employed as different sets of research techniques which can each make a valuable contribution to social psychology in their own right (Griffin, 1985).

This research project was primarily interested in the experiences of parents bereaved by cot death in so far as they relate to the care received from health professionals, as well as the experiences of professionals providing this care. The emotionally challenging nature of the topic demanded a flexible and sensitive approach which would allow interviewees the freedom to express their experiences as well as their emotions relating to all aspects of the cot death, alongside those specifically concerning health care. Thus, the qualitative method was adopted and a series of open-ended unstructured interviews was carried out with (a) bereaved parents and (b) health care professionals (general practitioners, public health nurses, hospital-based medical and nursing staff). These interviews were recorded on tape and subsequently analysed.

Parents: Parents who had suffered a cot death during 1988, and had contacted the Irish Sudden Infant Death Association at least once since the death, were invited by the Association to participate in the study. A total of 42 letters were sent to bereaved families, 15 in the Dublin area and 27 around the country (see Appendix 1 for breakdown). Of these, 25 families agreed to be interviewed and were visited in their homes where the interviewer spent between 2.5 and 4.5 hours with each family. In addition, the interviewer was introduced to five families by professionals. In all thirty families including, when possible, other close family relatives were interviewed.

The parents were encouraged to invite anyone who was involved or affected by the death to take part in the interview. Thus, some interviews included surviving children and/or grandparents. However, most parents spoke to the interviewer alone and in private rather than inviting grandparents, baby-sitters or friends who may have been directly involved at the time the death occurred.
As the opening question the interviewer asked parents to recount what happened, beginning with the day the cot death occurred. This allowed parents to focus on events they felt were relevant rather than imposing a “hierarchy of importance” through a pre-set interview schedule. The resulting “stories” were very detailed and thus produced a wealth of material. Whenever reference was made to professional services received by the parents the interviewer encouraged parents to describe their experiences with an evaluation of those services in as much detail as possible. All aspects of service delivery were explored including, for example, the role of the family doctor, the public health nurse, pastoral care, the postmortem, contact with the ISIDA. The interviews finished only when parents ‘ran out of things to say’ and when they had regained something of an emotional equilibrium, for example when they stopped crying or were themselves changing the topic.

Professionals: As many doctors were under pressure from a busy practice and the topic is not as personally involving for professionals as it is for parents, the interviews with professionals were much shorter, lasting between 30 minutes and one hour. The number of cases of cot death professionals had experienced varied. Some had no personal experience of dealing with parents bereaved by cot death at all whereas others had been called out on several occasions. Yet, all professionals had some knowledge of cot death occurring in their areas and most had had contact with parents who had lost an infant to Sudden Infant Death Syndrome (SIDS), but who were not their patients. Interviews dealt with interventions doctors or nurses found most helpful for parents, as well as those skills which were felt to be most relevant. The main focus of the interviews was the professionals’ personal feelings and experiences in dealing with bereaved parents. Arising from what they said any training requirements which could contribute to the provision of a less stressful but more effective service have been highlighted.

The design of the study allowed for much material to be gathered which was generally of tremendous importance to interviewees, but which reached beyond the immediate parameters of this particular study. This material was nonetheless extremely relevant in establishing the context for those items of information which dealt directly with service provision. The interviews with parents in particular thus produced sufficient information to gain some insights into the full spectrum of issues which parents may encounter.

Unfortunately, this report can only utilise a small portion of the information gathered. The intended audience for the report are those health professionals who are likely to be directly involved with cot death parents in their working lives, as well as those involved in the forming of policy within the health sector. Therefore, only information of relevance to health professionals and policy makers (as judged by the authors) was incorporated.

The specific aims of this report are to:

1) familiarise health professionals with the experiences and difficulties of parents who are bereaved by cot death and point to a number of circumstances which might influence a parent’s ability to cope following cot death;

2) highlight shortcomings within the present structure and obstacles to adequate service provision within the present system;

3) suggest a framework for service provision which is adequate for parents’ needs and which can be accomplished within the present structure of health service provision;

4) document necessary skills and training needs identified by professionals.

Cot deaths can occur in any family and to parents who may have experienced a wide variety of other difficulties in their lives before the sudden death of their infant. Health professionals generally keep a record of the previous history of a client’s health to allow them to understand the person as a whole rather than viewing a particular problem in isolation. Similarly this report aims, in as far as is possible, to represent the parents who were interviewed in their particular context, with their unique histories in mind.

This report may not adequately represent all those difficulties faced by parents which service providers need to be aware of when dealing with them. This is due to the fact that (a) the register of cot deaths is confidential and therefore the Irish Sudden Infant Death Association could write only to those parents who at some stage had contacted the Association and whose address was therefore included on the Association’s mailing list; and (b) that a self-selection process was employed (due to the sensitive nature of the project) which appeared to result in an under-representation of couples whose relationship/marriage had disimproved after the cot death.

6.
That couples who have problems in their relationship are apparently under-represented may be due to several reasons: they may be less likely, during the bereavement period, to contact the Association and/or they may be less likely to invite a stranger (the interviewer) into their home to talk about their lives (see also Cornwell et al., 1977). Thirdly they may still be too hurt and unable even to communicate with one another, let alone be interviewed about how they are feeling. In contrast, the majority of interviewees appeared very supportive of one another and able to discuss their fears, suspicions and often feelings of guilt in front of their partners.

The issues to be researched mainly focussed on health service provision (rather than the consequences of SIDS on the family’s life) and parents received this information in the letter of invitation. As parents could choose to participate in the research there may be a variety of reasons for not participating in such a study other than those of a personal nature mentioned above. Parents may, for example, have had no difficulties with service providers and thus they may have felt they had nothing to contribute. On the other hand, they may have had very positive or negative experiences with service providers or even with other research projects in which they may have participated. It is possible in such cases that some parents have a negative perception of research in general or particularly of research connected with or carried out by health professionals (a personalised explanatory letter was sent by one of us (WS) from the Royal College of Surgeons, together with a letter from the ISIDA). On the other hand, some parents were particularly keen to talk of their negative experience in an effort to spare other cot death parents the trauma they themselves had suffered.

The study population included families with older siblings, subsequent children, first-time parents, married and unmarried couples, separated parents as well as single-parent families. In several families the death occurred at a special time for the family, such as a wedding anniversary, just before the christening or perhaps at Easter-time or around Christmas.

Another aspect of parents’ circumstance which had to be borne in mind is the previous child-bearing history of the family concerned. A history of previous pregnancies which were miscarried, still-born or aborted may make acceptance of a cot death even more difficult. The sudden death may re-stimulate or exacerbate underlying feelings such as blaming the partner, self-reproach and particularly guilt.

Partly due to the lack of knowledge about Sudden Infant Death Syndrome, parents contemplate the circumstances surrounding the death for a very long time in an effort to come to some understanding of what led to the death. This lack of knowledge, in combination with the underlying feelings of guilt experienced by most parents renders the circumstances surrounding the death particularly relevant as these can produce mistaken beliefs and misapprehensions – beliefs that may, for example, diminish parents’ ability to cope with the death as well as undermine their self-confidence.
2. Present Service Provision

The interviews with parents began with an account of how they found their child dead or extremely ill, and what happened in the hours following their discovery. The excerpts below are three separate accounts of parents finding out that their child has died.

M: "(my daughter) walked in (...) and said "oh the baby has the measles" cause he was all patched up and I said "oh my God I don't want to get up and see him" and then the next minute he shouted "Oh Jesus Daddy ... he is dead" immediately ... of course he jumped out of the bed and said "don't ever" ... you know he was going to kill her talking like that ... and I stayed there for a few minutes until he got that far and said "oh no" and then I got out of the bed and when I went to go out the bedroom door he was standing there and said "no don't look and don't go near him" ... and I remember pushing him aside and saying "don't be so bloody ridiculous!" and went down and picking him up and showed him to him he was not dead.

M: 'I saw the back of his head and I knew straight away ... I sensed something wrong you know ... and I think I can recollect almost ... little beads of sweat on the back of his head ... and I just ran ... he was in a pram ... and I ran fast and picked him up ... and as I looked at him ... I'd no doubt he was dead ... there wasn't even a question as to check the pulse or anything ... he had death all over him ... he was white ... just everything about him ... it didn't even ... occur to me to check I just knew'.

F: 'I was out of the bed before they even (...) I was on the stairs when he said it ... I knew there was something wrong ... because I think I was sleeping ... I felt the fear in the back of my head ... that it might happen you know ... cause I had her ... she stayed in my house about three or four times ... and ... I didn't sleep at all when she stayed ... I stayed up all night watching her ... shaking her every few minutes ...'

There are three main sources of support from the health services available to parents who are bereaved by cot death. These are the hospital during the days immediately following the death, the family doctor and/or general practitioner on call at the time of death and the public health nurse. This section outlines the experiences of parents with these service providers and draws on the professional interviews to complete the emerging picture of current service provision to parents bereaved by cot death.

2.1 Service Provision in Hospitals

"Many parents have a vivid recollection of the moment of discovery, but the succeeding few hours are often lost from memory."

Walker (1985)

Both the general public and health professionals agree in principle on the primary role of medically trained service providers: to cure the sick and thereby, ultimately, to prevent death.

Consequently, when a child is seriously ill or appears to be dead or dying, a doctor or ambulance is called immediately and/or the child is rushed to the nearest hospital. Parents expect that everything possible will be done to save the child. And where there is the slightest hope, parents are normally not disappointed in these expectations.

F: "(the emergency unit) was ready from when we came in ... the minute we came in the door they had been prepared ... all ready ... straight away ... and I believe I could see ... they put me out of the room and I could see them just cutting off the clothes ... there was no taking them off just cutting them off him (...) and worked and worked at him ... though we'd been doing that up to then ..."
However, when there is any chance that the baby may survive, if hospital staff ‘fail’ to ‘cure’ the child, parents’ anger and resentment may be levelled against them.

M: 'I was very angry with them actually... I was very angry with the hospital because... somewhere deep down inside yourself... you’re brought up in the twentieth century to believe... that the medical profession has the answers for everything (…) when I got into the hospital I thought... it’s not my responsibility any more... they’ll save him... and when they didn’t save him I couldn’t believe it... I mean here is a cot death... that hadn’t actually happened and they had hours to save him and they still couldn’t save him...'

Most parents in this study, however, knew that their infant was dead before the arrival of any help and did not expect professionals to be able to do anything at all, either for the child or for themselves. What they did expect was some practical advice on how to proceed. At this point it is necessary that the attending health care professionals make a transition, from perceiving the infant as the patient to understanding the parents as the primary recipients of their care, although they are not in fact ill. The role of medical personnel changes from ‘curing the sick and preventing death’ to enabling parents to cope with their loss. Parents need to be given every opportunity to express their hurt rather than keeping it to themselves. This enabling process is ideally preventative. Long term behavioural and emotional effects on the whole family may be prevented by providing early help and support to bereaved families.

Cot death is a mystery not only to the medical profession but more importantly to the family of the infant. This, the complete lack of knowledge, is the single most important characteristic of a cot death in that it does not allow for a rational (or rationalised) approach to coping with the death. When a death cannot be explained there is abundant scope for unfounded beliefs and misapprehensions. If nothing is known, anything is possible. The most effective sources of information in this instance are those whom parents may perceive as people with authority and as trustworthy: e.g., hospital consultants or clergy.

2.1.1. Comments about Hospitals

Parents do not normally know what cot death is until it happens to them. All parents in this study were relying on the hospital consultant to explain the death to them or at least to give them all the information that they could possibly obtain. Some were not disappointed and were treated with great sensitivity and care — that is, they got the same attention as other patients. Others were satisfied with the hospital’s care of the child, but did not believe they received enough information or help themselves.

In a number of cases however, neither the child nor the parents were ever conceptualised by hospital staff as patients. The parents speaking in the excerpt below described the following incident several times during the interview and it was evidently the single most disturbing event following the death of their child:

M: 'she drove us into the hospital and... we went to the back of the hospital... we went to the mortuary (…) and a young lad came out and... I'll always remember he had a big bunch of keys... the door was locked and we went in by the side of the mortuary... we actually went into the morgue part if you like... where the bodies are laid out (…) F: that was the worst part
M: it was now... between half five and six on a Saturday evening... we didn’t go in through Casualty... we didn’t go into the front of the hospital (…) I don’t know the procedure... but as far as we’re concerned... the most horrific part of the experience... or one of the traumatic parts... is what happened now... we were taken into this... long room... and
F: and there were several slabs
M: several slabs... for putting bodies on... and
F: marble slabs
Such horrible scenes arose for several reasons: the hospital may not be equipped to deal with children; there may not be an emergency unit; or the death may have occurred outside normal working hours, that is, during the night or over a weekend. When we consider how many cot deaths occur under these circumstances, the chances that more parents will have to cope with such disturbing memories are in fact considerable.

Another cause of distress of this type was the (apparently not unusual) treatment of dead bodies.

Negative experiences of this type are extremely painful to parents. It appears to them that within the space of an hour their infant has lost all its relevance to the health profession, s/he is treated as 'a bit of rubbish' that 'needs to be discarded' (see below) and it seems to them that the child (or its parents) ever existed. The parents, however, have a very long road ahead of them before they will be able to go on living a reasonably adjusted life and from the very beginning need all the understanding and effective help they can get.

Unfortunately it is precisely those parents who have negative experiences with the health services in the first few days who have the most difficult obstacles to overcome. For instance, most of the parents who were received in such an unsympathetic manner in the hospital also found it extremely difficult to obtain the results of the postmortem, had no consultation with any doctor or even nurses in the hospital, and often found no encouragement to visit the baby during the days preceding the funeral. They 'slip through the net', as it were, and, as far as the hospital is concerned, they really do not exist as people in need of attention.

M: '... we didn't meet any (...) nursing or medical personnel at all ... we didn't meet a nurse ... doctor or anybody ... nobody asked us who we were ... anything ... there were no details taken from us ... nor perhaps maybe the doctor later on the phone ... gave details ... I don't know ... but as far as he was concerned (the pathologist) ... it was ... very much akin to "don't bring something ... that needs to be discarded" ... that's how I felt coming away ... I might have been dumping a bit of rubbish ...'
2.1.2 Accepting the child's death

F: '... all I did know was that he'd died and he was dead... but knowing it and accepting it was two different things'.

When the surviving family members are seen as patients, the few days before the funeral can be the most helpful stage for accepting the child’s death. Active participation in the preparations for the funeral, frequent visits to the child at the hospital, opportunities to hold the child as well as discussions with medical personnel about cot death appear to form the best foundation for coping with this unexpected tragedy.

Most mothers’ relationships with their infant are very physical, with feeding, bathing, dressing and generally caring for the child, whereas a father’s relationship is often comparatively less direct and less physical, though by no means less intense. Yet, this physical closeness can serve as the basis for an acceptance of the child’s death. In the following extracts mothers who were afforded and made use of the opportunity to spend time with the infant in the days before the funeral described very clearly the emotional work that was carried out at this early stage:

M: ‘the minute I went in I picked him up (...) ’I’m going to pick him up and bring him home and we’re gonna leave all this behind us’ at this stage (...) well I just wasn’t gonna let myself believe that he was (dead) (...) and even when I picked him up it was grand because I was fooling myself ‘I have him’ and I held him the way I usually hold him and it was still it was giving me the feeling I wanted to feel that (...) I had him in my arms so nothing can be wrong (...) like (the hospital) did say we could come back like every day and see him... which was great because... it took three days for me to realise... that wasn’t him any more I was holding’.

M: ‘if I had never been able to hold him I think that would have been really terrible... it would have been awful if I hadn’t gone back in... you know I really needed those days to let him go because like by the time we did put him in the coffin and everything I was at least able to accept that he was... I could do that’.

M: ‘but then when I got in the car (to bring the child to the funeral) just something switched and I said “that’s it now... she’s gone”’.

Many hospitals have developed an understanding of the needs of bereaved relatives and now invite parents to spend as much time as they wish with the baby. In some hospitals, particularly in those hospitals where a specific person takes on the responsibility of caring for relatives, parents are encouraged to become very active at this early stage of their bereavement, that is to hold the child, maybe dress the child.

HS: ‘I would advise them not to bury the baby... say the baby dies this morning... y’know not to bury it tomorrow... to keep it until the following day because they need that time to come in and out and spend time with their baby’

HS: ‘there is such a fear in them... they don’t want to see their baby... they’ll want to remember it as it was before... so you explain how important it is and eventually you get around them and they come and see the baby... and what has built up in them is a fear and once they see the baby they scream so they have broken that fear... and that’s the beginning of living with them... it at once can break that fear’.

Parents will remember if someone was strict with them on that particular point. They do not cherish the idea of seeing the baby dead but in retrospect most parents are grateful for firm guidance in this regard.

M: ‘I didn’t want to (...) go near (the nurse in charge in the hospital) or anybody else... but anyway she kept insisting and insisting that the family... go down there... and so we went down there and it was very good... what she did for us... she spoke to us... she let us talk... she brought us into the little oratory where she had him already laid out... she explained that there would be a postmortem... all that kind of thing (...) she was the one to one contact... she was the only person we had contact with’
Yet, it again depends on the way this firm guidance is offered whether or not it serves its purpose.

F: '(...) they were forcing me to drink tea and eat biscuits and all ... I just said "I just don't want ... just leave me alone" ... and they were sort of pushy ... just do this and do that'

F: '... but she was ... forcing me to tell her things that I didn’t want to talk to them about ... “are you married? ... do you intend getting married?” ... I didn’t need those questions that morning ... and when I went in (to visit the baby) ... I just lost all control and she was standing there and she was saying “calm down ... don’t be doing that you’ll upset (the mother)” ... I mean I’m totally as much upset as well ... she didn’t that ... how I could be upset ...'

These excerpts show the high level of sensitivity necessary in this type of work. In addition, great care has to be taken that these visits take place at a time when the child is nicely laid out. Visits at a time when the child is in any way unsightly (i.e. swollen, discoloured, not laid out) should be avoided as they only serve to distress parents further.

M: "‘no’ he said “I am telling you now, go down now, make arrangements, get yourself dressed up go down and see him” which I was sorry I did ... because it wasn’t the child ... that I had that they showed me down there I mean he was that size he had swollen up (...) ... his lower face was all marked he was ... stinking know he really was stinking and his happy and everything was ... he was just a mess ... and I just couldn’t take it I just couldn’t believe it was ... the same child ... I never wanted to see him again ... and ... it was like holding somebody else’s doll’.

Some family doctors showed much sensitivity to the needs of parents who had not been encouraged to visit the child and helped them to see and hold the child at least once before the funeral.

D: 'it was only when I went to the hospital I discovered that she hadn’t actually seen the baby afterwards ... nor had the husband ... so we went back to the house and ... she wasn’t anxious to come to see the baby but she agreed to come and ... just before the funeral the three of us just went to the mortuary (...) I felt ... I told her she’d never have another chance and that if she regretted it later nothing could be done ... I said that he looked lovely (...) and she needn't touch it or hold it if she didn’t ... want to do that ... you know (...) I think maybe she should see it anyway so ... the husband was a little more afraid to go ... in case the baby would be deformed or there would be something different about it ... and she brought up his rattlers and his little soother and all the other little things and (...) I don’t know I’d say they were glad they did it ... it probably didn’t make things any easier but at least they saw he still looked the same’

2.1.3 Grieving Fathers and Close Relatives

Hidden, unexpressed grief can impact on a person’s life for a very long time. Bereavement, misapprehensions and myths as well as frequently occurring feelings of guilt and resentment are common among those on the ‘sidelines’ – grand-parents, older children, baby-sitters. In most cases, these, and often even fathers, receive much less attention than necessary. Mothers not only receive most of the sympathy from all sources, but they are also the prime target of conventional service provision in relation to children. Public health nurses, for example, call specifically on mothers with small babies and build up a relationship with them. Among fathers in this study, however, experiences of professional help were limited to visits to the hospital and some contact with a general practitioner within the first week of the child’s death. (See also Dyregrov & Matthiesen (1987) on support received from hospitals).

During the interviews fathers seldom mentioned whether or not they had held the child when they visited the hospital. The majority of fathers were in fact rather more silent but also still more visibly emotionally upset than mothers. Most women were at a stage where they could identify a turning point in their bereavement, an event or conversation that marked a change in the coping ability. Many of the men, however, found it still difficult to express their feelings in such an interview and had generally talked less about their loss than the women. This is not surprising also in relation to the stereotypical myth that "men do not feel as much as women".

F: 'they say "oh I believe your wife had a bit of trouble" ... now ... your wife had a bit of trouble ... y’know as if you didn’t have ... terrible ...'
In most societies, the role in which men have been brought up actively discourages the expression of feelings. From an early age, for example, boys learn that crying is bad, and if they do cry they are called a 'sissy' or told that 'big boys don't cry'. Consequently it is often difficult for men to show their feelings openly, unless they are enabled to talk.

F: 'Well you know you asked me a question earlier on . . . I am a coward when it comes to hospitals . . . death frightens me so much I don't like talking about death (...) that's probably one of the reasons why I don't . . . talk about (the cot death!) that I am frightened of death . . . I see so much happening round at the moment you know that . . . it upsets me so much (...) it gets very frightening to start talking about it . . .'

In order to enable fathers to work through their feelings as effectively as mothers generally do it is important that they are doubly encouraged. From the first day onward fathers must be enabled not only to undertake practical tasks, such as arranging the coffin and the funeral, but also to encounter their own feelings although they may not express them. This may be done in the same way as for mothers, through physical contact with the baby while it is at the hospital, but also later on in giving men permission to feel their pain and express it openly rather than confirming the stereotype by expecting them to be "managing". The latter approach serves only to delay the grief process.

In anticipation of the later discussion of the role of general practitioners, family doctors (particularly male doctors) may be ideally placed to provide further vital help to fathers. Due to current practices and common stereotypes, fathers are unlikely to talk in depth to public health nurses or to allow themselves to express their emotions by, for example, crying, unless a safe environment is created for this expression of feelings. Family doctors, therefore, are ideally placed to provide further help to fathers. Due to current practices and common stereotypes, fathers are unlikely to talk in depth to public health nurses or to allow themselves to express their feelings by, for example, crying, unless a safe environment is created for the expression of feelings. Family doctors are in a position of authority, yet they are often close enough to be friends of the family. This places the general practitioner in an ideal position to help the father to express his feelings in confidence. Commonly experienced communication (and marital) problems within the family may possibly be prevented by the provision of services in which both parents are given the opportunity to relieve their anxieties. One female general practitioner expressed her view of the impact of gender relations on her work with fathers:

D: 'I'd say the fathers are very neglected in this situation (...) I'd say that's one area that we fall down on . . . but then I find it particularly hard . . . I mean . . . I'd say a man would find it very hard to cry in front of me'.

The father in the following excerpt was aware in retrospect that he did need to talk about his grief but that nobody had actually asked him how he was doing. When asked what he would have said if they had enquired, he answered:

F: 'that's a good question . . . again . . . would I have avoided it . . . saying that I was doing fine . . . its very very very hard to relate back to it . . .
M: it was a long time actually before you did open to . . . anybody . . .
F: it was . . . it was . . . nearly six or seven months I suppose before even I could begin to talk to anybody about it at all'

It is also important to understand that the reactions of both parents are related to one another. Many couples expressed a time difference. The mothers tended to at first be shocked and numb, but then get depressed, cry and feel very angry. The overt reactions of some fathers, on the other hand, appeared to be delayed, until the mother had regained some emotional stability. For many men, however, the time of the most intense emotions had then passed without finding expression and they had 'successfully bottled it all up'. It is this 'bottling up' that should, if possible, be prevented as such hidden grief can seriously affect a person's life and relationships for much longer than necessary.

Several of the interviews of married couples were carried out with only the mothers present. In each of these cases the women suggested that the men had found some non-communicative way of dealing with their own grief, for example by simply avoiding the topic altogether or by going out every night. In any case, these fathers had not shared their grief with their partners.

M: 'he just didn't want to talk . . . didn't want to open up the door . . . but I think that's probably true of males anyway . . . they kind of . . . bottle up you know (...) no he didn't like anybody to talk to him about it . . . he didn't like anybody mentioning it to him . . . he would just shy away from the whole thing.'

M: 'he is not talking about it at all . . . as if she never existed'
One father explained his own perception of mens' ways of coping:

F: 'I don't know... I miss him just like she does I suppose... but I think men are slightly different... they tend to be more inner than outer and... I do miss him yeah... miss him... probably more so afterwards than during the first couple of weeks."

Some professionals have incorporated the importance of involving both parents equally in their crisis management strategy.

HS: '... and the Dad at that stage would say "oh I'll do the identification" and I would say "well now... it's important for both of you... what you're doing from now on you do it together"'.

However, after some time and again in hindsight, even those fathers who were not given active help and support and who were trying to get over their crisis without re-living the pain recognised the futility of denying their grief and acknowledged how much easier it was to overcome the pain once they started to open up to someone else.

F: 'you're trying to work it out for yourself... it can't be done... except to be just talking I suppose... it helps there's no doubt about it... you have to get yourself into that situation where you can talk... that's the only... that's the hardest part... sit down and discuss your feelings... and talk... about the baby... mention his name and... remember the good times and even the bad times... you just keep on talking about it instead of trying to put him away and forget about him... and feel guilty then when you do forget or can't remember'.

The ideal outcome of the mutual effort of hospitals, general practitioners and public health nurses is to enable everyone affected by the death to arrive at this understanding: that the display of emotions and grief - either by the bereaved person or by the professional - is not pathological but is a vital stepping stone to a properly adjusted and fulfilled life.

When a cot death occurs the parents undoubtedly suffer most. Nonetheless, others may also be deeply affected by the death but are often forgotten. Grand-parents and older siblings in particular generally receive no outside help and parents themselves are not capable of supporting them through this crisis. Professionals who were interviewed often arranged meetings for the interviewer with parents who had lost their children several years earlier. One couple explained that while they themselves got much support and had recovered reasonably well within two years, little attention was paid to the grief of the grandmother.

M: ' (My mother) was going through it twice I suppose... for me and for the baby... she was very attached to him you know... she looked after him a lot and... she felt very close to him... I found it extraordinary that her friends didn't seem to understand her... they thought she should snap out of it you know... they tried to jolly her along and that's not what she needed... she wanted somebody just to listen to her for hours going over and over and over and showing the photographs... she'd show the photographs if she was on the bus... she'd show them to the person beside her... everybody got to see them but... she is really only getting over it now (four years later)... our GP wanted her to get therapy last year when he felt she really hadn't come to terms with it'.

Services for grandparents as well as for older siblings bereaved by cot death are almost non-existent. In this study professionals generally expected them to overcome the crisis on their own and tended to pay very little attention to their grief after the first two weeks.

M: 'but I have my parents here and I think often they didn't... get as much attention as they needed... because it was directed to me'.

M: 'still often at nighttime (I'm) thinking "I'd have to stay up all night (if I had another child) and I'd never survive all night and all day... how can I stay awake long enough" you know forever... and one day I was saying it here to my daughter and she said "Mummy I'll stay half and you'll stay half" I don't think she'll sleep either... she'd be awake all the time...'.

In addition to actual problems in coping with the death, communication between parents and grandparents about the cot death may break down and they may feel uncomfortable with each other if any feelings, doubts or questions they may have had in relation to the death were not dealt with early on.
M: 'I haven’t . . . I never really questioned her on it because I felt that if I really started questioning. . . it would be as if I was trying to find out had she done something you know (...) she doesn’t talk about it and she won’t . . . and I don’t want to question . . . I never want to ask questions because I feel I don’t want her to feel in any way that I think there was anything she could’ve done . . . I know she couldn’t have’

This study dealt specifically with services received by parents. As mentioned above there are many others affected by cot death and the needs of grandparents as well as older children are more often than not ignored. During the course of the interviews, parents spoke about some of the direct reactions their children had to the death of their sibling. In some cases when the official interviews were concluded parents also discussed in greater detail the difficulties they were having with their children. Most parents mentioned that their children were having some kind of difficulties in coping with the death. It appeared that parents required some practical knowledge about the difficulties children experience in understanding death. In addition, information about the emotional effects of death on children, in conjunction with some guidelines for providing effective help, also appeared to be lacking.

2.1.4 Summary

A minimum level of help is required by bereaved parents during their visits to the hospital to assist them in accepting the child’s death. This help consists of:

1) **Affirmation** of their parenting ability, **reassurance** that the child’s death was not due to negligence, and **information** on cot death in general and their child’s death in particular;

2) **Support** in accepting the child’s death in particular through seeing and holding the child and reassurance that parents can visit as often as they want. **Fathers** should be **doubly encouraged** during these visits;

3) Opportunities to discuss their child’s death with the **paediatrician**, including the initial postmortem results, as well as a follow-up appointment to be arranged for approximately six weeks after the child’s death.

If the hospital is not equipped to respond adequately to the needs of bereaved parents, contact should be made with the family’s general practitioner to fulfil the role of the paediatrician. Ideally, each hospital will have at least two staff members who are specially trained to support bereaved parents. In addition, all hospitals should adopt a policy to ensure that cases of cot death will be received in the casualty department so that parents are spared the trauma of delivering their baby to the morgue. Finally, additional service providers such as social workers and clergy should be attached to hospitals to assist bereaved parents in this major family crisis.

2.2 Service provision by General Practitioners

After the funeral parents have to find some way, their own way, of coping with their loss. In this effort of coming to terms with the tragedy there are some general, practical steps which can facilitate the acceptance of the child’s death. Clothes, cot, bottles and photographs, the birth and death certificates as well as the postmortem results are all part of the child’s belongings which help parents in their recovery. Unfortunately though, they often meet with unexpected difficulties with regard to these items.

Relatives or friends often clear the parents’ house of any reminders of the child, in the mistaken belief that the child’s clothing, cot or bottles will unnecessarily upset parents if they remain in the house. Unfortunately, although parents realised that relatives were trying to help them, most resented that this was done and regretted missing the opportunity of clearing away these things when they themselves were ready to let them go.
Families, however, experienced a variety of methods of handling the postmortem. These ranged from two interviews with a paediatrician in the hospital explaining the initial as well as the six weeks to six months or even over a year. Some parents found it utterly impossible to obtain them, the post several months after the death. The time span of waiting for verbal confirmation by their family doctor that the child was healthy, to receiving the results through it was only over time that parents could come to terms with putting the remaining things away. it seemed that exactly this process, where parents had to challenge themselves to voluntary relinquish items that belonged to the child, was an essential part of healing.

As part of the same healing process, some parents go to great lengths to obtain birth and death certificates as well as postmortem results. Although the mother in the following interview had received the postmortem results she was still not satisfied because not all the child’s belongings were in her possession. Her criticism in this regard was focussed on the health system as such, rather than on any particular person or service.

M: ‘(…) surely when they issue you with a postmortem it wouldn’t kill them to issue you with a death certificate at the same time… but I still think you should get it because to me it felt like… I had nothing to say he was born and nothing to say he died you know… I have nothing… it’s as if he came and went and… sometimes I ask myself was it all… in my mind… there is nothing’

The time and effort of trying to find the right person or even any information about how to obtain these items can be enormous. As one general practitioner put it: ‘postmortem results are notoriously slow’. In addition, there appears to be no consistency in, or policy for, the handling of these reports. The only certainty appears to be that the Coroner receives the results and that they must be lodged with the Garda (Police) records.

Families, however, experienced a variety of methods of handling the postmortem. These ranged from two interviews with a paediatrician in the hospital explaining the initial as well as the full postmortem results, to verbal confirmation by their family doctor that the child was healthy, to receiving the results through the post several months after the death. The time span of waiting for full postmortem results ranged from six weeks to six months or even over a year. Some parents found it utterly impossible to obtain this, for them, vital piece of information despite continual efforts, explaining to anyone who may possibly have been able to help how important these results were to them, and despite repeated reassuring statements of otherwise sympathetic general practitioners.

M: ‘I’m now waiting and waiting for the postmortem… never got any results… (seven months after the death)… I passed by (the doctor’s) (…) I went in and I got in and I started roaring crying (…) “look” I said “I want the results” (before the anniversary of the child’s birthday)… I said “you know the way you’d be in a heap probably about her birthday… her first birthday”… she said “I’ll get it sorted out for you”… no sign of her… (one month after the birthday) I met her down in the shops she said “never got around to that” says she is “terribly sorry”… oh Jesus I nearly got sick (…) she came into me (a month later)… she says “there was nothing now” she said… I said “how come”… “well” she said… “what actually happened was you were there at Christmas… you got mixed up in all the paper work… and you should have been automatically sent for… and had a chat with (the consultant)… no matter if he never had the results… and says I “I suppose that’s too late now”… well she said “yeah”… I said “that’s no bloody use to us now”… so she said “the results are gone from (the coroner) now and they’re gone into town”… and they’re in registered… so he’s after writing to him and asking… so he says he has to write to town… get them out to him and he’s going to send them onto her… and that is four months ago’

Although not all parents are as keen and persistent as this woman to get the actual piece of paper, the value of the family doctor or the hospital consultant meeting with parents to discuss the full postmortem results cannot be overstated. Interestingly, some general practitioners were not quite sure whether it was ‘allowed’ to show the results to parents.
The value of the report to parents is manifold: It serves as proof to the parents and to the 'world at large' that the parents were in no way negligent; that the child was perfectly healthy and there was no possible indication that the child was in need of medical attention; in alleviating fears that there were any congenital defects which may occur again in a subsequent child; and not least as a part of the child's belongings, as proof that the child existed.

In fact, many general practitioners have themselves expressed dissatisfaction with the current system of postmortem examinations.

Considering such difficulties among professionals in receiving State postmortem results as a matter of course, the frustration felt by parents who endeavour unsuccessfully to obtain them can be readily appreciated. Nonetheless, those practitioners who took the time to request the findings did receive them without difficulty.

2.2.1 Emotional reactions among General Practitioners faced with a Cot Death

In the course of his or her professional life, the general practitioner may deal with cot death parents who, at that point in their grieving, may have had vastly different experiences. The difficulties arising in each case are unique and although all have experienced a cot death, each family may have received varying levels of attention and support and be coping differently with their loss. The practitioner may or may not have attended in the home at the time of death and may thus not be informed fully as to the parent's initial reaction or current state of mind. Since a general practitioner only sees a cot death about once in seven years it is no surprise that many feel uneasy about how to cope themselves.

It must be acknowledged that many general practitioners in this study were of the opinion that the skills required to deal with a cot death situation and the subsequent bereavement period: '... (embody) a lot of what you do automatically in general practice'.

Some indeed thought that cot death required the same skills as any other death. Nonetheless, these same general practitioners also attested to such feelings as inadequacy, frustration, anxiety, sadness and anger that they themselves experienced amidst the chaos and confusion surrounding a cot death:

D: 'if I went in . . . I know . . . I feel it would upset me something desperate . . . I really think it would upset me terribly . . . to actually see the baby or you know the grief of the parents and everything'

D: 'one just felt an awful . . . an awful sense of helplessness really . . . facing that situation . . . what could I say . . . there was her dead child in the cot . . . perfect looking child'

As discussed earlier, the medical profession's essential role is to save life, to preserve it wherever possible. The general practitioner's ability to cope with a cot death is undermined by the very nature of the event: there is absolutely nothing the doctor can do to help the child but s/he can and must focus on the (healthy) parents as primary recipients of care.

D: 'you feel terribly helpless . . . presented with the baby that you feel . . . you should be able to do something about . . . a baby shouldn't die you feel'
D: 'you feel so inadequate . . you are already half redundant because the baby is dead and then you are trying to look after the rest of the family'

D: '.. its distressing . . it doesn't get any easier . . you develop coping strategies but it certainly doesn't get any easier'

Feelings of guilt, anxiety, uncertainty, helplessness, powerlessness and discomfort at dealing with the bereaved parents (whom, in some ominous sense, you have let down) are by no means uncommon among health professionals in the face of a sudden infant death. For instance, many general practitioners reported feeling a great sense of relief if they had not seen the child in the 48 hours preceding the death.

D: 'the first thing I felt when I heard it was "God that's terrible" and the second thing I felt was "thanks be to God I didn't see the child in the previous day or two at some point" . . I think it's always a dread that you will have seen the child with something minor . . you always feel at least in that situation you weren't called (.) at least I think it's easier to deal with (the parents) if you haven't seen them because you're not trying to make out you made a mistake originally and missed something'

D: 'one of the other aspects of medical training is that doctors are afraid of missing things all the time you know (...) people come along with a vague chest pain that "am I missing a coronary?"

D: 'its easier to deal with if you feel there's no guilt on your part . . you're going in feeling that they . . are maybe blaming you and not knowing you're kind of . . you're trying to get out of them whether they are laying the blame on you'

It appears that, at least in the early days and months, dealing with cot death parents is for several reasons an anxiety-inducing and emotionally draining task.

The crucial questions in this scenario are:

a) whether or not medical training has adequately prepared doctors for the emotional trauma of others whom they are likely to experience; and

b) whether at any point any emphasis has been given to enabling doctors to cope with their own feelings.

The above quotes appear to indicate that these emotions may limit the effectiveness of the doctor's work, in that doctors may be defensive of their own position in the tragedy, rather than supportive of the parents. Other studies support this finding. For example, Mandell et al. (1987) found that many health professionals felt uncomfortable following a cot death in their practice and that their feelings of anxiety often prevented practitioners from using even the most basic grief counselling skills.

2.2.2. Follow-up Services by the General Practitioner

According to general practitioners, follow-up services for cot death parents were generally approached in the manner of an open invitation to parents, that is, parents were invited to come to the surgery any time they needed help. Therefore, it was generally up to the parents to initiate this contact as few family doctors considered making house calls after the first few days.

D: 'well you see I haven't really (visited them) (...) I was more or less maybe waiting to see if there was any approach to me . . which there wasn't . . I do know that the public health nurse was in (...) but the family as I say seem to be . . managing'

Parents, on the other hand often felt very isolated and incapacitated and felt unable to contact anybody – friends, relatives, clergy, the ISIDA or their family doctor.

M: 'no . . my own doctor never came near me and I was in a couple of weeks after and he never . . all he said was . . "if you ever (...) want to talk about it" . . that was it like'
In this way it can turn out that each party is waiting for the other to do something with the result that nothing happens.

Furthermore, a very common attitude mentioned by parents was that they will have somewhat recovered, or should have recovered, within 4 to 6 months.

Many parents reported feelings of guilt in the first few months of bereavement if they were happy about something, maybe even laughing, or if, for a moment, they may have forgotten what happened to them. But when parents make an active effort to overcome the crisis and to live again, the memory of the child becomes less and less painful over time and becomes more of a treasure and source of comfort. This is not to say that parents are not still upset about losing the child. However, the memory of the child is integrated into the parent’s life as a positive and welcome, rather than a painful, memory in that the child will never be forgotten and remains part of the family forever.

How much time it takes to overcome the immediate, intense pain and to be able to live a generally happy and fulfilled life again depends on a person’s circumstances, their wishes and hopes for the future and whether these can be achieved. Too often other people, such as family, neighbours and professionals, are rather insensitive to feelings of bereavement and make parents feel guilty in one way or another for displaying their emotions for longer than is ‘convenient’. According to DeFrain & Ernst (1978) it takes individual parents an average of 15.9 months to regain the level of personal happiness they had held prior to the death. In the incident described below it was the public health nurse who could not cope with the parents’ grief and advised the mother to have another child to ‘make her forget’.

In the light of this example it can be seen how critical it is that professionals have all the relevant information available to them and are free of misconceptions about cot death. A professional who is ill-informed is more likely to feel unable to cope with bereaved parents. They may also perpetuate popular myths rather than base the support they provide on factual information. This will be discussed in detail below (Section 3.).
Many parents, general practitioners and public health nurses attested that follow-up services were provided to parents only if and when parents had a subsequent child.

D: ‘we don’t follow-up a lot afterwards ... unless they come into us we don’t really make a point of calling to them. . . I suppose we should but ... very often what happens is that they have another child . . . then you become very closely involved because they’re going to be so anxious about that ... and its then . . . its when you’re dealing with the next child ... that an awful lot of what they went through comes out . . . then they begin to talk about ... the other child and their fears and how they reacted”

As this event may never occur or in some cases occurs years after the cot death this arrangement is obviously unsatisfactory. Even if parents have another child soon after a cot death, these follow-up services focus necessarily on difficulties in relation to the subsequent child. Emotions that arise in direct relation to the cot death are thus dealt with indirectly, as it were. For intervention to be most effective, however, difficulties must be addressed as they arise.

The platitude that “You can always have another one” was repeatedly complained about by parents and deserves special mention. Parents were often harrassed with it not only by well meaning, yet ignorant, acquaintances but even by professionals. This attitude of other people was very painful for parents. It negates the importance of the baby to the parent’s life, the relationship the family has established with the infant as well as the uniqueness of this particular baby. For a variety of reasons, for many women the assumption that “they can always have another one” was indeed painfullly false.

A number of family units interviewed for this study had previous experience of miscarriage, abortion or still-birth, circumstances which may change a parent’s perception of the cot death and/or undermine the ability of a parent to cope with this infant death. If a woman has had an abortion in the past, the cot death may be seen as a punishment or if a woman has had a miscarriage or still-birth, she may feel much hopelessness about her child-bearing ability after the cot death.

Fertility, both for women and men, is in many ways the essence of a person’s (gendered) self-esteem. For example, the effects of loss or impairment of one’s fertility by a hysterectomy on a woman’s self-esteem have been amply documented; particularly in women’s writings.

Again among women, there has been a strong tendency to perceive one’s child-bearing ability and the outcome of a pregnancy as proof of one’s feminity and, particularly among Catholics, as a reflection of one’s previous moral conduct. A pregnancy and its outcome are, as it were, a mirror of one’s conscience. In case of complications the questions arise almost involuntarily: “Am I being punished for my sins? What have I done wrong?” In one way or another, women are held ultimately responsible for their children. Thus, when anything happens during a pregnancy or to a child; the mother feels responsible:

M: ‘and I mean even people you meet like . . . they made you feel like as if you were at fault . . . you done something . . .’

M: ‘I prayed for a better marriage . . . look what I got’ . . . I said “I got (the baby) . . . he made us better and now he’s gone” . . . and I felt guilty as hell over that’

Women who, in the months preceding the interview, had tried without succes to have another child were particularly hurt by such platitudes. The assumption that any woman can have a child exemplifies ignorance and lack of thinking. In particular if such mistakes are made by professionals they cannot be excused lightly. It is vital that any person, and more so any professional, dealing with sensitive issues such as cot death, miscarriage and stillbirth should be sensitive to a family’s background, especially the personal and social circumstances. Parents may not want to have another child; they may be afraid that the same tragedy will occur again; a woman may be reaching the end of her child-bearing years or either parent may have had a sterilisation carried out.

M: ‘and also I’m single . . . a lot of people would be referring back to . . . a marriage situation and I’m not in a marriage situation . . . they turn round and they say things to you like “people have another baby” (..) well you can’t when you’re single . . . its not that easy . . .’

There are many different factors which make such uninformed platitudes unacceptable. Thus any person, but especially a health professional, should take care not to sweep over these issues in passing.
2.2.3 Summary

There are various ways in which general practitioners can be of help to bereaved parents. The most important aspects are (1) to keep visiting parents at regular intervals and (2) enabling them to express their feelings and fears in confidence. In cases where maintaining contact with parents is difficult, obtaining and working through the postmortem results can be utilised by the family practitioner to facilitate communication with (and between) parents. Where no other opportunity presents itself for follow-up visits to the parents, the family doctor can readily obtain the postmortem results from the authorities and make contact with parents for an in-depth consultation.

Unfortunately, this opportunity is often missed, with doctors conveying the results by telephone rather than during a visit or completely disregarding this ideal opportunity for lending further support to bereaved parents. Sharing information contained in the postmortem report, as outlined earlier, appears to be a useful beginning to longer term follow-up services. Some general practitioners did meet the parents to give them the results but unfortunately did not make full use of this opportunity, leaving parents dissatisfied.

Nonetheless, when general practitioners are properly trained and informed about cot death they are ideally placed to take on the central role of ensuring that parents are adequately supported and have received all the help they need. This role requires the family doctor to monitor the parents' progress over time and communicate with them on a close and confidential basis. Some, though by no means all, doctors are already fulfilling this role:

D: 'I would make myself freely available to the parents (...) I would call to them maybe on the first day a couple of times... come again on the second day for longer... and supervise in a way unobtrusively how things were getting on now... see whatever help could be given... usually in the line of just talking (...) they do need constant reassuring... they have to be told over and over again that it wasn't their fault... and I think that is probably one of the most helpful things that anybody can do... and you can only do that in person (...) there's so much good can be done by going visiting... it's a very neglected part of the mechanics of medicine... there's a certain quality about going to see patients at home than seeing them coming up here (...) I think it's terribly important because... it is actually the doctor (who) takes the initiative and does the call... because patients are not always very good at looking for support and help and (...) you don't have the privacy in a surgery that you have in a patient's home and patients are more relaxed at home... and they can talk to you better...'

2.3. Service Provision by Public Health Nurses

In the triangle of health services (hospital, GP, PHN) provided to parents bereaved by cot death, the potential value of services provided by the public health nurse is often underestimated, particularly by other sectors in the medical profession:

D: 'other professional help as far as I can see it doesn't exist... I don't think (public health nurses are) prepared for the role at all... I don't think they have any... they have no sort of background training... they've no training in bereavement counselling (sic)...(parents) don't need a public health nurse... (...) I think that all of us... should be trained in counselling skills... I think that as regards specifically dealing with cot death I think that the public health nurse (could help) sure... but they don't take the time... they're too much... there are too few public health nurses and they've too much work... and most of the time they... try to do their best but they have too much on on-board and they can't do anything very well because of that... they do their best (...) the resources aren't there'

This assessment of the situation, that there are essentially no resources available to the public health nurse, is of course true. In theory, each public health nurse covers a specific geographical area with a population of between two and three thousand people. In practice, each nurse currently divides her time between a client population of five to six thousand people. Nonetheless, the public health nurse has a very beneficial and effective role to play in the care of bereaved parents. In the present more or less ad hoc scheme of service provision to bereaved parents, the public health nurse is the only health professional who, as a matter of course, visits families in their homes. That is, she is the only person who comes to parents to offer them help rather than requiring parents to ask for help themselves. The mother in the following extract clearly expressed the difficulties and obstacles parents are facing when they need to ask for help. It should not be forgotten that parents were acutely aware of the frequency of occasions where they required help and many were worried that they may be seen as a 'nuisance' by people if they called too often.
The most persistent problems arising for parents in relation to public health nurses were due to complete lack of information currently provided to nurses. Most nurses received their information that a child had died through the grapevine, e.g. from friends and neighbours. Many public health nurses spend much of their time informing themselves about their patients through talking to the family’s neighbours, in an effort to avoid embarrassing and painful situations. Despite these efforts such painful situations still occur. For instance, some parents reported that they were very upset when their public health nurse called to see the baby weeks and sometimes months after the death, at a time when parents had hoped that everyone knew about their loss. At times, such visits were preceded by notification from the health board of the need for immunisation for the infant!

M: 'That’s right yeah ... the second injection was due and when I got the notice ... I nearly died when I got that ... but anyway ... that was just you know ... red tape it came out I suppose in the load but ... (the nurse) from the local health centre ... called about four weeks ago ... it was a year later when she came she had only just heard ... she nearly died .'

Other problems arise when a nurse (in some cases also general practitioners) evidently did not know how to handle bereaved parents. Often, instead of leaving the parents to express their grief and concerns themselves, the ‘support person’ added to their upset rather than relieving it:

M: 'I met (the PHN) for the first time after (the baby) died and she came up and talked to me ... and she was awful ... she sat there and she did all the ... “oh you’re obviously getting over it” “you know and I could put on the right face because I knew what she wanted to hear so I ... gave her the right answers you know ... and I felt she was just being prying ... quite honestly I just didn’t see the point in her coming up to talk to me ... and at the end of it she turned round and she said ... “you’re very attractive ... didn’t you ever think of getting married” . ... and I felt like just hitting her at that point ... I thought this is the most irrelevant remark'

In many cases, particularly if the child was some months old, the public health nurse was the health professional who most frequently saw the child and whose help and advice was sought by the mother prior to the death. In addition, in families with older siblings the relationship with the public health nurse can often be long established and can therefore be a solid basis for giving support.

Public health nurses themselves often under-estimated their role. There appeared to be a consensus among public health nurses and female general practitioners that the help that could be given to parents was largely based on “just” listening; for that reason it was thought to be much easier to deal with parents who were able to express their distress verbally than with parents who may “just sit there” and be silent and “uncommunicative”. It is clear that non-verbal communication is less valued and understood by many doctors and nurses. In the following extract a nurse describes her own behaviour in a situation where the infant’s mother dealt with her distress by talking:

PHN: 'I didn’t see her then (for) a few days after the cot death and I just found all she really wanted to do was re–line the whole thing and talk and talk and talk ... and I just sat there listening ... there was very little I could say and I suppose I felt a little bit ... inadequate in the situation as you nearly inevitably do ... but she really just seemed to want to keep talking ...

I: ‘How did you find that?’

PHN: ‘I hadn’t any problem with that ... I suppose if anything it made it easier for me ... the fact that she could talk so much because it meant I didn’t have to talk so much (...) which is probably a cop. out but ... I just felt she did all the talking and I just sat back ... and just played a very passive role ... and (...) between (my colleague) and myself we got her a little ... bouquet of flowers just for the baby’s grave (...) I don’t know if it meant anything to her or not but .’

The key feature in the nurse’s behaviour is the passivity she describes: ‘I just sat there listening ... there was very little I could say’, ‘she did all the talking and I just sat back’ and ‘just played a very passive role’. It is in fact almost impossible to listen passively, that is, a person is not likely to talk to you for very long if you are not an active listener. It appears then, that although the nurse herself describes her behaviour in passive terms, she was in fact actively listening and encouraging the mother to talk. The nurse however is doing a job that, as for the doctor, differs from her usual role.
Many bereaved parents often cannot express the way they are feeling verbally for some time after the crisis because words are inadequate. Basic counselling and active listening skills are particularly useful to professionals when they are dealing with patients who are living through such an emotionally draining and upsetting crisis in their lives, in that they furnish doctors and nurses with the tools to help parents to get in touch with their feelings and express them in whichever way is appropriate to them. Being trained in such skills can also give the professional more confidence and alleviate some of the awkwardness which is commonly experienced and eventually verbalised in situations such as the interviews summarised in this report.

The benefit parents derive from the involvement of a sympathetic public health nurse can be substantial. Although parents do want and require the medical expertise of general practitioners and hospital consultants, the sympathetic and warm care and support received from public health nurses as well as hospital nurses is much appreciated and respected.

"The health nurse came a while later... she was really nice... she was really nice now... she came a couple of times... I knew that she was there... she was really nice now"

And naturally, if a family has another child, the input of the public health nurse increased dramatically. As this is a time of high anxiety for parents, special efforts made by the nurses are doubly appreciated and ensure that the parents can feel more secure with the new baby.

"Then the public health nurse again arrived out at three weeks and she arrived out at six weeks... and they gave us special numbers where they could be reached day and night... and they were great"

With the appropriate back-up services available first in the hospital and then through the general practitioner, the public health nurse can provide a good basis for parents, and particularly mothers, to work through their anxieties in relation to child-bearing and child-rearing as well as feelings of guilt inadequacy and self-reproach. It must be understood that health care professionals who are close to the parents will be identifying problems but will only actually deal with those for which they are themselves adequately trained. If any particular problem lies outside the brief of the professional, appropriate additional services should be organised for the parents.

2.4. **Current Services Provision: Commentary**

The health services available to parents bereaved by cot death are centred around the Hospital Emergency Unit, the General Practitioner and the Public Health Nurse. Although there is plenty of scope for different interventions on behalf of each of these, services received by parents in this study were mostly cursory. For those who were afforded the facility to visit the child frequently while s/he was in the hospital, this was by far the most memorable positive aspect of the services they received.

Although parents' perceptions of the services they received were often positive, the amount of time spent with a public health nurse, general practitioner or hospital based staff was very often negligible. Public health nurses often called only once or twice and general practitioners spent some time with the parents during the initial critical days but their involvement was generally of very short duration. and although doctors, particularly the families' own doctors, tended to make themselves readily available to parents, the initiative for making contact was more often than not left to the parents themselves. Few family doctors thought it appropriate to make follow-up home visits.
Some public health nurses did make an effort to visit parents more often but in many cases they did not hear about the baby’s death until many weeks or months later. In a few cases nurses were uninformed of the child’s death and called to see the infant or reminders for injections were sent to the parents. In addition, many professionals were not sufficiently informed or sensitive enough about the feelings of parents in relation to their child, often annoying parents with rather irrelevant or unfeeling remarks.

With the exception of relatively consistent and good services provided in the children’s hospitals in Dublin, the experiences of parents as well as professionals suggested that, at this point, health service provision for parents bereaved by cot death in Ireland is sparse and uncoordinated. At best, it becomes available to parents if, and when, they have a subsequent child. Even then, however, services are by no means well coordinated.

The benefit of adequate bereavement counselling and active support by health professionals cannot be over-emphasised when we consider that parents may want to have another child; may have additional problems, particularly if they are for one reason or another unable to have another child; or may have other children who require their love, support and attention. These services are invaluable not only for coping with the immediate crisis but in preventing long term difficulties within the family unit such as anxiety and depression. The range of emotions may include specific anxieties about the safety of their children, lingering feelings of resentment against other family members or feelings of self-reproach, guilt, and sometimes inadequacy as a parent.

In the event of cot death, then, what is the role of hospital staff, or the general practitioner and the public health nurse in relation to SIDS parents? The parents as patients are not ill, they do not require medical attention in the sense of a cure.

As Limerick (1983) points out:

“The most important need is opportunity to talk about the experience with someone who is compassionate and informed about babies and sudden infant deaths, who can explain the necropsy finding, dispel misapprehensions, help restore relationships in the family, and rebuild parental confidence.” (P. 467)

In Ireland, however, unless there is somebody in the hospital who takes the responsibility upon him/herself to help and guide parents through these difficult days and weeks, the opportunity to talk to someone knowledgeable about cot death is often afforded only at a perfunctory level.

M: ‘I don’t think I would have been half as bad now . . . if from the start like . . . I had been able to talk to someone’

It is an extremely important but sensitive, time-consuming and emotionally draining task to listen attentively to bereaved parents and to give them the emotional support they require.

As discussed above, during the days preceding the funeral the hospital is the ideal location for offering effective help and support to the parents. It appears that the longer parents spend with their child before the funeral the better they cope later on with the funeral and the loss.

Ideally the role of general practitioners would be to inform themselves as to whether parents are receiving the necessary support from all possible sources, including the health services, family and friends. This may be done by making short, but most importantly, regular visits to the family’s home. Such visits enable the family doctor to keep abreast of developments within the family and to be aware of any difficulties which may arise. In addition, regular visits reassure parents that those who were in charge of the baby’s welfare still care and have not forgotten the family. Regular visits also offer opportunities for clarifying any misconceptions or feelings parents may harbour.

The general practitioner, as a professional and medical authority, is likely to be in a position of trust and confidence and is thus ideally placed for identifying particular difficulties and advising parents. Such a ‘monitoring role’ of the general practitioner may involve a variety of actions should a deficiency of service provision be identified. Follow-up visits, consultations regarding the postmortem and the provision of additional information if required form the practical steps to be taken. The general practitioner can also contact other sources of support, such as the public health nurse and the representative of the Irish Sudden Infant Death Association to avoid confusion for parents and to enable better coordination of these support services.

24.
If needs are identified which the general practitioner cannot deal with adequately, s/he should refer the family to the appropriate service providers, such as child and family services, psychologists or social workers. In some areas in Ireland, such services may not be available to primary carers. In this case, the communication and basic counselling skills training proposed in this study would be an invaluable resource for carers and help in alleviating some of the stress currently felt in such situations. For this reason alone communication skills training must be a priority for primary carers.

Such training in listening to and communicating with bereaved parents, a sympathetic attitude, and a basically human and personal approach to caring are the essential ingredients for good care for bereaved parents during this difficult period. The care received at the very early stages of bereavement can give parents much of the reassurance, understanding of cot death and support they will need and provide them with a firm basis for overcoming this crisis in their lives.

The following quotes illustrate the positive feelings that remain with the parents when they were treated sympathetically at the various stages of their bereavement, as well as some of the varied needs and difficulties they may have in the months following the death.

M: 'I have a lock of her hair . . I even have the little bracelet from the hospital . . I've everything . . (the nurse) when we went in that morning . . the morning of the funeral . . she put it in my hand . . she said "here that's something for you to keep" she said . . now it was lovely . . like I was in bits at the time but I mean it was lovely to have'

M: ' . . it was dreadful I thought leaving the hospital and leaving (our baby boy) behind . . that was the worst part of it and they brought us back out to say goodbye to him before we left the hospital that night . . and I presumed they would have had his face covered but they took that off before we went in to see him . . they were great really'

When the child has been buried further problems may arise which can be addressed by primary carers:

M: 'and the way we were and the rift that grief was driving between us . . then if somebody could have come in and make us talk about it and make one or both of us cry . . and to bring it all out . . that it might just help smooth the road a little bit'

In conclusion, when a child dies of SIDS, the bereaved family members are in need of regular help and support to enable them to overcome the variety of difficulties they may experience. The hospital staff, general practitioners as well as public health nurses each have much to contribute to the well-being of the family, yet, at the time of writing there are some difficulties with the services received by these families. The following section will deal with obstacles to good service provision which have been identified.
3. Obstacles to Good Service Provision

During the course of this study, several issues were identified which combine to render the quality of services currently provided to parents bereaved by cot death less than satisfactory:

a) uncertainty of how to deal with emotions;

b) inadequate co-ordination among services;

c) lack of up-to-date knowledge about cot death;

d) lack of information for clients; and

e) lack of training in communication and basic counselling skills.

This is not to say that professionals are not doing their best as carers. On the contrary, the professionals interviewed for this study, as well as those who had attended the parents we interviewed, had on the whole, done everything in their power for the bereaved parents, given the limited amount of training and resources available to them. The issues listed above have become obstacles to good service provision in so far as they undermine a carer's confidence and ability to identify and deal with their patient's difficulties as effectively as possible. With better preparation, that is, with the appropriate training, all carers would be enabled to serve their patients better without necessarily having to spend any more time with them.

3.1. Professional Carers displaying Emotions

Health professionals in their daily work deal with a variety of different problems, many of which are emotionally challenging to the professional him/herself. During the interviews with professionals much time was spent discussing the appropriateness of displaying their own emotions in particular situations.

An earlier section in this report referred to the feelings experienced by health professionals when they were dealing with a cot death. The feelings discussed were varied including guilt, inadequacy, frustration, anxiety, sadness, anger, powerlessness, helplessness as well as discomfort at dealing with the bereaved parents. Although only a few parents remembered any display of emotion by professionals, those who did remarked on this rather positively.

M: 'I remember that nurse (in the hospital) . . . she brought a bit . . . a human effect to it . . . like . . . she even cried . . .'

M: '(the hospital doctor) made some kind of . . . said something like . . . "we don't bloody well know what it is" or something (...) I thought that was helpful . . . because he was angry'

Yet, the few health professionals who did show emotions were themselves very unsure as to the benefits of displaying their feelings if they are emotionally upset. The main worry appeared to be that the quality of their work would suffer from such display of emotionality and parents would not be served as well. In the following extract a general practitioner was even worried about showing distress to bereaved parents who were not patients, but friends.

D: '. . . again I went over to see them after it because I know them personally even though they weren't patients of mine . . . and I felt that this was quite distressing because I have children of my own . . . and you wonder in some ways was that distress helpful to them because if I was upset too . . .'

In the following dialogue between several professionals, a public health nurse who had not experienced cot death among her clients expressed her difficulties in even listening to a conversation amongst her colleagues dealing with such emotionally challenging material. This discussion took place in a group setting which allowed a number of public health nurses and general practitioners to exchange their ideas:
expressing emotion are identified in support and comfort anyone can offer appears to be simply closeness, reassurance, comfort and other hands were extremely grateful and appreciative of any professionals who not only empathised with understanding the situation have gone through it and maybe identify their problems between them (..)"

Later during the same discussion the following exchange arose, where the origins of their difficulties in expressing emotion are identified in the training received by these professionals:

PHN: ‘It’s so upsetting to have to listen... you’re doing your best to try and say the right things... that you feel so like you could sit down with her and cry away... I have often felt like that but you wouldn’t do it... but you’d feel like it...’
D: ‘I couldn’t help myself...’
PHN: ‘I never cried in front of anyone but I’ve often often come out now and... sat down and I’d come out to see the road kind of (hazy)... I’d be wiping my eyes or something... but I think that they wouldn’t expect me to cry in front of them or cry with them...’
D: ‘They probably weren’t expecting me to but I couldn’t (avoid crying)...’
PHN: ‘You know you can only go so far after the event with them... because you’re just still sitting there listening to them... that’s a help in itself but I still think they need the support of others who understand the situation have gone through it and maybe identify their problems between them... (..)’

There appeared to be a dilemma in crying with the patients. Professional training was traditionally geared towards being in control of a situation. Emotion was seen to be counteractive to this control and thus inappropriate “we’re conditioned ourselves to be just that bit detached if you can...”. This training is based on a firmly established fallacy: That the display of emotion equals a loss of control. Parents on the other hand were extremely grateful and appreciative of any professionals who not only empathised with them but also displayed their emotions. It appeared that the effect of a professional showing emotions took some of the distance and awe away from the patient-professional relationship.

In no instance did parents complain about a professional ‘breaking down’ or being in any way visibly upset about the death. In fact, reactions of surprise and shock about the death by the family doctor were generally seen as very positive and parents in some ways appeared to make allowances for any lack of knowledge about cot death by a professional;

M: ‘Oh he (the doctor) was lovely... he nearly died (..) he did a lot of reading up on cot deaths and everything else like that afterwards’

Anyone who was visibly moved or upset by the parents loss was remembered with the same fondness, be they professionals, friends or neighbours.

F: ‘(all the friends) the support we got off them was unbelievable... they really helped us through it... to see that they were hurt too meant a lot... to show that they cared that much... they were very upset’

The display of emotion was sometimes exactly what parents were asking for. When words fail, the best support and comfort anyone can offer appears to be simply closeness, reassurance, comfort and sometimes physical expressions of sympathy.

M: ‘(a friend) came up to me and she said... where’s the baby... and I told her... she hugged and hugged me and rocked me back and forth (..) and this woman hugged me... it was just beautiful...’

M: ‘I think just at that minute I wanted (a hospital doctor) that was going to give me a hug... talk to me...’
In general, when primary carers are dealing with a crisis situation the focus is on providing active help such as healing an illness or wound or giving practical advice, and there may indeed be little time for professionals expressing any emotions. When a death occurs, however, carers ideally spend some time actively listening to patients and helping them in a less activity-oriented manner. If professionals are expected to control their own emotions in such situations, they will spend much of their energy on controlling these emotions rather than on helping the patient. As parents generally react very positively to others showing distress over the death of their child the display of emotions can also have the additional benefit of adding further closeness and trust into the patient–professional relationship.

3.2. Coordination of Service Provision and Information Flow

D: 'the sort of degree of contact I think between the public health nurses and the GPs in general ... that isn't good ... although there are some very outstanding exceptions ... the relationship is almost non-existent'

As we have seen above, in the initial days the staff at the hospital where the child was admitted play a key role in the services provided to bereaved parents. It is the hospital consultant who ideally will provide the parents with detailed information on cot death (preferably printed) as well as conveying the initial results of the postmortem examination. In addition, the nurse in charge at the emergency unit will be providing much support and comfort to the parents. The nurse ideally will actively encourage both parents (and, where appropriate, close relatives) to visit the hospital as often as they wish, to hold the baby and to advise them in relation to funeral arrangements and other practical details.

On admission to the hospital, particulars of the family including the name of their general practitioner are recorded. In some cases the family doctor may even be with the family when they arrive or soon after. The family's address, on the other hand, identifies which public health nurse is responsible for the home nursing care of the family. Despite the fact that this information is readily available, most hospitals do not appear to have a policy of informing the relevant carers when a cot death occurs. That public health nurses are not informed as a matter of course is surprising in view of the fact that they regularly receive lists containing other information relating to their patients, such as births, school medical reports and contagious illnesses.

Under ideal circumstances, both the family doctor and the public health nurse will always be informed. In fact, when an infant dies at less than six weeks old, the maternity hospital should also be notified to avoid unnecessary emotional trauma when the mother has to attend for the six week check-up.

One of the most immediate issues which must be addressed within the health services is the lack of information flow between professionals in the event of cot death. Both public health nurses and general practitioners are aiming to provide a complete service to their patients. However, with insufficient information available to them these professionals are often ignorant of the fact that a cot death has occurred and may unwittingly cause unnecessary upset to bereaved parents:

M: 'Well actually when I went back to see him for the six week check-up ... I presumed he would have been informed from the hospital and he just said "how's your baby?" ... and I had to say "well actually he's dead" and he had no idea ... and I presumed somebody else would notify him ... because they had asked who had delivered him and that ... so that I thought now should really have been done'

In general, contact between each of the three primary sources of care tended to be very limited, particularly in urban areas. In the cities it may happen that a cot death occurs when the family doctor cannot be reached and an emergency service is called for help. The general practitioner, under the present structure, is unlikely to find out about the death of her/his patient unless the family informs him/her. In this study however, most families were under the impression that their family doctor had been informed by the hospital because they had actually been asked who their doctor was:
Rural areas are often at an advantage in terms of gaining information. In most smaller communities the grapevine carries an excess of information about everyone. In the event of a cot death the (otherwise mostly dreaded) grapevine is a rather reliable medium of information transfer in that both the public health nurse and the general practitioner will soon know that one of their patients has lost a child, even though the family may not have called them. It is also easier to keep in contact with the family without giving the impression that something is wrong. In addition, if the child was brought to a local hospital both nurse and doctor normally have some connections with the hospital staff.

It is vital for the general practitioner to be in regular contact with the hospital. If no on-going contact is established, for example, s/he may be unaware of whether the parents have seen and held the child or whether the hospital consultant has spoken to them and discussed the postmortem with them. Ideally, the general practitioner will be in close contact with the hospital consultant (and if possible the head nurse) and keep informed about the support parents are receiving in the hospital.

The acute reactions to the bereavement within the family may last for some time, often for a year or even longer. It is of great importance that one carer takes responsibility for the well-being of the family, stays in touch and identifies any difficulties that may arise, over time. Parents need a 'reference person', someone whom they can trust, who is available to listen to them and support them by providing, or at least co-ordinating, all the back-up services they require.

The general practitioner is ideally placed to take on this role for several reasons. S/he often knows the family concerned for some time and has become a person who is trusted by the family. On this basis s/he is also better able to identify the source of any particular problem, be it physical or emotional. To fulfil this role adequately and in order to gain the necessary support in dealing with bereaved parents from the hospital and the public health nurse, all primary carers require the appropriate skills. These skills include good communication skills, including active listening, as well as basic counselling skills. These training requirements are discussed in Section 4 below.

Another kind of information is a vital part of adequate service provision: Adequate information about the facts of cot death. When even health professionals do not know the facts they can easily perpetuate myths that exist about cot death by giving parents advice which is unfounded. Myths as, for example, the impact of breast or bottle feeding or of the body temperature of the child on the likelihood of cot death occurring in the child can easily be perpetuated by professionals who do not have adequate knowledge of cot death. Parents who have experienced a cot death will pay particular attention to everything a health care professional says, so that it is of the utmost importance that the professional be well-informed.

As mentioned above, printed information is of great benefit to bereaved parents. For this reason, ideally all health care professionals should have some literature readily available to them that can be given to parents at the earliest opportunity. Should such information not be available an information leaflet can be obtained from the Irish Sudden Infant Death Association.

There is an extensive on-going debate at present regarding the appropriateness, effectiveness and capability of general practitioners to provide bereavement counselling to patients. Certainly among the primary carers interviewed for this study none claimed to be providing counselling, although many spend time talking and listening to their patients.

Some thought that counselling was a necessary yet neglected part of service provision, a service they certainly did not feel trained to provide:

D: 'You must I think be willing to accept (the) responsibility of dealing with bereaved parents (...) if you feel unable then you should delegate it to somebody else (...) if you're not prepared to give the necessary support and counselling then you shouldn't get involved at all''

D: 'I think there is .. an urgent need for more professional counsellors'

D: 'I think (counselling) was something that was grossly missed out on .. I missed that .. I'm very conscious of that'

Others felt that parents required the type of help general practitioners were already providing as an integral part of their work, whether it is called counselling or not:

D: 'I feel the major aspects of our sort of help are not the medicines we give or anything else .. its the method .. the support and comfort and so on that we give people .. I think you do have to know a fair amount of medicine to be able to do that .. to be absolutely certain in your own mind that what is the best thing for the patient is comfort and reassurance .. '

D: 'I know we're all supposed to be good at non-directive counselling but there are times when people want a bit of directive counselling .. they actually do want to be told what to do .. when somebody wants somebody there who .. who is very solid about what they're doing'

D: 'when you say special counselling skills .. one sort of visualises pulling a card out of your pocket and saying "this is the name of the Sudden Infant Death Syndrome Association .. this is the telephone number I think you should contact them" (...) I don't think there is a special aspect to it other than what I've said so far because .. a death is a death.

D: 'I think anyone can do it .. when they're in a position of authority that in fact the mother can lean on .. and she would be able to say "well if they say its alright well then it must be alright" you know .. I think that is the sort of message .. '

It is not necessary, or indeed possible, at this point to propose a solution to this debate. What is necessary, however, is to keep a close focus on those in need, in this case bereaved parents. As outlined above, apart from those few hospitals which provide specific support in cases of cot death, bereaved parents rely mainly on their family and friends for help. For many parents this support was vital, particularly if their needs were neglected by the health services.

Those aspects of the cot death which often remained painful for parents were for example marital problems, anxieties about future child-bearing, anxieties about older siblings, doubts and self-recriminations despite good knowledge of cot death as well as deep hurts in relation to other people's attitudes.
Counselling is not an ability that is easily acquired. It is a specialised field of practice in which some health professionals are trained in depth. The suggestion made here is not to turn every general practitioner (or public health nurse) into a counsellor. It would indeed be detrimental to dilute the distinctions between the different professions and propose that any one branch, be they psychologists, psychiatrists, general practitioners, social workers or nurses should possess all-round talents and be able to do everything. Such a suggestion, if it were carried out, would lead to nobody being sufficiently able to do anything particularly well. However, general practitioners as well as public health nurses should be provided with basic academic knowledge on bereavement and other reactions to stressful situations. Furthermore, every general practitioner and nurse should be trained in basic counselling skills, in active listening as well as in communication skills. Confident ability in these skills is necessary, enabling the professional to communicate effectively with the parents and to facilitate parents to express their emotions (and doctors and nurses to cope with theirs). This will furnish the general practitioner, in the proposed monitoring role, with the necessary insight into the parent’s situation to decide what type and degree of help and support is required.

It is extremely relevant here that none of the general practitioners interviewed for this study recalled ever referring a parent to receive professional help elsewhere. Such referrals were not made despite the fact that several doctors and nurses related stories of parents under their care having obvious problems (e.g. not communicating with one another or with the outside world, difficulties regarding living in their own home, problems with older siblings or ‘prolonged’ grief reactions) which the doctor/nurse him/herself did not address in their work. The role of general practitioners should not be to identify and ‘treat’ every problem parents may encounter themselves, but to identify problems and communicate with parents and other professionals as to the best possible means to deal with them. In this respect then, the general practitioner could become a vital ‘care manager’ in the bereavement process.

Training in basic communication and counselling skills could make a significant difference both to the carers themselves and those whom they attempt to help. Even if the training were to provide communication skills and basic counselling skills, but stop short of full counselling training, primary carers would still be better prepared and more likely to succeed in their task. Repeatedly, interviews with parents and families indicated that what cot death parents ‘most needed were active listening, sound information as well as good co-ordination of services. In addition, doctors and nurses must be able to identify more complex difficulties to enable them to refer patients to other services. A gentle, well-informed approach is all important when dealing with the family as is the capacity of the carer to allow patients to ventilate their many fears and anxiety repeatedly, in a supportive environment. Given appropriate training, general practitioners and others in the front line of the health service would themselves be much better prepared to cope with their own emotions in the face of cot death. If they proceed to develop some of the skills of counselling, so much the better, but at the very least they need to understand the principles of counselling and know where to refer the bereaved for further expert care whenever this is indicated. Initially therefore, we recommend that all general practitioners, accident and emergency staff and public health nurses undergo a general basic course or courses in communication skills and a more specific course in communicating with and counselling the bereaved.

D: 'I do hope that counselling is high on the agenda (for the study leave in the Irish College of General Practitioners) . . . the ability to be a good listener a good adviser'

D: 'I think that we're going to become better educated about things like bereavement now . . . its the sort of thing you learnt about by default before'

At the time of writing, only one of the five Irish medical schools makes special provision in its syllabus for the training of its medical students in basic communication skills. This is not a series of lectures but rather a practical course designed to help students in their dealings with patients and families. Medical students receiving this basic communication skills training have given the clear feedback that their anxiety in dealing with patients is thereafter significantly reduced. Only a fraction of doctors entering general practice has specific training in how to communicate and consult better with their patients. With reference to general practitioners’ early post-graduate training (known as vocational training) this, if properly resourced and expanded from the cottage industry it now is, could be the ideal time in which to provide both in-depth communication training and basic counselling skills for all general practitioners entering practice today.
This inevitably means that the majority of Irish general practitioners have no grounding in the elements or principles, let alone the practice, of developing either communication or counselling skills. Doubtless some have “picked it up as they went along” in practice, but many others will not have done so. We have every confidence that young doctors in training would grow in confidence and competence if only such training were widely introduced at the early post-graduate level. Indeed many established doctors in practice for several years, some of whom were interviewed for this study, are keenly aware of their deficiencies in training and would benefit enormously from continuing education courses aimed at developing their practical skills in good communication and basic counselling.

D: ‘I think for GPs they would want to have an amount of care skills and practical knowledge of bereavement and that takes a considerable amount of time to put together...and the practical theory of it and of course getting the practical experience’

Public health nurses and casualty staff at hospitals may have fared somewhat better in their training but the evidence from parents who are quoted in this study shows that in this area there is also much scope for improvement.

As we have seen from the lengthy interviews summarised in this report, parents are often left in the dark about many aspects of cot death and in particular about their own baby’s tragic death. Left in such an information vacuum it is small wonder that guilt and blame rear their ugly heads instead of being dealt with by a professionally trained carer with both accurate information and adequate skills. The former may be largely acquired through study of the enormous literature on cot death but the latter can only be developed by appropriate training, which is itself demanding of both time and skill and requires a series of supervised training sessions. It is remarkable how carers in both the medical and nursing professions are left entirely on their own in coping with the cascade of emotions surrounding a tragedy such as cot death, amongst others. No attention is being given to the prerequisite of how to cope with one’s own emotions at such a stressful time.

Many other caring disciplines such as clinical psychology, counselling, psychiatry and social work would not attempt to engage in the care of the bereaved without first undergoing appropriate training, which naturally includes many hours of supervised sessions. We therefore advocate and indeed make a plea for such basic training to be introduced for all front line carers and, in view of this study, particularly general practitioners, public health nurses and hospital casualty staff. The daily work of such practitioners is already stressful enough without adding to their burden by expecting them to deal with their own emotions and with those whom they serve without the basic training referred to above. At a time of growing stress amongst caring professionals, it is timely that care for the carers gets the appropriate emphasis and resources. Investment in developing the necessary training programmes could in turn bring enormous relief to clients and patients in need and specifically in this case to the families stricken by all the feelings of guilt and grief attendant upon the tragedy of cot death.
5. Conclusions and Recommendations

Primary health care services are invaluable for families bereaved by cot death. Such services can contribute significantly to the families' ability to cope with the immediate crisis as well as help to prevent long term difficulties within the family unit such as anxiety and depression. Long term difficulties may include anxieties about the safety of their children, lingering feelings of resentment against other family members or feelings of self-reproach, guilt, and inadequacy as a parent.

With the exception of relatively consistent and good services provided in the children's hospitals in Dublin, the experiences of parents as well as professionals suggested that at this point health service provision for parents bereaved by cot death in Ireland is sparse, and uncoordinated and too variable in quality. At best, it becomes available to parents if, and when, they have a subsequent child. Even then, however, services are by no means well coordinated and generally focus on any difficulties in relation to the subsequent child rather than the bereavement. Services to bereaved siblings and grandparents were found to be almost non-existent.

A gentle, well-informed approach is all important when dealing with bereaved families, as is the capacity of the carer to allow patients to ventilate their many fears and anxieties repeatedly, in a supportive environment.

Services: a) Hospitals:

In the first few days after the child's death, the hospital can provide much help to the families to enable them to come to terms with the death. This help consists of:

1) Affirmation of their parenting ability, reassurance that the child's death was not due to negligence, and information on cot death in general and their child's death in particular;

2) Support in accepting the child's death in particular through seeing and holding the child and reassurance that parents can visit as often as they want. Fathers should be doubly encouraged to deal with their grief during these visits;

3) Opportunities to discuss their child's death with the paediatrician, including the initial postmortem results, as well as a follow-up appointment to be arranged for approximately six weeks after the child's death.

This help is vital and when these steps are taken parents are generally much better able to cope with the death and express their grief in the following weeks and months.

If the hospital is for any reason not equipped to respond adequately to the needs of parents bereaved by cot death, contact should be made with the family's general practitioner to fulfil the role of the paediatrician and to support the parents.

Ideally, each hospital will have at least two staff members who are specially trained to support bereaved parents.

In addition, the nurse in charge at the emergency unit will be providing much support and comfort to the parents. The nurse ideally will actively encourage both parents (and, where appropriate, close relatives) to visit the hospital as often as they wish, to hold the baby and to advise them in relation to funeral arrangements and other practical details.

All hospitals should adopt a policy to ensure that cases of cot death will be received in the casualty department so that parents are spared the trauma of delivering their baby to the morgue. Finally, additional service providers such as social workers and clergy should be attached to hospitals to assist bereaved parents in this major family crisis.
On admission to the hospital, particulars of the family including the name of their general practitioner are recorded. The family's address, on the other hand, identifies which public health nurse is responsible for the home nursing care of the family. It is recommended that hospitals put into operation a policy of informing the family doctor as well as the public health nurse of cot deaths occurring in their area. If an infant dies at less than six weeks old, the maternity hospital should also be informed to enable staff to be sensitive to the mother's needs when she attends for the six week check-up.

b) Primary Care:

The acute reactions to the bereavement within the family may last for some time, often for a year or even longer. It is of great importance that one carer takes responsibility for the well-being of the family, stays in touch and identifies any difficulties that may arise, over time. Parents need a 'reference person', someone whom they can trust, who is available to listen to them and support them by providing, or at least coordinating, all the back-up services they require.

We argue that the general practitioner already carries out many of the functions required for this purpose but what is additionally required is that s/he takes on the role of 'care manager' for the bereavement period.

The general practitioner, as a professional and medical authority, is likely also to be in a position of trust and confidence and is thus ideally placed for identifying particular difficulties and advising parents. The role of general practitioners should not be to identify and 'treat' every problem parents may encounter, but to identify problems and communicate with parents and other professionals as to the best possible means to deal with them. The role of 'care manager' may involve a variety of actions:

- Follow-up visits during which parents are encouraged to express their feelings and fears in confidence.
- Consultations regarding the postmortem examination;
- Provision of adequate information on cot death; and, if necessary,
- Referrals to other services.

The general practitioner may also contact other sources of support, such as the public health nurse and the representative of the Irish Sudden Infant Death Association.

The public health nurse, in general, was the health professional who most frequently saw the child and whose help and advice was sought by the mother prior to the death. In addition, in families with older siblings the relationship with the public health nurse can often be long established and can therefore be a solid basis for giving support.

The public health nurse can provide the family with regular visits and active support throughout their bereavement. To ensure good coordination of visits, the public health nurse should make contact with the general practitioner. Ideally, the public health nurse will visit the family regularly and enable parents and, where possible, siblings to express their grief. This can provide a solid, on-going basis for the family to work through their grief.

Factual information on cot death:

1) Adequate information about the facts of cot death is a vital part of adequate service provision.
2) It is very important that both public health nurses and general practitioners have all the relevant information available to them and are free of misconceptions about cot death.
3) Health professionals who do not know the facts about cot death can easily perpetuate myths by giving parents advice which is unfounded.
4) Parents who have experienced a cot death will pay particular attention to everything a health care professional says, so that it is of the utmost importance that the professional be well-informed.
Training:

Repeatedly, interviews with parents and families indicated that what cot death parents most needed were active listening, sound information as well as good co-ordination of services.

It is an extremely important but sensitive, time-consuming and emotionally draining task to listen attentively to bereaved parents and to give them the emotional support they require. Every general practitioner and nurse should be trained in basic communication and active listening skills as well as in basic counselling. Confident ability in these skills is necessary, enabling the professional to communicate effectively with patients and to facilitate them to express their emotions (and doctors and nurses to cope with theirs). This will also furnish the general practitioner, in the proposed monitoring role, with the necessary insight into the parent's situation to decide what type and degree of help and support is required.

Initially therefore, we recommend that all general practitioners, accident and emergency staff and public health nurses undergo a general basic course or courses in communication skills and a more specific course in communicating with and counselling the bereaved.

With reference to general practitioners' early post-graduate training (known as vocational training) this, if properly resourced and expanded from the cottage industry it now is, could be the ideal time in which to provide both in-depth communication training and basic counselling skills for all general practitioners entering practice today.

In summary, there are four areas which need improvement to ensure adequate services are provided to families bereaved by cot death:

a) Notification of cot deaths to the general practitioner, the public health nurse and, if appropriate, the maternity hospital;

b) Provision of adequate factual information on cot death to families and professionals;

c) Coordination of service provision: Ideally, one professional will be in charge of ensuring that a bereaved family receives adequate services;

d) Provision of the appropriate training for primary carers, including communication and basic counselling skills.
Appendix 1: Geographical breakdown of letter sent to bereaved families:

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<th>Number</th>
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</tr>
<tr>
<td>Wicklow</td>
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TOTAL           42
References


Limerick, S.: 'Sudden unexpected infant death. 1 Paediatric counselling'. Archives of Disease in Childhood, 58, 467-471, 1983.


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