The impact of sudden death syndrome on families.

David A. Bennett
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LA THÈSE A ÉTÉ MICROFILMÉE TELLE QUE NOUS L'AVONS RÉCU
UNIVERSITY OF WINDSOR
THE SCHOOL OF SOCIAL WORK

THE IMPACT OF SUDDEN INFANT DEATH SYNDROME
ON FAMILIES

by
David A. Bennett
and
Richard G. Bough

A Thesis
Submitted to the Faculty of Graduate Studies through
the School of Social Work of the University of Windsor
in partial fulfillment of the requirements
for the degree of Master of Social Work

August, 1977

Windsor, Ontario, Canada
Research Committee:

Professor R. G. Chandler   Chairperson
Professor M. Harman       Member
Dr. M. E. Bunt           Member
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ABSTRACT

The title of this research project is: The Impact of Sudden Infant Death Syndrome on Families. The purpose of the study was to explore the impact of Sudden Infant Death Syndrome on families by looking at the points of stress surrounding a S.I.D.S. death, the contributing factors to the stress and the perceptions of families about who was helpful to them and why they were helpful. The study was also designed to generate areas for future research on the psychosocial impact of S.I.D.S.

A review of the literature was conducted in the areas of 1) Death and Bereavement, 2) Crisis Intervention with Families, 3) Theories of Causation of S.I.D.S. and 4) the Psychosocial Aspects of S.I.D.S. The literature indicated that the unexpected death of an infant produces a myriad of effects on a family and neither professionals nor friends and relatives are well equipped to deal with a family which has lost an infant suddenly.

A sample of ten families was obtained through newspaper advertisement and personal contact by the local coordinator of the Canadian Foundation for the Study of Infant Deaths. All ten families were interviewed in person by the researchers.

From the findings of the study, the researchers noted that the discovery of the death, the funeral and burial, and
the care of subsequent children were identified as major
points of stress. It was also noted that funeral directors
were perceived to be helpful by most of the respondents
while health professionals were not considered to be as
helpful as friends and relatives. Friends and relatives
were identified as being helpful before the burial but not
helpful after the burial in the majority of cases. It was
noted that feelings of guilt and anger resulted from the
death and from attempts on the part of various people to
deal with the family. These feelings did not diminish
appreciably in the years following the experience. The
impact of the death extended beyond family boundaries in
all cases.

The researchers drew some conclusions from the
findings of the study and recommended that further research
be conducted in several areas, most notably the effects
of a S.I.D.S. death on children and extended family
members.
ACKNOWLEDGEMENTS

The researchers would like to express their appreciation to the members of the Research Committee, Professor Robert Chandler and Professor Mae Harman of the School of Social Work and Dr. Miriam Bunt of the Department of Psychology for their support and assistance in making this study a reality. Special thanks to Professor Chandler for being there when we needed him.

Thanks are also extended to our colleagues, friends and professors who encouraged and helped us throughout the study.

The researchers are grateful to the families who participated in the study and to Kathy Hubbell, the local coordinator of the Canadian Foundation for the Study of Infant Deaths, who helped us reach these families.

To Cheryl, wife, friend and typist, we are grateful.

This study is dedicated to Lisa, Billy and all children who have died of Sudden Infant Death Syndrome and all families who have experienced the loss of a child through S.I.D.S.
CHAPTER I

PURPOSE OF THE STUDY

Is it not for us to confess that in our civilized attitude towards death we are once more living psychologically beyond our means, and must reform and give truth its due? Would it not be better to give death the place in actuality and in our thoughts which properly belongs to it, and to yield a little more prominence to that unconscious attitude towards death which we have hitherto so carefully suppressed? This hardly seems indeed a greater achievement; but rather a backward step...but it has the merit of taking somewhat more into account the true state of affairs... (Freud, 1915 p. 316).

Getting in touch with the true state of affairs means recognizing and accepting death as part of the life process, not viewing it as some macabre abstraction external to our process of being. This recognition involves purging ourselves of the soap opera notion that death is timely; in the sense that there is always time even if only a few minutes, to pull loose ends together, before with a final parting platitude, we peacefully turn our heads to one side, close our eyes, and "pass on".

Thus purged and ready to meet death on its own terms we will readily recognize its real character. Death is terrifying, it is sometimes ugly, it is unjust, it spares no one and more times than not it is a cruelly sudden and inexplicable crisis. If we as survivors are to be helpful to each other, we must be able to face the realities of death. Otherwise the tools we use to cope will
be tools for coping with a phenomenon that is only an imagined one. Weisman in his article, "Coping with Untimely Death," talks about the implications of the untimeliness of death in relation to the coping process for survivors.

It would seem that few deaths are not untimely. However, this does not mean that all untimely deaths are alike and therefore we must not assume that what can or cannot be done about the victims or the survivors can only fall into already established patterns for coping with death in general. (Weisman, 1968 p. 361)

Weisman distinguishes three kinds of untimely death (1) premature deaths (2) unexpected deaths (3) calamitous deaths. This brings us to Sudden Infant Death Syndrome (S.I.D.S.).

S.I.D.S. is premature death. It is unexpected and certainly calamitous. This particular image of death called S.I.D.S. is especially painful and poignant because the child in most cases, is just beginning to develop a personality of his own. This kind of death damages our social and emotional reality, including our belief in a future in which potentials are realized. The innocence, trust and blamelessness which adults identify with childhood makes them feel that in some way they have failed to protect the child in his vulnerability. In the case of S.I.D.S., the sudden transition of the child from being alive and well to being dead shocks the sense of reality of even professional participants let alone those whose lives will be seriously changed.
The social work background of one of the researchers is in the area of psychiatric and family social work. In the five years which this researcher spent in the mental health field in various capacities and in his B.S.W. field placement experience working, in particular, with families, it was his impression that families were being serviced poorly, inappropriately, inadequately or even being ignored.

This unfortunate treatment started the researcher thinking about his and his family's experiences with the social and health delivery system when he suffered the loss of a daughter to S.I.D.S. In his situation, the services available and those actually provided seemed to be disorganized and, in the researcher's opinion, of little help. In retrospect it seemed that many helpful behaviours were not forthcoming. Other than the priest and close relatives, no one who was not intimately involved offered support other than condolences. The researcher and members of his family have been working in the local medical and health system, and in retrospect, feel that people who were involved in the same system and who could have helped, either didn't know what to do or seemed to be too consumed with dealing with their own attitudes toward death in general, and in particular, the death of a baby to help. It was at this point that this researcher began to be concerned about what happens to other families in a S.I.D.S. crisis who do not go to their
hospital of choice, are not aware of medical and hospital procedure, and are unaware of why people may be behaving toward them in an aloof manner. These families are in shocked disbelief with regard to what has just happened to them. They may already be experiencing feelings of anger, guilt and resentment. It is the researcher's impression that they are left, for the most part, to deal with these feelings on their own.

The researcher is concerned about this. It seems that there is a need to understand the impact of S.I.D.S. death on the survivors and to gear treatment to meet their needs. When the child is pronounced dead, it is the researcher's belief that the job of friends, relatives, clergy, doctors, social workers and other medical personnel has just begun. Having experienced two S.I.D.S. deaths in his own family, this researcher feels he has a degree of expertise to offer in regard to feelings and needs as they relate to impact and the ensuing grief process. The researcher is also fully aware that as a result of his experience with S.I.D.S. and how it is presently handled, he manifests strong feelings with regard to the present attempts of social service systems and health systems to deal with S.I.D.S. survivors. However, it would seem that the amalgamation of the researcher's experience and interest with that of the second researcher, whose interest in and experience with S.I.D.S. is of a more objective nature, would result in a potentially valuable study.
The second researcher's social work background is in the area of medical social work. In the four years which he spent as a full-time medical social worker and in his B.S.W. field placement experience, he has been able to see how families in crisis were dealt with in the hospital setting. It was and is his concern that families of patients are often neglected in the rush to treat the medical needs of the identified patient.

When this concern was amalgamated with the personal experience of the other researcher, it seemed that a research project to examine the impact of Sudden Infant Death Syndrome on families would be of interest to both researchers and would allow them to examine their concerns in an objective, in-depth fashion.

Once the general topic had been arrived at, the researchers did some preliminary reading in the area of Sudden Infant Death Syndrome. It became readily apparent through the course of the researchers' reading that the vast majority of literature on this subject was geared toward the medical aspects of S.I.D.S., most notably, theories of causation. With the exception of several articles which detailed clinical impressions, very little has been written on the impact of S.I.D.S. on the family.

This knowledge led to a discussion of which aspect of the problem would be the most appropriate focus for the research project.

It has previously been stated that the researchers...
arrived at the selection of Sudden Infant Death Syndrome as a topic for research partly as a result of their backgrounds. The researchers' backgrounds have to a large extent provided the "felt need" which is the subject of this research.

It is felt by the researchers that some medical personnel have been reticent to deal with that emotional element of serious illness and death. The training of medical personnel focuses on the treatment of physical illness, and as such, death usually means that their job is completed. However, it has been noted by at least one author that in the case of Sudden Infant Death Syndrome "the survivors are the victims and they outnumber those who die". (Salk, 1971 p. 248) It has been the researchers experience that hospital medical staff are not geared to deal with families who are more in need of "treatment" than the identified patient. These families may be seen as disruptive or a nuisance to medical staff; or they may be viewed as deserving sympathy but beyond help because of the constraints of the job and medical training.

Therefore, because the researchers feel that the families of the infants should be one of the major concerns of health professionals, and because the training and job descriptions of some health professionals do not allow them to deal effectively with the emotional impact of Sudden Infant Death Syndrome on the families, there is a
need for training of all health professionals in the area of the emotional impact of S.I.D.S. on families. The researchers feel that there is also a need for further social work involvement with S.I.D.S. families. It is felt that, based on the experiences of the researchers, the types of problems experienced by the families of S.I.D.S. victims fall more within the realm of expertise of social workers than that of medical personnel. It is the feeling of the researchers that social workers who have a knowledge of crisis theory and crisis intervention techniques should be employed to work along-side medical staff in order to provide a more complete service to families in which a S.I.D.S. death has occurred.
CHAPTER II

REVIEW OF THE LITERATURE

Death and Bereavement

Every society has had its taboos. As religion gave way to secularism in western society, death replaced sex as a prohibited topic. This taboo is gradually being lifted. But forbidden areas still abound (Simos, 1977).

Death is a subject that is evaded, ignored, and denied by our youth-worshipping, progress-oriented society. It is almost as if we have taken on death as just another disease to be conquered. But the fact is that death is inevitable... Death is as much a part of human existence, of human growth and development, as being born... Death is not an enemy to be conquered, or a prison to be escaped. It is an integral part of our lives that gives meaning to human existence. (Kubler-Ross, 1975 p. ix)

Kubler-Ross suggests that one of the major reasons why many of us avoid talking about death is the terrible feeling that nothing we can say or do can be helpful to another person experiencing a death.

Whereas birth is a cause for celebration, death has become a dreaded and unspeakable issue to be avoided at all costs. Perhaps it is that death reminds us of our human mortality and vulnerability in spite of all our modern technological advances, says Kubler-Ross. Death, she says, strikes indiscriminately - it pays no heed to the status, age or position of the one it chooses. The good and the innocent die as often as the bad. It is this inevitable and unpredict-
able quality that makes death so frightening to people. Those who have a strong need to be in control of their own existence are especially offended by the realization that they, too, are subject to the forces of death.

Other societies have, suggests Kubler-Ross, learned to cope better with the reality of death. No group has ever welcomed death's intrusion on life, but others have managed to integrate the expectation of death into their understanding of life. Why do we as a society find it so hard to do this? It is difficult to accept death in this society because it is unfamiliar. Kubler-Ross suggests that in spite of the fact that death occurs all the time, we seldom see it. When a person dies in hospital, he is quickly disposed of. "A magical disappearing act does away with the evidence before it could upset anyone" (Kubler-Ross, 1975 p. 5).

In coming to grips with death, it is important to be part of the dying process, the death and the burial. This may include seeing and perhaps interacting in some way with the body.

We routinely shelter children from death and dying, supposedly protecting them from emotional harm. However, it is apparent that by depriving them of this experience, we are doing them a disservice.

Pearson (1969) suggests, as does Kubler-Ross, that the subject of death has long been viewed as a taboo area. Pearson points out that this is particularly so in the case
of health professionals, doctors, nurses, social workers and others who are closest to death. Pearson notes that as recently as 1963, a book on taboo topics of research was published which contained a paper on death (Pearson, 1969). He points to an increasing number of journal articles and books as evidence of increased interest in, and concern about death as a legitimate topic for scientific investigation by sociologists, psychologists, social workers and medical specialists.

Richard Kalish (1969) believes that the opportunity to read about the dying process, to think about it, and to talk about it is most helpful. He suggests that we as a society, must stop avoiding death, and that part of the process of putting ourselves back in realistic touch with death should be the organization of training programs for professionals who work with death. Such programs for doctors, nurses, social workers and the like would eventually lead to a more open and realistic attitude toward dealing with death.

According to Robert Blauner, death is a biological and existential fact of life that effects every human society. He states that "mortality tends to disrupt the ongoing life of social groups and relationships, all societies must develop some forms for containing its impact" (Blauner, 1966 p. 379). He suggests that mortuary institutions address themselves directly to the disposal of the dead and the ritual of transition from life to death; and that fertility practices, family and kinship systems, and religion take their
shape partly in response to death and also serve to ease the disorientation, fear and confusion that accompanies the death impact.

Death in modern societies is controlled through bureaucratization, our characteristic form of social structure, by which we remove social functions from the family and the household and place them in the hands of specialized institutions independent of kinship considerations. Today the hospital cares for the dying and manages the crisis of dying. The mortuary industry whose establishments are called "homes" prepares the body and takes care of most other funeral arrangements. This separation of the handling of death from the family minimizes the exposure to death and its disruption. When the dead and dying are segregated among specialists for whom contact with death has become routine and even somewhat impersonal, neither their presence while alive nor as corpses interferes greatly with the mainstream of life (Blauner, 1966 p. 384).

Another principle of bureaucracy, says Blauner, is the "ordering of regularly occurring as well as extraordinary events into predictable and routinized procedures" (Blauner, 1966 p. 384). The modern hospital is committed to the routinization of the handling of death.

Its distinctive competence is to contain through isolation, and reduce through orderly procedures, the disturbance and disruption that are associated with the death crisis (Blauner, 1966 p. 384).

Hospitals organize themselves to hide the fact of
death. A major text in hospital administration attests to this fact:

The hospital morgue is best located on the ground floor and placed in an area inaccessible to the general public. It is important that the unit have a suitable loading platform which is concealed from hospital patients and the public (Owen, 1962 p. 304).

Hospital staff use a variety of techniques to render death invisible and routine. Bodies are not removed during visiting hours, supposedly to protect relatives. Dying patients are most often moved to private rooms when the end is in sight. This is done to protect other patients. However, some deaths are unexpected, says Blauner. These deaths are considered troublesome because they are difficult to conceal from survivors.

The rationalization and compartmentalization of death is accomplished by the hospital through the procedures of covering corpses, discretely removing the body, identifying the deceased, informing the next of kin, and completing the death certificate and when required, completing the autopsy release.

Coombs and Powers (1976) discuss the socialization of physicians as this relates to death. They report that upon entering medical school, students have essentially similar attitudes and feelings about death as the lay public. On an emotional level as well, new medical students respond to death similarly to the general public, with fear, phobic reactions and shock. In these initial stages
of training, personal identification with dying patients, particularly if the dying person is young, is commonplace. Eventually, students develop the necessary detachment but it is a painful process involving not only the acquisition of intellectual understanding but also the appropriate ability to manage feelings in relation to death. Initially, students find the coolness of case-hardened colleagues offensive. They still, at this point, view the physician like the country doctor who is always seen as being warm and compassionate. Witnessing the detachment in hospitals is at best disillusioning.

In summary, Coombs and Powers observe that the social processes which condition physicians to handle death rationally do not visibly foster empathy and compassion. In medical settings, talk about "death as a stressful human vicissitude" is almost non-existent (Coombs and Powers, 1976 p. 33). People cannot face death directly and because of this human frailty, a wall of silence surrounds the dying or dead and their significant others at the time when "feelings cry for expression" (Coombs and Powers, 1976 p. 33).

Present medical orientation and socialization is not conducive to preparing physicians emotionally so they can meet the needs of the dying and their families in depersonalized hospital settings. If he is to fulfill the role of meeting the emotional needs of dying patients and their families, a role that is increasingly expected of him, the
physician must be better prepared to handle the subjective elements of the death crisis, suggest Coombs and Powers.

Also within the medical context of dealing with death is the special role played by the coroner. Charmaz describes the coroner's office as "one organizational setting where dead individuals are processed through institutionalized procedures" (Charmaz, 1976 p. 61). Coroners are involved only when a death occurs under specified atypical conditions. Consequently, informing the survivor of the death may pose some rather touchy interactional problems for the coroner who, "Typically attempts to maintain a routine bureaucratic definition of his work" (Charmaz, 1976 p. 61).

Coroners, being confronted with death on a day to day basis, employ strategies to routinize their work and to keep them uninvolved in the on-going scene. This is apparently related to self-protection. They claim not to hold any unusual views or beliefs about death and in fact reflect to a surprising degree, typical cultural taboos. According to Charmaz, they manifest an avoidance of death, discomfort in relating to grief-striken survivors, and an absence of subjective views on death. They view death as an "external event" which is separate from their everyday lives (Charmaz, 1976 p. 68). The routine aspects of their work are the only "real" activities with which they concern themselves.

In conclusion, Charmaz notes some special aspects of the coroner-survivor relationship. The setting of the
relationship is usually in the domain of the survivor. The interaction is characterized by "its intensity, rapidity of sequence, and strategic control manipulated by the deputy" (Charmaz, 1976 p. 80). The coroner controls information that is vital to the survivors but of routine nature to him. The properties of this kind of interaction provide an interesting area of study for researchers.

Grollman describes death as the most significant taboo of our society. He quotes La Rochefoucault, a French philosopher: "Neither the sun or death can be looked at with a steady eye" (Grollman, 1974 p. xi). As a result, death is disguised through euphemistic language. People do not just die, they "pass on", "pass away", "perish", or "expire". Grollman believes that death is avoided to such an extent that we actually have developed the superstition that if we don't talk about it, it will disappear.

The kinds of feelings expressed by modern man in reacting to the death of a loved one, are related to our lack of preparation for death. Our limited exposure and our denial of death, account for this lack of preparation, claims Grollman. As a result, the pain, fury, outrage and terrible feelings of guilt - all of these strong emotions take us completely unaware. Because we in modern society are so ill prepared to deal with death, we seldom fail to blame ourselves, ask "why me?" or "what did I do wrong?" or "why am I being punished?" as we struggle to face the reality
of the death crisis.

The hospital emergency room is increasingly the place to which the layman turns first when he needs medical help (Angevine, Bachmann, Plumb, Simon, Hall and Dorr, 1976). They suggest that, although the care rendered in the Emergency Room is for the most part good, this is to no avail when the patient is dead on arrival. When this occurs, the crisis of which the patient is the focal point expands to envelop family and friends, and the "staff is called upon to respond also to the needs of these stressed others."

... (Angevine et al., 1976 p. 93).

Angevine et al. describe the Emergency Room staff and their response to families as follows:

Staff who are assigned and gravitate to the Emergency Room and to intensive care units are there because they are competent; they want to render effective service in an immediate kind of way; they want to put their skill on the line; they want to respond to human needs. Often in the face of an onslaught of duties, they manage sympathetically and more than adequately to meet the needs of families who are bewildered, angry, in terror, or in grief. They do all that anyone could do. But staff are human, too. They feel the strains. There are times when family needs are lost in the multiplicity of events taking place, or in the primary concern for the patient himself. There are times when emotional energy is exhausted and staff must retreat behind an 'official facade to save themselves from being overwhelmed. There are times, particularly when the staff has lost the battle to save a patient, when the frustrations, the helplessness, the pain, and perhaps even the fury of the family which is vented on them is too much to bear. Staff turns away, and the family is not helped (Angevine et al., 1976 p. 93-94).

The authors go on to suggest that we now live in a society where, for the most part, people die or are pro-
nounced dead in emergency rooms at hospitals. Thus it is in
the emergency rooms of hospitals where families in the most
acute phases of anticipated and actual loss quite naturally
converge. In the case of a patient who is dead on arrival,
the family's stay at the hospital may be very short and
contact time is brief. However, regardless of the contact
time involved, the quality of the interaction between family
and hospital staff will have important implications for the
family functioning in the future.

Angevine and his colleagues support that in their
experience, families undergo a kind of "imprinting
experience" (1976 p. 108) when they first reach a hospital.
As a result anyone, chaplain, social worker or crisis
worker, attempting to intervene other than at the time of
arrival of families in crisis will find it more difficult
to gain family acceptance because of the lack of initial
involvement.

These authors state that help flows when response to
family need is immediate; when communication is open; when
information is made readily available to them; when families
are encouraged to ventilate their feelings; when feelings
are accepted and treated as normal; and when families are
helped to hear what they may not want to hear.

She has been standing there for several minutes, the
telephone receiver still in her hand. Now she
examines the telephone in a dreamlike manner, as
though seeing it for the first time. Everything is
in slow motion. Time just sits in the room as if
it had no place to go.

Her face twists into a sudden grimace. She
tightens her grip on the telephone, squeezing and shaking it as though it might be made to take back what it has said. Later—(minutes, hours, days?) she sits alone in the dark room. The fingers of her right hand ceaselessly rub back and forth across the gold band on the third finger of her left hand. From the next room the sound of a clock beats upon her. It has never sounded so loud before—or so bizarre and menacing. Somehow it happened. Between one tick and the next. A wife then. A widow now. How could this be true? Unbelievable, ridiculous! Yet her life was now at a stop, while the clock continued heedlessly to mark a time that had no relationship to her. Why did the clock bother? Why didn't it end this mocking torment that life was supposed to go on? (Kastenbaum 1977, p. 241)

According to Kastenbaum, even the above words do not adequately convey what trauma a death can bring upon the survivors.

Bereavement, says Kastenbaum, is an objective fact. It also represents a change in status for the survivor. The wife becomes a widow or the child an orphan. Bereavement status may suggest what a survivor is experiencing or how he is adapting to a loss.

Kastenbaum describes grief as "a response to bereavement" (Kastenbaum 1977, p. 242). Grief is how the survivor feels, thinks, eats, sleeps and copes. The term grief does not really explain anything, says Kastenbaum. When we talk about a grief-stricken individual, we are merely focusing our attention on the way in which the individual's "total way of being has been affected by the loss" (Kastenbaum 1977, p. 242).

Other responses to bereavement are as common as grief, says Kastenbaum. Anger, indifference or even a disassociat-
ive flight from death's impact are all major alternatives to the grief response. Although there is more evidence of concern about bereavement and grief responses, we as a society still lack understanding about bereavement, says Kastenbaum.

Kastenbaum indicates that the various responses to bereavement can result in despair, bewilderment, physical illness or pain, shock, and all manner of somatic and psychosomatic complaints. Also there are no time limits in the coping process. The problems of grief continue after the funeral, when people turn back to their everyday life and turn their attention away from the bereaved person, thinking the crisis is over. Kastenbaum points to the Harvard Bereavement Study as evidence that perhaps the most difficult period for the bereaved is in the months after the funeral.

Kastenbaum also notes that a death can draw attention and energy away from the needs of children. In the case of a sibling death, parents are often so involved with their plight, that they neglect other children. The child then has to deal with two sources of stress, his own grief and a temporary lack of parental attention and love which he may or may not comprehend.

The bereaved child may express his distress in many ways that do not appear to be related to the actual loss. He may become hostile with playmates. Fear of being alone or fear of the dark may reappear. Parents often make it clear
to the child that he must be brave and therefore, the child often manifests his grief in ways such as those that do not necessarily indicate sorrow.

In a discussion of the general attitude of society toward supporting the bereaved person, Kastenbaum says: "Our society seems to have taken a direction that informs the bereaved person that his loss is not a matter of profound general concern" (Kastenbaum, 1977 p. 261). People will still gather round the bereaved person for the funeral and a limited amount of related ritual and visiting. Following this somewhat short demonstration of concern, the bereaved person is expected to handle things on his or her own. Any continued expression of distress or grief may be viewed as deviant.

Kastenbaum (1977) points out that the period of time during which the bereaved can expect support and sympathy is becoming increasingly shorter. He has noticed a trend toward increased impatience with the bereaved in our society. He feels that at times it seems like society prefers that no grief should be felt or expressed after the funeral. Although the bereaved person seems generally to be adjusting to this "hurry up" attitude, it is doubtful if this arrangement meets the emotional needs of the bereaved adequately.

In summary, Kastenbaum says:

It is highly doubtful that our culture can eradicate or foreshorten the basic human response to grief. It can only isolate the bereaved and add to the
suffering by insisting upon business as usual soon after a loved one has died (Kastenbaum 1977, p. 264).

Lindemann (1944) carried out a study of grief based on the experiences of people who lost loved ones in the Coconut Grove fire in Boston.

The study attempts to clarify four main points:

1. Acute grief is a definite syndrome with psychological and somatic symptomatology.
2. This syndrome may appear immediately after a crisis; it may be delayed; it may be exaggerated or apparently absent.
3. In place of the typical syndrome, there may appear distorted pictures, each of which represents one special aspect of the grief syndrome.
4. By appropriate techniques these distorted pictures can be successfully transformed into a normal grief reaction, with resolution. (Lindemann 1944, p. 141-48).

Lindemann suggests that the person experiencing acute grief shows a tendency toward sighing and generally complains about lack of strength or physical exhaustion accompanied by digestive problems such as inability to eat or abdominal discomfort. The bereaved person may demonstrate a sense of unreality and detachment from others, and intense preoccupation with the image of the dead person. Feelings of guilt will generally abound. There may be a loss of warmth for others. Expression of anger is common says Lindemann.

Bowlby (1969), in his discussions of attachment and loss, suggests that anger is a normal component of grief.

Lorenz (1963) and Price (1967) on the other hand, have suggested that there is a diminution of courage and aggressiveness which commonly accompanies loss.

Parkes (1972) notes the viewpoints of Bowlby, Lorenz
and Price and points out that grief is a process, not a state and that the expression of anger often varies with the passage of time. He further suggests that although anger seems to be a key component in grief reaction, its expression varies widely in human beings, further complicating the picture.

Parkes notes the most common expressions of anger in relation to bereavement to be general irritability, bitterness and protest, a punishing of the deceased by the bereaved which is related to reaction to separation. Bowlby (1969) has described protest as the means whereby a child punishes his mother for deserting him.

Rosenblatt (1975) suggests that overt expression of anger and aggression are less common in societies in which "ritual specialists have an important role in dealing with a death up to and during initial disposal of the body" (Rosenblatt, 1975 p. 43). This knowledge gives us an interesting view of the effects on the bereaved of clergy, funeral directors and other ritual specialists, says Rosenblatt.

Parkes (1972), Rees and Lutkins (1967), Carr and Schoenberg (1970) have shown that there is a high rate of morbidity and mortality following the death of a loved one, that the necessary coping process for the individual and the family can result in severe stress, and that there can be dysfunctional reactions. It is further recognized that the extended family provides more supportive help than does the
nuclear family and that the latter poses a particular problem today (Krupp, 1972). We are also aware that readjustment to living without the deceased — with its attendant reorganization and formation of new relationships — can be a tremendously slow and agonizing process. It has also been shown that management by a bereaved parent can be emotionally and physically overwhelming (Wargottz, 1969). It has also been noted by the New York Times (1972) that social workers are sensitive to the emotional and economic drains on a family suffering a recent death involving a protracted illness. The family’s emotional restabilizing process can be staggering; there must be a recovery process (Ochoa, Prichard, and Shwartzer, 1975).

Ochoa, Prichard, and Shwartzer say that preparation for the bereavement process and grief work is not an integrated part of helping the families of the dying, nor has society by and large sufficiently recognized the need to establish structured, organized support for the bereaved (1975 p. 244).

It is only recently, suggest Ochoa, Prichard and Swartzer, that social workers have recognized the significance of the social work role as it relates to behavioural and maladjustment problems which have recently been shown to stem from loss of loved ones. They suggest that, when the bereaved are isolated or abandoned, it is because of society’s inability to handle feelings in regard to death. Ochoa, Prichard and Swartzer suggest that the time limited rituals, such as funerals, intended to show concern for the bereaved,
do not indicate a real awareness of the long arduous coping process bereaved families must face. Responsibility for the bereaved, they say, has been assigned to clergy and other caring individuals.

Abrams (1977) stresses the social worker's responsibility to the bereaved and presents the challenge to the profession of Social Work.

Kalish offers special insight into the impact of death on survivors when the dying or dead person is a child. He suggests that the younger the dying or dead person is, the more distress is caused. The death of a child visibly upsets entire hospital staffs. A child's life has tremendous social value. "He has not had a chance to live, and we feel he is entitled to this" (Kalish, 1969 p. 102). The uniqueness of a child's death intensifies the impact. No longer are we prepared for such a death, because medical advances and improvements in health care have rendered the occurrence of childhood death unique rather than common.

Another factor which intensifies the impact of childhood death on the immediate survivors and society in general is the blamelessness that we attach to children in terms of responsibility for behaviour leading to their death.

Kalish says that the death of a child has a "tremendous impact upon the family constellation" (Kalish, 1969 p. 107). The parents are likely to feel extreme guilt because they somehow hold themselves responsible for the
child's death. Arguments as to which parent is more at fault in the death may occur. Responses to the guilt and blame are likely to take the form of anger, fear and displaced hostility and may be intensified by the belief that other family members or acquaintances will blame the parent.

A sense of loss and normal and abnormal bereavement may also be present in the death of an adult, says Kalish. He draws an interesting parallel between the widow who decides to remarry quickly and the parent of a recently dead child who may decide to have a substitute child via an immediate pregnancy or through adoption. In some cases, says Kalish, the substitute child will be given the same name as the dead child and may be expected to be as much like the dead child as possible. This puts a tremendous burden on the new child and allows him little opportunity to be himself.

In conclusion, Kalish says that those of us in the social and medical sciences are just beginning to be willing to look at the significance of death in modern society. Kalish suggests that the "willingness to talk and write and read about death and its impact is an important first step, one that is beginning to make a difference in the kind of care and attention we can give the dying patient and his family" (Kalish, 1969 p. 105).

Kalish and others have indicated that any death, but especially a child's death, causes a unique situation
with a family. This unique situation has been termed a "crisis" and crisis literature has much to say about the crisis of death and how it can be handled by helping persons.

Crisis Intervention with Families

Crisis has been defined in its simplest terms as "an upset in a steady state" (Rapoport, 1965 p. 24). In an effort to describe this steady state for use in the social sciences, the terms "homeostasis" and "equilibrium" have been borrowed from other disciplines, particularly in the area of crisis intervention.

Lydia Rapoport (1965) set out three sets of interrelated factors which combine to produce a crisis. These are: 1) a hazardous event which poses some threat, 2) a threat to instinctual needs which is symbolically linked to earlier threats which resulted in vulnerability or conflict, and 3) an inability to respond with adequate coping mechanisms.

Minuchin and Barcaii (1972) note that a crisis presents elements which are radically different from ordinary living, in that change is required. In this sense Minuchin and Barcaii distinguish between an emergency, which requires the mobilization of resources to an unusual extent, and crisis which requires change.

Within the realm of crisis theory, several assumptions, hypotheses and concepts appear in the majority of the
writings. These have been synthesized by Naomi Golan (1970).

These are:

1. An individual (or family or group) is subjected to various internal and external stresses at different stages in his life and seeks to maintain his state of equilibrium through the use of a series of adaptive maneuvers and problem solving activities....

2. The impact of a stressful event disturbs the individual's homeostatic balance, resulting in a series of predictable phases:....

3. During the course of the crisis situation, the individual may perceive the stressful or hazardous event as a threat, either to his instinctual needs or to his sense of autonomy; as a loss (of a person, an ability, or a capacity); or as a challenge (to survival, growth, or mastery).

4. Each of these reactions calls forth a characteristic emotion: "threat" brings out anxiety; "loss" is expressed through depression or mourning; "challenge" stimulates a moderate degree of anxiety plus some feeling of hope and expectation, releasing new energy for problem solving.

5. The state of crisis is not an illness or pathological experience; instead, it reflects a struggle with the individual's current life situation....

6. During the crisis situation, customary defense mechanisms have become weakened, and the ego is more open to outside influence and change....

7. The state of active crisis is time-limited, depending on the total field of biopsychosocial forces:....

8. Usually within four to six weeks, a new state of equilibrium is reached. This may be better than, the same as, or worse than the precrisis level of functioning,....

9. During the reorganization phase, new ego sets may emerge and new adaptive coping styles develop which will enable the individual to deal more effectively with future crisis situations. However, inadequate or maladaptive patterns may emerge which can result in weakened ability to cope in the future.

10. Crisis intervention is not a truncated version of long-term therapy but a unique form of treatment especially adapted to the critical situation (Golan, 1970, p. 421-22).
Using the concepts of crisis as identified by Golan and Rapoport, the death of an infant would appear to constitute a crisis for the infant's family. Rapoport has stated that

...there are certain common hazardous events, such as loss by death and its sequel of grief and bereavement, which will induce a state of crisis of lesser or greater intensity, or lesser or greater duration in nearly all individuals (Rapoport, 1965 p. 25).

The duration of a crisis is ordinarily considered to be between one and six weeks (Caplan, 1964). Shneidman (1973) however, feels that where a death is involved, the generally accepted duration needs to be modified. He feels that the crisis of death seems to last up to a year.

Irwin Gerber (1969), in attempting to explain bereavement as a period of crisis, gives the following reasons for feeling that bereavement does in fact constitute a crisis:

1. There is an imbalance between the severity of the problem and the resources available to cope with it.

2. It is a social situation not often experienced in one's lifetime. The evolution of the modern "nuclear" family has tended to isolate people from death and also from sources of support during the period of bereavement.

3. Modern society does not offer socially sanctioned ritualistic means of support except—in rare instances (e.g. national mourning upon the death of a leader).

4. Individuals perceive that within the first three months following the death, customary means of support are inadequate and, because of an "attraction to normality", outside sources are not sought.

Rapoport and Gerber's proposition that death and bereavement constitute a legitimate crisis is shared by Hill (1965), Morrice (1976), Parad and Caplan (1965) and Williams.
Williams uses the term "social atom" to describe the smallest social unit, consisting of the individual and those people to whom he is emotionally related at a given time. He reinforces Gerber's third reason for defining bereavement as a crisis by stating that "without adequate cultural supports in the form of mourning rituals and rites, the social atom may disintegrate" (Williams, 1973 p. 142).

J.K.W. Morrice (1976) has stated that "no matter what specialized care is needed, bereavement is generally a family crisis and is best dealt with in the family" (Morrice, 1976 p. 57). Pasewark and Albers (1976) have also made the point that an individual needs the members of his immediate or extended family or friends to surmount a crisis.

The development of a framework within which one may study families who are in crisis has been the subject of several articles.

Reuben Hill (1965) has developed the following classification of crises as they relate to families: 1) crises of dismemberment - including the death of a member, the hospitalization of a member, and separation, 2) crises of accession - including unwanted pregnancies, some adoptions, returning deserters and other unexpected additions, 3) crises of demoralization - including infidelity and alcoholism, and 4) crises of demoralization plus dismemberment or accession - including illegitimacy, divorce and suicide. Hill different-
iates between extra-family events which, he says, tend to solidify the family and intra-family events which tend to disorganize the family.

Williams (1973) has stated that a death in the family seems to set off a series of schisms which ultimately destroy family solidarity and cohesion. This seems to fit in with Hill's observations about intra-family crises. I.N. Korner (1973) has differentiated between "exhaustion" crises which arise from prolonged unsuccessful attempts to deal with overwhelming problems and "shock" crises which stem from a major precipitating event.

The sudden unexpected death of a family member would, within Korner's classification of "shock" crisis and the perception of the family members regarding the cause of death, determine whether the event is defined as intra-family or extra-family. Hill's formula for determining the severity of a crisis is given as A+B+C=X where A represents the hazardous event, B represents the family's crisis - meeting resources, C represents the family's definition of the event and X represents the severity of the crisis (Hill, 1965 p. 40).

Howard Parad and Gerald Caplan (1965), in attempting to establish a framework for studying families in crisis, developed the following classifications: 1) family lifestyle - which is a reasonably stable pattern of family organization which can be subdivided into a) value system, b) communication network and, c) role system, 2) intermediate problem-solving mechanisms - which is described as the
family life-style in action during a situational crisis that calls forth the family's efforts for coping with stress, and need-response pattern - which is the way in which a family perceives, respects and satisfies the basic needs of the individual members.

Further clarification of the family life-style classification is offered by Parad and Caplan in their statement:

when the family faces a stressful event, its life-style places at its disposal a range of problem-solving possibilities from which the family members individually and collectively may choose according to their perception of the demands of the situation (Parad and Caplan, 1965 p. 57).

During a crisis there may be a temporary shift in the family's need-response pattern, according to Parad and Caplan. These temporary shifts are not harmful per se except where the new patterns take on a sense of permanence and tension is reduced in the family at the expense of an individual member. This type of destructive shift in the family need-response pattern can occur either passively through emotional neglect of a member or actively through emotional exploitation. According to Parad and Caplan, emotional exploitation involves assigning a role to a member which "does violence to his needs as an individual" (Parad and Caplan, 1965 p. 59).

With specific respect to the crisis of death, Hill (1965) has stated that
dismemberment creates a situation in which the departed one's roles must be reallocated and a period of confusion - delay ensues while the members of the family cast learn their new lines (Hill, 1965 p. 38).
The crisis of bereavement has been identified by Williams (1973) as having two components: mourning and grief. According to Williams, mourning and grief are attempts to bring about "closure" in the Gestalt sense of the word to the experience. Further to this, Williams has stated that, together with mourning, grief as the second component of the bereavement crisis also serves as an adaptive function on behalf of individual and social integration (Williams, 1973 p. 143).

The concepts of mourning and grief are occasionally used interchangeably with bereavement but the literature would indicate that, however they are used, they are components of the bereavement crisis.

How a particular family will react to a crisis situation is difficult to determine. Hill (1965) has suggested that "family adequacy" will in large part determine how a family will handle a crisis. The components of family adequacy as identified by Hill are: 1) family adaptability, 2) family integration, 3) affectional relations between family members, 4) marital adjustment, 5) parent-child relationships, 6) family decision-making processes and, 7) previous experience in dealing with crises. Previous coping patterns of the family have been mentioned in the majority of the literature on family crisis intervention.

Rapoport (1965), feels that the pre-crisis level of functioning is important in understanding how a crisis will be handled. She is joined in this belief by Golan (1970), Morrice (1976), Parad and Caplan (1965) and Minuchin and
Barcai (1972), among others. Minuchin and Barcai have stated that permanent change requires negotiation between old patterns of coping and new ones.

The importance of successful weathering of previous crises has also been dealt with in much of the literature on crisis intervention. Waldfogel and Gardener (1961) have stated that

residuals of unresolved previous conflicts cause distortions in perception of pertinent elements in the present situation and restrict the individual's capacity for modifying his behaviour in order to cope with the difficulty (Waldfogel and Gardener, 1961 p. 213).

Morrice (1976) feels that, with respect to bereavement, previous successful experience is a boon even to people who are in a position of assisting the bereaved. "A helper or therapist, who has faced his own crisis of misery and done his own grief-work, is in a good position to aid others with theirs" (Morrice, 1976 p. 50).

Earlier statements have been made to the effect that crisis of bereavement is not one which is experienced often in our society, particularly for its younger members. It would appear that young families who are experiencing a bereavement crisis have little personal experience to draw on although this experience is felt by several authors to be invaluable. Morrice adds to this point specifically by stating that

in some cases, however, particularly in the event of unexpected death, the funeral arrangements can prove distressing and the task altogether unfamiliar... (Morrice, 1976 p. 53).
Because of the unfamiliarity of it and the lack of support from the extended family, unexpected death and its resulting tasks and emotional hazards are likely to be defined as a crisis by the family experiencing them.

Intervening in a crisis situation involves considerations which have been described at length in the literature. J.K.W. Morrice (1976) defended the use of crisis intervention in instances where the family is overwhelmed by an event. He has stated that,

...an approach which seeks to uncover interpersonal disturbances and support the family's own resources in resolving them, can be demonstrably effective and clearly appropriate (Morrice, 1976 p. 5).

Morrice appears to be echoing the sentiments of Lydia Rapoport (1965) who has stated that

a little help, rationally directed and purposefully focused at a strategic time is more effective than more extensive help given at a period of less emotional accessibility (Rapoport, 1965 p. 30).

One of the critics of crisis intervention, Edwin Shneidman (1973) has made the point that crisis intervention deals primarily with precipitating causes and not personality. Judith Lang (1974), in describing the activities of the Quick-Response Units of the Jewish Family Service in New York, has stated that in order for the crisis intervention system to work, it is important for the workers to hold the conviction that clients can be helped in a brief period of time and that the integration of changed behaviour can be accomplished by the client on his own.

The hallmarks of these units, according to Lang are instant
availability, flexibility of response and mobility. This approach is not seen as being negative but rather the most appropriate method of dealing with a crisis situation for those families whose coping mechanisms are adequate under ordinary circumstances. Naomi Golân (1969) has dealt with the crisis intervention aversion to personality restructuring by stating that "while not many people may be motivated to change their ways of behaving and feeling, all people in distress are motivated to obtain relief from suffering" (Golan, 1969 p. 394).

In a five month long pilot study conducted at the Montefiore Hospital in New York to determine if recently bereaved families would accept an offer of unsolicited professional assistance, the "emotional accessibility" of families in crisis was demonstrated when it was found that 90% of the families contacted accepted the offer of help (Gerber, 1969). Some of the reasons suggested for the success of the project include good cooperation between social workers and physicians and timely response to the crisis. Morrice feels that this cooperation and interest on the part of health professionals is not always shown.

Often it seems that the protection, reassurance, and active help which are needed and might be expected from doctors, nurses, clergymen and others is given ineptly, without understanding, or not at all (Morrice, 1976 p. 46).

Teamwork is suggested by Lang (1974) as being an important part in the delivery of crisis services. Crisis intervention with families is not and need not be the sole territory
of helping professionals (Shreidman, 1973). A well orchestrated, collective effort on the part of important members in the family's social orbits can be invaluable in bringing the crisis to a swift resolution.

The process of crisis intervention has been discussed by several authors. Parad, Selby and Quinlan (1976) have outlined four steps in providing crisis intervention service to families. These steps are: 1) search for the precipitating event and its meaning to the clients, 2) search for the coping means used by the clients, 3) search for alternative ways of coping which might better fit the situation and, 4) review and support the clients' efforts at new coping means. Parad et al. have suggested that throughout this process the social worker is active in defining the purpose of the family crisis session... and the means that can be used for achieving these purposes (Parad et al., 1976 p. 322).

Rapoport (1965) feels that healthy crisis resolution is fostered by help with the following: 1) correct cognitive perception of the situation, which is furthered by seeking new knowledge and by keeping the problem in consciousness, 2) management of affect through awareness of feelings and appropriate verbalization leading toward tension discharge and mastery, 3) development of patterns of seeking and using help with actual tasks and feelings by using interpersonal and institutional resources.

How the goals and theories of crisis intervention are operationalized is a matter of personal preference for
each therapist. Lang (1974) has reported on a system of interviews involving a single therapist over a six-week period of time. Goldstein and Giddings (1973), reporting on research done by MacGregor et al., stated that a favourable outcome was obtained in forty-nine of the sixty-two families using Multiple Impact Therapy which is used only for a matter of days with many therapists. It was found in MacGregor's study that favourable outcomes occurred in families where movement was in the direction away from a stereotyped balance of power where each member of the family is assigned a single role. More flexible interaction, allowing growth changes for all members, was found to occur in these successful families.

Whichever method is chosen and whatever the setting, it would appear that crisis intervention theory and techniques have validity for studying the situations of families who have experienced a Sudden Infant Death Syndrome death. Success in helping these families is contingent on a great many factors but a solid base from which to work is one of the most important.

Theories of Causation of Sudden Infant Death Syndrome

Of the material which has been written on Sudden Infant Death Syndrome, the majority has been etiological or epidemiological in nature. Medical researchers have sought the cause of Sudden Infant Death Syndrome for many years. Epidemiological and pathological studies regarding S.I.D.S.
first began to appear in abundance in the 1940's and these studies laid the foundation for further investigations into the nature and cause of S.I.D.S. (S.I.D.S., 1974 p. xvi). Since the 1940's a great many investigations have been conducted into the causation of S.I.D.S. and medical journals as well as newspapers and family magazines have reported on the resultant theories of causation.

While it is important to understand the basic theories of causation of S.I.D.S. in order to deal effectively with the families of S.I.D.S. victims, it is outside the scope of this study to report extensively on the investigations into the cause of S.I.D.S.

In the interest of conciseness, the following table has been reprinted from The Sudden Infant Death Syndrome by Beckwith (1975) with modifications. The table illustrates the major theories of causation of S.I.D.S. as well as some of Beckwith's comments about them.

Table 1 -- Theories of Causation of S.I.D.S.

Extrinsic Theories

Infanticide  
(Mt. Sinai J. Med. 35:214, 1968)  
Certainly the most malignant theory ever proposed. Inconsistent with narrow pathologic spectrum viral isolation rates, etc.

Suffocation

Spinal epidural hemorrhage  
Refuted (Am.J.Clin.Path. 52:289, 1969). We have not seen these in our series.
Table 1 continued

Aspiration of gastric contents
(Lancet 1:343, 1948)

Refuted by author's
own subsequent work
and by Peterson.

Climatic Changes

Hypothermia
(Lancet 1:343, 1971)

Refuted. We have
noted no increase
during cold weather.

Exogenous hyperthermia
(Frequent death certificate
diagnosis)

Usually supported by
scant evidence.
Obviously not the
cause of most S.I.D.S.

Nutritional and Metabolic Theories

Rickets
(Beitr.gericht.Med.26:278, 1969)
(Zischr.Kinderh.84:565, 1960)

Might be occasional
contributing factor,
but obviously not a
major one. Two cases
of our 425 showed
rachitic changes.

Selenium, vitamin E deficiency
(New Zealand M.J. 71:32, 1970)
(Brit.M.J.4:559, 1971)

Refuted (J.Pediat.81:
415, 1972). Also
refuted by the fact
that breast-fed babies
frequently die of
S.I.D.S.

Scurvy
(M.J.Australia 2:292, 1970)

We have not seen
oseoporosis in ribs
or vertebrae.
Petechiae limited to
chest. Most of our
cases got supplemental
vitamins, including
vitamin C.

Renal dysfunction

Postmortem autolysis
not excluded. Others,
including ourselves,
have not seen the
lesions described.
No definite amino acid
or protein abnormality
was found.
<table>
<thead>
<tr>
<th>Condition</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Magnesium deficiency</td>
<td>(Lancet 2:258, 1972)</td>
</tr>
<tr>
<td>Normal magnesium levels in vitreous humor of 12 consecutive S.I.D.S. cases were found</td>
<td>(Lancet 2:871, 1972)</td>
</tr>
<tr>
<td>Deficient vitamin D</td>
<td></td>
</tr>
<tr>
<td>Acidosis</td>
<td>(J.A.M.A. 206:1446, 1968)</td>
</tr>
<tr>
<td>Hypokalemia</td>
<td>(Brit.N.J. 3:646, 1972)</td>
</tr>
<tr>
<td>Subclinical aminoacidopathy, protein overload</td>
<td>(Lancet 1:914, 1966)</td>
</tr>
<tr>
<td>Endocrine Theories</td>
<td></td>
</tr>
<tr>
<td>Adrenal insufficiency</td>
<td>(J.Pediat.67:248, 1965)</td>
</tr>
<tr>
<td>Refuted by our cortisol data (Clin.Res.18:503, 1970)</td>
<td></td>
</tr>
<tr>
<td>Parathyroid deficiency</td>
<td></td>
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<tr>
<td>Anatomic Theories</td>
<td></td>
</tr>
<tr>
<td>Conduction system abnormality</td>
<td>(Am.J.Cardiol.22:479, 1968)</td>
</tr>
<tr>
<td>Disputed by Valdes-Dapena’s data (Am.J. Path.70:272, 1973)</td>
<td></td>
</tr>
<tr>
<td>Cartilage in conduction system</td>
<td>(Lancet 1:64, 1971)</td>
</tr>
<tr>
<td>Rare lesion</td>
<td></td>
</tr>
<tr>
<td>Aspiration of malformed uvula</td>
<td>(Schweiz.med.Wchnschr.97:62, 1967)</td>
</tr>
<tr>
<td>Impressive photo, but applies only to rare cases.</td>
<td></td>
</tr>
<tr>
<td>Aspiration of edematous uvula</td>
<td>(Munchen.med.Wchnschr.52:435, 1905)</td>
</tr>
<tr>
<td>Collapse of trachea</td>
<td>(Arch.Dis.Childhood 45:147, 1970)</td>
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Table 1 continued

Postinfectious dislocation of atlas
(Brit.M.J. 4:625, 1971)

Enlarged thymus

Choanal atresia Refuted (J.Pediat. 81: 1145, 1972)

Positional airway narrowing

Immunologic Theories

Anaphylaxis to intrauterine infection No abnormality of IgE
(Lancet 1:912, 1966) observed, no reduction in complement and
(normal cord blood-IgM normal cord blood-IgM. Our studies have not
shown evidence of mast cell degranulation.

Anaphylaxis to cow's milk
(Internat.Arch.Allergy 24:214, 1964)

Immune complex disease
(Lancet 1:210, 1972)

Reaction to immunization
(Nederl.Tijdschr.geneesk 108:2061, 1964)
(Deutsche Zischr.ges.gericht.Med.56:66, 1965)

Hypérimmunisation, "anti-antibody" Failure to find evidence of anti-antibody.

Anaphylaxis to nucleoprotein

Hypogammaglobulinemia Refuted (J.Pediat.63: 290, 1963 and Pediat-

Anaphylaxis to house dust mites
(M.J. Australia 2:1240, 1972)

Infectious Theories

Streptococcal sepsis
(New England J.Med.211:154, 1934)
(Brit.M.J. 2:1234, 1959)
Table 1 continued

Bacterial sepsis

Combined bacterial and viral infection

Coliform enteritis-endotoxemia
(Pediat. News 1:3, 1967)

Staphylococcal enteritis
(Deutsche Gesundh. 21:1441, 1966)

Bacterial pneumonia

Otitis media
(Deutsche med. Wchnschr. 86:2402, 1961)

Laryngotracheobronchitis

Bronchiolitis
(Deutsche Ztschr. ges. gerichtl. Med. 45:7, 1956)

Desquamative pneumonia
(Frankfur. Ztschr. Path. 69:314, 1958)
(Proceedings of the 8th International Congress on Pediatrics, 1956)

Interstitial pneumonitis
One of the commonest theories. Major problem is minor nature of the lesions.

Virus infections

Cytomegalovirus infection
(Frankfur. Ztschr. Path. 70:409, 1960)

Neurologic Theories

Diving reflex

Hypersensitive carotid sinus reflex with neck extension

Palato-glossal reflex
(M. J. Australia 2:292, 1970)
Table 1 continued

Arrhythmia due to autonomic immaturity
(AmJ. Cardiol. 22:469, 1968)

Dive reflex or laryngospasm due to aspiration of saliva

Apneic spells

Laryngospasm

Vasovagal reflex
(Arch. Pediát. 61:341, 1956)

Cervical cord lesion -- "Ondine's curse"
(J.A.M.A. 233:330, 1973)

Miscellaneous Theories

Cerebral "red substance"
(J. Forens. Sci. 9:157, 1964)

Nasal obstruction
(Arch. Dis. Childhood 46:211, 1971)

Fibrinoid laryngeal necrosis
(J. Forens. Sci. 3:503, 1958)

Hyperpyrexia
(Lancer 1:757, 1971)

Pulmonary thrombosis

Cerebral edema
(Paediat. Grenzgeb. 10:228, 1971)

Deranged eosinophile function
(Maryland M. J. 18:70 1969)

Chromosomal abnormalities
Table 1 continued

Maternal methadone addiction
(J.A.M.A. 220:1733, 1972)

Toxic follicle reaction
(Zischr.Kinderh.96:335, 1966)

Vascular injury
(Am.J.Path.25:730, 1950)

Myeloid leukemia
(Brit.M.J. 4:423, 1972)

Myocardial electrolyte distrubance

Genetic cardiac conduction defect
(Lancet 2:56, 1966)

Pulmonary surfactant deficiency
(Scarpelli, E.: The Surfactant
System of the Lung (Philadelphia:
Lea and Febiger, 1968)

We have only two heroin-addicted mothers and no known methadone addicts in our series.

Purely speculative -- one of the easiest theories to discard.

Cites sparse or absent surfactant layer in 20 S.I.D.S. lungs. However, the pulmonary edema fluid is clearly frothy in S.I.D.S. Also, edema per se can decrease surfactant.

Sudden Infant Death Syndrome: Psychosocial Aspects

Sudden Infant Death is premature, unexpected and calamitous. This image of death is particularly painful and poignant because the child is in most cases just beginning to develop a personality of his own. It scars our social and emotional reality and shatters our belief in a future in which potentials are realized and dreams are fulfilled. The innocence and trust which adults associate with childhood makes them feel that they have failed in some way to nurture
or protect the child who had died so suddenly and seemingly for no apparent reason. In Sudden Infant Death, the sudden transition of the infant from being alive and healthy to being dead shocks the senses of even professional participants let alone those whose lives will be permanently and more seriously altered.

For thousands of years, unexpected deaths of infants during sleep were attributed to overlaying by mothers or wet-nurses. An instance of this interpretation can be found in I Kings 3:19-20:

And this woman's child died in the night because she overlaid it. And she arose at midnight, and took my son from beside me, while thine handmaiden slept, and laid it in her bosom, and laid her dead child in my bosom.

Beckwith notes that Sudhoff, cited by Garrison, mentions a German placard, dated 1291, warning of the danger of suffocating infants by overlaying and forbidding mothers from taking infants under three years of age to bed with them (Beckwith, 1975).

It is not surprising that deaths of this type did not receive a great deal of attention in the pediatric works of early times. High infant and childhood mortality rates from currently preventable conditions such as infectious diseases and malnutrition attracted much greater concern and also conditioned people to a more casual acceptance of early unexpected death. Furthermore, throughout most of early recorded human history, deliberate infanticide by exposure or suffocation etc. was accepted practice, as illustrated in
Garrison's history of Pediatrics (Beckwith, 1975 p. 5). Thus, an infant death presumably due to overlaying was likely to be tolerated in most societies.

Based on this somewhat small and anecdotal mention of this type of death, we can only "presume that S.I.D.S. was a fairly frequent phenomenon prior to the 19th century" (Beckwith, 1975 p. 5).

The introduction of the thymic theory, that deaths hitherto believed to be caused by suffocation were attributable to an enlarged thymus, was a major step toward the development of a body of scientific literature on S.I.D.S. and also resulted in the appearance of several articles, suggesting a somewhat modern and humanitarian approach to the problem.

Berthold's (1898) paper cited in Beckwith (1975) suggests this new, more humanitarian attitude.

Gentlemen! it is known to you all, that not uncommonly one hears or reads of a previously healthy child found dead in his bed, and that these situations easily give rise to dreadful suspicions of gross neglect or even murder, especially when an illegitimate foster child is involved. The severest blame often descends upon babysitters, foster mothers, wet nurses and nursemaids when this horrible catastrophe occurs, as it is usually assumed that the young life was ended by suffocation in the bedding, which could have been avoided by due prudence (Beckwith, 1975 p. 6).

Grawitz (see Beckwith, 1975) describes such a case, in which a servant girl was entrusted with the care of an infant who was sleeping in its cradle near her. In the morning the previously healthy baby was found dead in the cradle. The
girl was imprisoned, and the authorities ordered an autopsy, which was performed by Liman and Grawitz. Liman was unable to disprove Grawitz' contention that death was attributable to a colossally enlarged thymus pressing on trachea, bronchi, and vessels. The magistrate released the woman.

The thymic theory persisted until the late nineteenth century when, with the acquisition of definitive normal data on the size of the thymus in health and disease, thymic explanations of death subsided into the background. As the thymic theory declined, blame again descended upon those persons caring for infants who died suddenly. An extreme example of this condemnation is Templeman's (1893) paper cited in Beckwith (1975). He claimed that from 1882-1891, in the town of Dundee, Scotland, 399 infants were reported to the police as having been found dead while in bed with their parents. Beckwith suggests that with an 1891 census of 153,587, this 'overlaying' death rate of forty per year is indeed impressive and perhaps implies that S.I.D.S. was more frequent than at the present time (Beckwith, 1975 p. 7). Beckwith further suggests that from Templeman's description of pathological findings, higher winter incidence and age distribution, "it is clear that the population was composed predominantly of S.I.D.S. cases" (Beckwith, 1975 p. 7). The point of Templeman's paper was that an unusually large number of deaths occurred on Saturday nights, which, he said was due to the frequency of alcoholic intoxication on Saturday evenings. Templeman was bitter in his accusations
of those parents and advocated harsh legal prosecution in cases where parents went to bed intoxicated. Since he was a police surgeon of Dundee, we can only imagine his attitude might have biased his courtroom testimony and resulted in cruel, unfounded miscarriages of justice.

Although there were a few short reports in the early twentieth century, suggesting that sudden unexpected infant deaths might be due to natural causes, the modern era of S.I.D.S. research was not ushered in until the landmark papers of Werne and Yarrow (see Beckwith, 1975). In a series of well documented papers produced between 1942 and 1953, Werne and Yarrow presented strong evidence of natural, and probably inflammatory mechanisms at work in many of these deaths, discounting suffocation. This research emanated, not from a research centre, but from the offices of coroners and medical examiners (Beckwith, 1975).

For sometime thereafter, the major contributions which led to the present interest and concern in S.I.D.S. came about as a result of the sacrifice and dedication of these persons. Recent work has accelerated and at present S.I.D.S. is generally considered to be a definite disease entity by various medical investigators, despite a lack of agreement as to its definition, terminology and etiology. Further to this, there has been a gratifying increase in the number of publications, both scientific and non-scientific on the subject.

An important result of this growing awareness and
concern is the proliferation of articles concerned with the impact of a S.I.D.S. death on the survivors. It is this social-emotional impact that is the major focus of this thesis and it is that area of S.I.D.S. literature which the researchers will now review.

The shock of an infant's death is perhaps greater today than in the past when childhood death was not such a rare event. Current social attitudes and practices surrounding death interfere with the ability of families to accept death as reality and work through their grief (Swoboda, 1976 p. 24).

Bergman (1972) suggests that, while much has been learned from research in the past ten years, little progress has been made in the handling of sudden infant death. Almost every parent whose infant dies in this fashion feels somehow responsible for the death. The sometimes callous and inhuman way sudden infant death cases are presently handled merely reinforces this guilt response and creates a large toll of broken people. Bergman goes on to describe how a typical S.I.D.S. case is often handled.

When an infant is discovered lifeless, a call for help goes out to the police or firemen. Frantic resuscitation efforts are undertaken while the shocked parents hover in the background. They hear thoughtless comments: "It looks like another case of suffocation," or "Probably choked on his food"...Police detectives come by to "just ask a few questions". "Did the baby give you any trouble?" "Could the other kids in the family have hit it?" Child abuse and S.I.D.S. are two separate entities, each with distinctive characteristics. Regrettably overzealous and misinformed investigators confuse the two without recognizing the tragic consequences for the parents. Sometimes an autopsy is performed, sometimes not. A coroner's inquest may be held. "What kind of care did you give this baby?" The verdict comes back - "death
by suffocation, "smothering", "overlaying", "aspiration". The results of the autopsy may come back in a week, in two weeks, a month, six months - perhaps not until a year later (Bergman, 1972 p. 776).

Bergman says that these actions or proceedings suggest crime, with the result that many parents of crib-death infants are inexcusably treated like criminals. Crib-death, he says is neither "predictable nor preventable" (Bergman, 1972 p. 777). Divorces, mental illnesses, the torment of guilt - all the unnecessary hurt that parents may experience is preventable. "What is needed is the humane handling of infant death cases" (Bergman, 1972 p. 777).

Margaret G. Norman, M.D. (1974), in describing the emotional impact of crib-death on parents, says that the impact can be devastating. Parents more often than not feel guilty and blame themselves or each other for the baby's death. They become depressed and angry because they do not understand how a seemingly healthy baby can die so suddenly without warning and without reason. She further says that parents very often become overprotective of their other children or may develop feelings of inadequacy in their capacity as care-givers to their surviving children.

Surviving children in S.I.D.S. families may blame themselves for their sibling's death or be afraid of dying in a similar fashion. These children sometimes revert to infantile behaviour. They seek reassurance and demonstration of parental love and concern. In short, they need their parents' presence to help them cope with their feelings'
regarding the death.

Norman says "Death is handled poorly in our Society" (Norman, 1974 p. 2). Parents often find others to be sympathetic but feeling uncomfortable or unable to talk with them about the baby's death. Neighbours, relatives or friends may in fact blame them for the death. Families need to be reassured that their grief reactions are normal and will gradually subside or be resolved.

Pomeroy (1969) having visited and talked with some 130 S.I.D.S. families while acting as a project nurse attached to a S.I.D.S. research team, discusses the impact of the death on the family. She says that "generally, we find that women need to talk it out; men want to try to forget it" (Pomeroy, 1969 p. 8). Often, discomfort or signs of friction between husband and wife surface during interviews with families. Problems, existent before the death of the child, may be intensified by the death crisis. She suggests, as other writers do, that family members may blame each other and that divorces apparently related to the S.I.D.S. death do occur.

Pomeroy notes that parental reactions can be further complicated when the baby has died while in the care of a babysitter. They may blame the babysitter or agonize over having left the baby with a sitter.

The characteristic suddenness of S.I.D.S. catches parents entirely off-guard and unprepared to deal with death. As a result, their grief reaction, although typical
of the classic grief reaction described by Lindemann (1965) in his work "Symptomatology and Management of Acute Grief", is somewhat unique. Parents frequently have difficulty concentrating, the mind wanders, reading or writing may become almost intolerable, some even think they are "going crazy". Another common reaction noted by Pomeroy is the fear of being left alone in the house where the baby died. Pomeroy cites a particular incident:

One young mother was sitting on a tree stump in the backyard when I visited. After the interview, she went right back outside because she "couldn't bear to be in that house alone" (Pomeroy, 1969 p. 9).

Loss of appetite, insomnia and time confusion have been noted. Despondency, expressed as a loss of meaning in life may occur. Occasionally, there is a failure to accept reality. Pomeroy notes that some mothers have continued to prepare the baby's food or fix his bath for a time after the death. Anger and guilt are generally all pervasive.

Children in a family are going to be affected in some way by such a death as this, says Pomeroy. Toddlers are too young to comprehend what has happened, but will feel the family's emotional turmoil and will need the security of lots of love and affection from the parents. They may have a fear of being taken away as they have been told that this is what has happened to their deceased sibling.

Relatives are not always understanding. They have been known to suggest that the baby must have been sick or
neglected in some way.

Pomeroy also presents some interesting observations in regard to her interviews with unmarried mothers. She says that "one might suppose that the unmarried mother would not be as deeply affected and might even feel a certain amount of relief when S.I.D.S. occurs. But this is most decidedly not the case" (Pomeroy, 1969 p. 10). The unwed mother chooses to keep her baby and raise him or her alone. This is far from easy. She organizes her life to a large degree around this decision and suddenly the need is no longer there. She may be left desolate, without support of family or friends. Illegitimacy may be used by others to degrade her, thus compounding any guilt feelings or blame she is already experiencing.

Davis (1975) says that "S.I.D.S. usually presents the surviving family with an emotional crisis of enormous proportions" (Davis, 1975 p. 648). He, too, reports on the universality of feelings such as guilt, shame, fear and anxiety. The disability that can occur when the grief process is retarded, prolonged or denied has been well documented in Lindemann's description of the survivors of victims of the Coconut Grove fire. This has provided an awareness for psychiatrists, says Davis, of the impact of an unexpected death on family members.

The psychiatric damage occurring in S.I.D.S. families is often considerable. Parents have been submitted to exhaustive examinations by police, firemen or neighbours
concerning the death of their child. Accusations of child battering, abuse or neglect are not uncommon and parents have occasionally been jailed or indicted for murder. Even under the best of circumstances, says Davis, parents may be "told erroneously that their child died of pneumonia, implying that the parents were negligent in not having the child examined and treated by a physician" (Davis, 1975 p. 648).

Parents are not the only victims, notes Davis. Siblings may be implicated because parents need someone to blame. Displacement of anger by parents onto the deceased's siblings is not uncommon. Psychiatric patients have been treated, who recall as an extremely traumatic experience, the death of a brother or sister many years earlier, probably from S.I.D.S.

Davis, quoting Caplan, points out that

Primary prevention is a community concept. It involves lowering the rate of new cases of mental disorder in a population over a certain period by counteracting harmful circumstances before they have a chance to produce illness (Davis, 1975 p. 649).

This indicates, says Davis, that S.I.D.S. is a classic example of how crisis intervention by mental health professionals can prevent future emotional breakdown or illness from occurring. Early crisis intervention, including factual information about S.I.D.S. and the performance of an autopsy (and informing the parents of its results as soon as possible) are keys to the prevention of subsequent emotional illness in parents and siblings.
Green (1974) says about the handling of unexpected infant death by doctors:

It is a time-honored tradition of pediatrics and family medicine not only to treat disease but also to practice preventive medicine on a personal basis. The practitioner of child health is thus committed both to forestalling sudden unexpected death in infants and children through attention to accident prevention, and to minimizing the secondary psychological disability that often afflicts surviving members of the family when a child does die (Green, 1974 p. 113).

In discussion of parental reactions to the sudden unexpected death of a child, Green suggests that "the physician's role often extends far beyond the period immediately after death" (Green, 1974 p. 114). This again points up the necessity for openness and understanding in dealing with these grieving families.

I never remember being prepared during my training about what to say to a family whose child has died. I do have a vivid memory of my instruction as an intern on how to obtain permission for an autopsy on my first patient who died. My resident told me, "Go in and get the autopsy permission signed" (Bergman, 1974 p. 115).

Bergman is speaking here of the general lack of preparation of student doctors in terms of dealing with death and its survivors.

Sudden unexpected death, including S.I.D.S., allows no time for preparation. Bergman (1974), quoting from Friedman, says that the impact of this kind of death is "intense, disruptive and almost intolerable" (p. 116). Bergman goes on to say, that an understanding of normal grief reaction is essential if the physician is to fulfill
his obligation to comfort as well as cure.

In the course of dealing with some 1,000 S.I.D.S. families, Bergman says he has learned to appreciate the family's point of view regarding the physician's management of these deaths. Overall, he says, his profession does not come away with high marks. Complaints are numerous. Some common complaints Bergman has personally encountered are: "I couldn't reach my doctor". There is every indication that those who cope best with crib death do so at least in part because they were attended throughout by their family physician. He suggests that, because of an inverse relationship between Sudden Infant Death and socioeconomic class, a large number of families lack any personal physician and tend to suffer the worst consequences, having to cope with faceless emergency room staff.

Another complaint is: "I reached my doctor but he said there was nothing he could do and wouldn't come". Bergman suggests that this kind of inaction by a physician is blatant malpractice. The fact that the physician may be frightened at his own inadequacy in dealing with this kind of death does not excuse this kind of behaviour.

"The doctor told us an autopsy wasn't necessary — it wouldn't show anything". "The doctor told me my baby died of crib death but something else was written on the death certificate". "I didn't understand all that scientific stuff he was explaining to me". "He kept wanting to tell us about his experiences with crib death rather than listen to ours".
"He told me to get pregnant again right away". "When I took my other child to be checked, the doctor didn't even mention the child who died of crib-death". "We didn't get any help with what to say to the other children". These are all common road blocks of parents dealing with doctors, says Bergman.

As part solution to these problems and as an organized approach to dealing with S.I.D.S., Bergman recommends that information and counselling be provided for all such parents by specially trained public health nurses. He suggests that the training need not be particularly elaborate, it merely involves learning some basic facts about S.I.D.S. and its attendant grief reactions. Pediatricians should take the lead, he says, in insisting that co-operative programs exist in each and every community, involving the coroner's office and the health department, to deal with this urgently needed service for all families.

In summary, Bergman suggests, as did Davis earlier, that "no greater opportunity for preventative psychiatry exists than in the management of Sudden Infant Death Syndrome" (Bergman, 1972 p. 120). Of great importance is the necessity for the physician to feel comfortable with his own feelings about death and a desire to function as a person who comforts as well as heals.

Merritt (1975), commenting on the role of the emergency room physician in S.I.D.S. cases suggested that when confronted with such a case, "no matter how busy he is,
he then must assume several responsibilities" (p. 1096). Grieving parents need to be informed with sensitivity of the presumptive diagnosis and assured that they were in no way responsible for the baby's death. They should be told of the sensibility of an autopsy. Often the greatest service a doctor can render is that of his immediate and attentive presence and his further availability to parents if the need should arise later, to talk with him again. Because of the torment and frustration created by the death and the lack of an explanation which will relieve the parents' confused feelings, communicative relationship becomes of vital importance, says Merritt.

Segal (1974) reports observations similar to those of Pomeroy and other heretofore mentioned writers. To inability to concentrate, inability to sleep and a feeling of going crazy, he adds chronic fatigue, muscular problems or other physical symptoms related to the stomach or heart. Some mothers, Segal says, have reported that their arms ache to hold their recently deceased baby. There may be an urge to run away and unreasonable fear of danger. Parents experience constant anxiety about the care of other children yet they may draw away from caring for them. The physician, according to Segal, has a definite role to play from the moment a S.I.D.S. death occurs. Because the cause is unknown, the physician needs to guard against creating any further confusion or guilt. He should, if at all possible, try to be the one to inform the parents of the death. Both
parents should be seen together, if possible. The physician should not run the risk of allowing one parent to inform the other, if it can be avoided. Often the beginnings of parents blaming each other can be traced to one parent being left alone to tell the other.

Segal, like Bergman, lists common parental complaints and suggests that the clearest facts available be interpreted as quickly as possible to the parents. He too, suggests that perhaps the greatest contribution a physician can make to helping parents cope is to be present when he is needed and to remain involved and concerned. He further recommends being available for follow up interviews or arranging such interviews with parents a few weeks after the initial critical period.

In summary, Segal states that perhaps the most emotional damage to families happens as a result of ill-timed but innocent and inadvertent remarks.

Salk (1971) says that in crib-death, the "survivors are the real victims and they outnumber those who die." (Salk, 1971 p. 248). He goes on to say that the impact of the trauma of S.I.D.S. is intensified because parents are generally still in a state of excitement over their new born child when the death occurs. Salk points out that, aside from the sense of loss and inevitable grief that the crib-death experience brings to families, the experience also causes a "modification in attitudes which tends to be permanent and to affect all subsequent behaviour" (Salk, 1971
Helmrath and Steinitz (1976) conducted a study involving seven families who had lost an infant. It is not possible to report at length on this study titled "Death of an Infant: Society Fails Parents", because the researchers were not able to locate a copy of the study and are only aware of the existence of this study as a result of having encountered a short abstract mentioning the study in pediatric literature. The abstract reported that, in the cases investigated for the study, friends and relatives viewed the dead child as replaceable. They tended to desert the family after the death, leaving no one to deal with the emotional residuals of the death. Emotional problems were reported to be common in the seven families used for the study.

The review of the literature has been of major importance in terms of helping the researchers to formulate the methodology for this study.

Crisis literature has identified death as a legitimate human crisis in which emotions run high and the psychological damage to survivors can be devastating. The impact of a death crisis on survivors, in many cases can be lessened by immediate intervention on the part of caring and knowledgeable individuals such as friends, relatives, health professionals and clergy.

The literature related to death and bereavement has indicated that in our modern North American society,
death is still for the most part a taboo subject. People have great difficulty handling feelings relating to death. Because death strikes suddenly and indiscriminately, they are seldom ready for it and attempt to avoid the reality of its impact. Death is hidden and disguised. It is dealt with directly only through established rituals such as the funeral process. Survivors attempting to cope with loss through death are generally given little time to grieve and are supported through this grief by others for only that period immediately following the death. Prolonged displays of distress by survivors usually result in their being isolated and ridiculed by others or, worse, they may be considered to be abnormal and treated as if they had a psychiatric aberration.

Death is real and inevitable and, as a society, we need to be more realistic in our handling of death. Our society has bureaucratized death through hospitals, the legal system, funeral homes and other organizations.

Bereavement is a process with no specific time limits and no definite reaction or response patterns. Response to bereavement affects a person's whole way of being for a time. Any combination of feelings may be manifested and physical illness and emotional breakdown are common in the bereavement process. Anger and protest reactions are mentioned by a number of writers as common grief responses.

Special consideration was given to the impact of
the death of a child on parents and other survivors. Feelings of parental guilt, responsibility, shame, disgust, anger; of being isolated, ignored and blamed, have all been noted as common to this particular kind of death loss.

The literature specifically concerned with S.I.D.S. seems to tie together many of the concepts presented in the crisis, death and bereavement literature. Parental responses to crib death as described by authors of S.I.D.S. literature, show that parents manifest emotions such as extreme guilt, anger and confusion. These parents receive little help or concern beyond the funeral process. The impact of crib death is perhaps uniquely stressful because, as epidemiological studies have shown, there is as yet no known cause of death and also because the death of a child or infant has become a somewhat rare event, one that causes concern and suspicion in our society.

Bowlby (1969), (1973), has developed theories of attachment and loss which have provided the foundation for much of the conceptualization of loss, grief and bereavement that the researchers encountered in literature on death and its impact. Hence, Bowlby's work provides the theoretical backdrop for this study.

From the review of the relevant literature and in keeping with attachment and loss theory, the researchers formulated the following research questions:

1. What are the readily observable points
of stress for the family surrounding a S.I.D.S. death?

2. What might the contributing factors to these points of stress be?

3. What types of intervention did the families feel were helpful?

4. What is the impact of a S.I.D.S. death and subsequent intervention on the family?

The rationale for these research questions will be discussed in detail in the following chapter.
CHAPTER III

RESEARCH DESIGN AND METHODOLOGY

The research design of a study serves to clarify the method by which the researchers plan to conduct their research once the problem has been formulated and refined.

A research design is the arrangement of conditions for collection and analysis of data in a manner that aims to combine relevance to the research purpose with economy in procedure (Selltiz, Jahoda, Deutsch and Cook, 1959 p. 50).

The research design is dependent upon the purposes and classification of the study and helps to lend further focus to the study.

Classification

Research may be conducted for a variety of purposes. The research purposes to which this study has addressed itself are:

1) to gain familiarity with a phenomenon or to receive new insights into it...in order to formulate a more precise research problem or to develop hypotheses; and (2) to portray accurately the characteristics of a particular individual, situation, or group... (Selltiz et al., 1959 p. 50).

The purposes of this study have led the researchers to select the classification of exploratory research, sub-type exploratory-descriptive (Tripodi, Fellin and Meyer, 1975 p. 21) for the study. There is a dearth of research literature on the psychosocial aspects of Sudden Infant Death Syndrome.

64.
and, because of this, the researchers felt that it would be most appropriate to gear their research efforts toward describing objectively the situation of families who experienced a S.I.D.S. death and gaining some new insights into the situation with the goal of establishing some priorities for future research (Selltiz et al., 1959 p. 51).

Within the realm of exploratory research, three methods are commonly used in order to search out information which is relevant to the research purpose and "insight-stimulating" (Selltiz et al., 1959). These methods are: a review of the related literature in the area selected for study, a survey of people who have practical experience with the subject of the study and an analysis of insight-stimulating examples (Selltiz et al., 1959 p. 53). The researchers have selected the second of these methods, using a sample of families who have experienced a S.I.D.S. death within the recent past and gathering information about their experiences and perceptions as they related to their own situation.

Assumptions

The researchers made several assumptions which have a bearing both on the research questions and methodology. These assumptions are:

1. That the sudden unexpected death of an infant would cause a situation within a family which would be defined as a crisis by that family.
2. That the effect of the death on the family would be such that recollection of the events and feelings surrounding those events would be reasonably accurate for a period of five years after the death.

3. That the recollection of some family members about the reactions of other family members would have some reliability.

4. That people have insight into their own experience.

5. That the interview schedule is a valuable research tool for investigating the S.I.D.S. family experience.

Population

The population for this study consisted of all the families in Essex and Kent Counties who have experienced a S.I.D.S. death within the past five years. However, the exact size of the population was unknown because centralized records did not appear to be kept and time did not afford the researchers the opportunity to perform a thorough search of hospital records. There also appeared to be situations whereby the cause of death which was given verbally to the family did not match the official cause of death which appears on the death certificate.

The Sample

The sample for this study was a non-probability
sample in that no attempt was made at randomization. The population for this study was unknown and, as such, representative sampling procedures could not be used.

The sample was purposive in that the subjects were chosen contingent upon their meeting the requirements of the study in the hope that they could provide the researchers with new insights into the subject under study.

Exploratory research is often not amenable to representative sampling procedures (Tripodi et al., 1969) and the major result of this is that the findings of the study cannot be generalized to a larger population.

The sample for this study consisted of those families who voluntarily responded to an advertisement which appeared in The Windsor Star on March 19, 25 and 26 and those families who were known to and contacted by the Windsor-Essex representative of the Canadian Foundation for the Study of Infant Deaths and who agreed to participate in the study. All available members of the family who were in the family at the time of the child's death were interviewed. The researchers felt that this combination of procedures, although not the original intent of the researchers, allowed for some variation within the sample and allowed the researchers to select subjects who were most likely to provide some new insights into the situation under study. "Social scientists who work with this approach have frequently found that the study of a few instances may produce a wealth of new insights..." (Selltiz
et al., 1959 p. 61). This was the hope of the researchers.

Research Questions and Definition of Terms

In order to give some direction to the study, the researchers discussed and subsequently discarded several research areas. One of the first areas discussed was the perception of the services delivered to S.I.D.S. families as perceived by both the families involved and various professionals in the community. Another area which was discussed was the area of the differences and similarities between S.I.D.S. experiences and other death experiences. Both of these areas were discarded in favour of a more extensive look at the specific experiences of S.I.D.S. families. The researchers felt that since a study of this nature had not been attempted in Canada to the best of their knowledge, it would be more appropriate to explore the experiences of S.I.D.S. families in depth prior to making any comparisons with other experiences.

As a result of this desire to focus on the specific experiences of S.I.D.S. families, the following questions were formulated for research:

1. What are the readily observable points of stress for the family surrounding a S.I.D.S. death?
2. What might the contributing factors to these points of stress be?
3. What types of intervention did the families
feel were helpful or would have been helpful?

4. What is the impact of a S.I.D.S. death and subsequent interventions on the family?

The question of "impact" is omnipresent in the study and the question was asked as it related to the total experience of the family as well as each point on the experience continuum. For the purpose of the study "impact" was defined as "a noticeable behavior change in one or more family members or a verbal or non-verbal expression of intense feeling surrounding the death or the circumstances before or after the death".

The second concept is "Sudden Infant Death Syndrome". Because the exact nature of S.I.D.S. is as yet unknown, a formal definition was not attempted. For the purposes of this study, Sudden Infant Death Syndrome was defined as "a death occurring in a child between the ages of three weeks and eighteen months where the child died in sleep with no signs of struggle and where there were no indications of previous ill health, abuse or neglect by parents or guardians. This definition will include all instances where parents or guardians were informed by medical personnel that the child died of crib-death or cot-death, whether or not any of these diagnoses appeared on the death certificate".

The next concept which originates from the research questions is the concept of "family". "Family" is defined as "a unity of interacting persons that is close and
enduring enough to sustain a sense of commonality" (Broom and Selznik, 1968 p. 32).

For the purpose of this study, "family" was defined by the following situation: any person or persons living under the same roof who had guardianship of the child at the time of death and any child living with these persons subsequent to the S.I.D.S. death.

Another concept is the concept "points of stress". "Stress" is defined by Dr. Hans Selye (1974) as "the nonspecific response of the body to any demand made upon it" (p. 27). For the purposes of this study, a "point of stress" was defined as "any event, recollection, or behaviour on the part of any person which has an impact on a family member, as recounted by that family member or another family member".

The next concept is the concept of "contributing factors". The researchers do not feel that a formal definition of this concept is appropriate to this study and therefore, for the purposes of the study, a "contributing factor" is defined as "any attitude, belief, value, statement or behaviour of any person in relation to the death which is defined by a family member as having brought about or been associated with a point of stress and which is recounted to the researchers."

The concept of "intervention" which arises from the fourth research question was defined for the purposes of this study as "any behaviour or series of behaviours
performed for the child or the family by any of the following people: doctors, nurses, medical attendants, social workers, funeral directors, clergy, insurance agents, police, firemen, ambulance attendants, employers, relatives and friends. These behaviours may have occurred prior to the death or following the death.

For the purposes of this study, the concept of "helpful" will be defined as "assisting in the process of coping with the death of the child in the opinion of a family member". A "helpful behaviour" will be "one which is felt by the family to be of value to them".

Data Collection Procedures

The two major means by which data may be collected for an exploratory study are the questionnaire and the research interview. The advantages of the research interview are that it permits a greater depth of questioning, permits probing to obtain more complete data, allows for the establishment of a rapport with the respondents and provides a means for checking the effectiveness of the communication between the interviewer and the respondent (Isaac and Michael, 1974 p. 96).

The disadvantages of the research interview, as opposed to the questionnaire, are that it is expensive and time-consuming, it requires training on the part of the interviewer, and it may introduce subjective bias, eliciting responses that are more inclined to please the interviewer.
than to be honest (Isaac and Michael, 1974 p. 96).

The researchers selected the semistructured (Isaac and Michael, 1974 p. 96) interview as the most appropriate method of data collection for their study. The interview was built around a series of "core" questions which relate to the research questions. The researchers felt that, because they were dealing with sensitive issues in some cases, it was desirable to allow as much flexibility as is possible within the interview structure. The core questions were designed to lend focus to the interview but allow for further probing into what appeared to be other significant areas. The interview also allowed for the establishment of a rapport between the interviewers and the respondents and the expression of acceptance, empathy and support by the interviewers. Since the subject matter of the interviews might have been painful for the respondents to deal with, the researchers felt that it would be unwise and unethical to delve into such areas without offering support, counselling or referral opportunities. In order to facilitate further a rapport with the respondents and minimize feelings of fear and defensiveness, the researchers had the representative from the Canadian Foundation for the Study of Infant Deaths make the initial contact on behalf of the study with those families who had previously dealt with the foundation representative. Those families who responded to the newspaper advertisement were contacted initially by the
researcher who is himself a S.I.D.S. parent in the hope that this would facilitate the development of a rapport with the respondents. The initial contact also had the purpose of detailing the interview procedure in order to prepare the respondents for the interview.

Since the area of this study was relatively unexplored, the researchers felt that the flexibility of the semistructured interview would allow unanticipated subject material to surface.

Because the study was done as a Master's thesis and the researchers were not being paid, the element of expense was not a factor in the consideration of which data collection instrument to use. The researchers felt that the time consumption aspect of the interview schedule would be in part offset by the small sample size. Both researchers had received extensive training in interviewing and this in part led to the selection of the data collection instrument.

Bias was a problem which the researchers felt warranted some consideration. In an effort to minimize subjective bias on the part of the researchers, the following steps were taken:

1. Both researchers were present at all interviews. One researcher conducted the interview while the other observed and made notes about significant exchanges between family members and the family and the interviewer.
2. All interviews were tape recorded with the permission of the respondents.

3. The interview schedule was pretested and changes were made where suggested by the respondents, the researchers or the thesis committee.

4. The semistructured form of the research interview was used to minimize subjective bias through selective questioning.

Throughout the interviews, the researchers paid close attention to the emotional reactions of the respondents and, in all cases, the needs of the family superceded the needs of the researchers for information.

The instrument itself was constructed around the research questions. Because the researchers are interested in recalled experiences, the instrument was designed so that the questions are in chronological sequence from the time of death of the child to the time of the research interview. The core questions centered around the effect of the death on family relationships, the respondents' feelings about those people with whom they came in contact following the child's death.

The instrument was constructed so that major open-ended questions were asked in four main areas: the time of the child's death, the hospital experience (where applicable), the funeral and burial of the child, and the family experiences during the time following the burial.
Data Analysis

The data gathered in this study was, for the most part, non-quantifiable. The information gathered was grouped according to categories outlined in the research design and a description of the material within each category was given.

Since the purpose of the study was to describe, descriptive statistics such as frequency were the only ones used. One attempt was made at correlation but it was found that the data collected was not amenable to this type of analysis.

The information was described both verbally and in chart form. Analysis from the descriptive material took the form of comparison of the data with that which was reported in the available literature.
CHAPTER IV

PRESENTATION AND DISCUSSION OF FINDINGS

As has been previously mentioned, the researchers decided to present the data in a case history format. The case histories presented in this section were drawn from the taped interviews with respondents. Of the twelve respondents who were originally suggested to the researchers, two were vacationing and were unable to be reached. The sample then consisted of ten families. In five cases, both husband and wife were present for the interviews.

No respondent who was contacted by the researchers declined to take part in the study.

The case histories in this section are presented in chronological order and as such do not represent the order of questioning in all cases. Direct quotations from the interviews have been added where appropriate in order to give an idea of the feeling tone of the responses.

Following the case histories, the data has been grouped according to experiences and the frequency of occurrences is noted.

The final section of this chapter is devoted to an analysis of the data, including a comparison of the experiences of the respondents in the study with the experiences cited in the available literature. An attempt to answer the four research questions outlined in Chapter Three is
also contained in this chapter.

Within the text of the case histories, the researchers have added punctuation and words where the responses were given in incomplete sentences.

It should also be noted that in the designations for the cases, the letter "I" has been eliminated to avoid confusion with the rest of the text.
CASE #1 (Mr. & Mrs. A.)

Mr. and Mrs. A. were a couple who lived in a rural area of Essex County. They lost a male child to S.I.D.S. in March, 1974. The child was approximately three months old at the time of death. At the time of the child's death, the family consisted of Mr. and Mrs. A., a five year old daughter and a two year old son. This was the second marriage for both marital partners. Mr. A. had three children by a previous marriage but they were not living with the family at the time of the death. Both older children in the family were Mrs. A.'s from her previous marriage. The child who died was the only child between Mr. and Mrs. A. Both Mr. and Mrs. A. were pleasant throughout the interview and responded to the questions with a moderate amount of affect. The other children were present during the interview but did not participate.

Mrs. A. described her pregnancy as normal with nothing remarkable except that the child was her largest. The child was born two weeks before the due date but labour was not induced. Mr. and Mrs. A. had decided to have one child between them and everyone in the family was happy to have the child. After the birth of the child, Mrs. A. had a tubal ligation performed.

The child died on a Saturday morning. Mrs. A. recalled that she was awakened in the early morning by her two year old son who had wet his bed. She changed her son, checked on the baby, put the soother back in the baby's mouth and returned to bed. Mr. A. arose at 7:30, looked in on the baby briefly and saw him "laying still". He figured that things were alright and went to take a bath. After his bath, Mr. A. woke his wife. Mrs. A. recalled that when she got up, she could sense that there was something wrong and said to her husband that something was wrong with the baby. Mrs. A. went into the bedroom to check on the baby. She knew as soon as she saw the baby that he was dead. He was already beginning to stiffen as Mrs. A. recalled. Mrs. A. was unable to touch the baby. "I despise death and I don't handle it very well" is the way she put it. Mrs. A. described her first reaction as shock and she stated that her memory was fuzzy on exactly what she did at that point. She did recall however that she ran to call the doctor. Mr. A. went in to see the baby and recalled that the baby's face had begun to turn blue. "I knew it was dead but I still wanted to hold it" was Mr. A.'s first reaction. He held the baby for a few moments then put him back in the crib but did not cover his face as he thought that there "still might be some hope". Mrs. A. reached the doctor's wife by phone and was told that the doctor would call right back. The doctor returned, Mrs. A.'s call some fifteen minutes later and
arrived at the A's house very shortly thereafter. After calling the doctor, Mrs. A. called her mother and sister and also a girlfriend to ask if she would come and take the children for a while. Mr. A.'s reaction at this point was that he had to calm his wife down. He took her into the kitchen and then went to get the children ready to go with his wife's girlfriend.

The first person to arrive at the house was the doctor. Mrs. A. remained in the kitchen with the children while Mr. A. followed the doctor into the bedroom. Mr. A.'s recollection of that event was that the doctor did not spend much time examining the baby. After the examination, the doctor covered the baby's face and confirmed that the baby was dead. He said that he could find nothing wrong with the baby and mentioned the possibility of crib death. The doctor also said that he could not give the exact cause of death because he was not the coroner. He said that the police would have to become involved as a "routine" procedure. The doctor then left.

The first time that one of the children noticed the death was shortly after the doctor left. The five year old daughter noticed that the baby's face was covered and asked her mother why. Mrs. A.'s response to this question was "he has gone to visit baby Jesus. I'll talk to you more about it later". Mrs. A. recalled that her daughter appeared sad but did not shed any tears. Mrs. A.'s mother, sister and girlfriend arrived shortly thereafter and the children went with Mrs. A.'s girlfriend. The family sat in the kitchen and did not say much to each other.

The police arrived at approximately 11:00 A.M. and proceeded to measure the height of the ceilings, check for gas leaks and check the baby's formula. Mr. A. recalled that he was very bothered by the police "investigation". He stated that, at that point, he knew nothing about crib death and was wondering if he had done anything which might have caused the baby's death. While his wife and her relatives stayed in the kitchen, Mr. A. followed the police around and asked questions about what they were doing. The police sensed that Mr. A. wanted to talk and they proceeded to give a running account of everything that they were doing. Mr. A. found this helpful. He also recalled that one of the policemen mentioned crib death but he could not recall the exact context. The police had Mr. and Mrs. A. sign a permission to perform an autopsy. The police then left and the baby was taken to a hospital for the autopsy. However, the autopsy was never performed, although both Mr. and Mrs. A. were in favour of one.

Mr. and Mrs. A. went to make the funeral arrange-
ments that afternoon. The funeral director was described by the A's as very helpful. He "took right over" and made suggestions about what arrangements should be made. The funeral director suggested that the funeral take place the next day. The A's found this helpful in that they did not feel they wanted to "prolong the hurt". The funeral director also suggested that Mrs. A's parish priest not officiate at the service because it was the second marriage for both partners and because Mrs. A. was Roman Catholic and her husband was not. It was agreed that Mr. A's minister would officiate. The A's found this helpful in that they did not feel that they could have endured any "hassle" which they might have received from Mrs. A's parish priest. The funeral director made all of the arrangements for the service and the A's found this very helpful as neither partner was in a suitable emotional state to make the necessary arrangements. The only arrangement that Mrs. A. did not approve of was the open casket. For reasons which she did not explain, Mrs. A. stated that she wanted a closed casket but "they wouldn't do it for me". While they were at the funeral home, Mr. and Mrs. A. had the opportunity to talk with one of the directors who had done some studying in the area of S.I.D.S. Both Mr. and Mrs. A. found it extremely helpful to obtain information which they felt they needed badly.

While Mr. and Mrs. A. were away at the funeral home, one of Mrs. A.'s girlfriends went to the house and packed up all of the baby's things. Mrs. A. stated that she "couldn't have gone back to that" and was thankful that the baby things had been removed when she arrived back home.

The baby was "laid out" on Saturday night and friends and relatives came in. Mrs. A. recalled that she was bothered by people who came up to her and really didn't know what to say. Mrs. A. said "I can't stand mourning" and "I would rather have been left alone". She also recalled that some friends couldn't look at the baby. Mrs. A. took them over to the casket and said "don't remember him that way". Mr. A. recalled that he found it helpful that some people came to him and began to reminisce about times when the baby was alive.

The funeral was held the following day with relatives and friends in attendance. By agreement of both parents, the children did not attend. Mrs. A. stated that the burial was the most difficult time for her because "I knew I would have to leave him. That's when I really broke down". Mr. A. recalled that he also was on the verge of breaking down at this point and handled this feeling by directing all of his energy to consoling his wife. Mrs. A. recalled that this activity by her husband was helpful.
"He was there to help me, the words I can't remember but they really helped". Following the funeral, friends and relatives went back to the house and both partners found that helpful.

In the months following the funeral, several experiences stood out in the minds of Mr. and Mrs. A. Two days after the baby's death, Mrs. A. went to see the doctor to see if she could get some sleeping tablets as she hadn't been sleeping at night. The doctor spent a good deal of time with her, and explained in detail the nature of S.I.D.S. He also made a special point of telling her that there was nothing she could have done to prevent the baby's death. Mrs. A. stated that she found both the explanation and the reassurance that she was not to blame very helpful. Mrs. A. recalled that she cried only for a few nights after the baby's death and, after the doctor's reassurance, harboured no feelings of guilt. Mrs. A. attributed part of her lack of crying to her feeling that she had to remain "strong" for the sake of her children. She also attributed her adjustment to the support which she received from her husband. Mr. A. recalled that shortly after the death, he and his wife would sit up all night and talk and cry together. He found it helpful to talk about the sharing which had taken place in the care of the baby and the happy times which they had spent with the baby. Mrs. A. also recalled that she went out immediately after the death and had some pictures which had been taken of the baby developed.

Three weeks after the death, a local television station broadcast a special on S.I.D.S. and, although they had been advised by their friends not to watch, both Mr. and Mrs. A. felt that they wanted to see it. Both stated that they had been helped a lot by the broadcast as it allowed them to see other families who had not reacted as well to the death. Mr. A. made the comment that he felt reassured by the fact that he and his wife had been able to talk about the experience rather than closing off communication or blaming one another the way that other couples had done.

The topic of the baby's death has not come up often in family discussions but the children were brought to the cemetery whenever the parents went. Visiting at the grave has been infrequent for the A.'s and Mrs. A. stated that they make no special point of going. Mrs. A. recalled that her religious beliefs were helpful, particularly in explaining the death to the children. Christmas is celebrated as the birthday of baby Jesus and their baby's birthday although he was actually born three days after Christmas. The children have not asked many questions about the death of the baby, and according to their parents, have shown no
ill effects as a result of the death.

Mr. A. changed jobs several times during the period which followed the death. His brother was killed six months after the death of the baby and his wife recalled that he "exploded" following that experience. Mr. A. had five appointments with the family doctor in the five weeks following his brother's death and he felt that it helped him to talk about both experiences with the doctor.

Mrs. A. recalled that a month before the interview, a girlfriend who had never talked about the death came over and broke down while talking about it. This friend was pregnant and terribly worried about the possibility of her child dying of S.I.D.S. Mrs. A. made the comment that "a lot of our friends still can't accept it".

The A.'s felt that the experience had affected them in a number of ways. Both partners stated that they felt the experience brought them closer together. Mr. A. made the statement "we had something together and we lost it, now all we've got is each other". Both partners agreed that they have gone out more as a couple since the death and have spent more time together. Mrs. A.'s individual reaction to the experience was that it had made her stronger and helped her to grow a little. She said "I don't take things for granted anymore". Mrs. A. stated that she had no regrets about having the tubal ligation. Her reaction was "I'm glad I had him and I'm glad I don't have any more. When I see a baby I like to go over and hold it but I'm glad he's going home with his mother". Mr. A. stated that he has had similar reaction with regard to other children. He said "when there is another baby in the house, I like to pick it up and play with it. I don't compare it to our baby but seeing another baby brightens me up; it brings back good memories". Mr. A. stated that he does not feel hurt for himself anymore but it makes him feel bad when he hears about it happening to someone else.

In retrospect, Mr. and Mrs. A. felt that it was helpful for them to be able to talk to each other, to the doctor and to friends and relatives who were there throughout the experience. They appreciated the information which they received from the funeral home, the doctor and the television special. They also appreciated the practical matters which were handled for them by the funeral director and some of their friends.

The unpleasant experiences which the couple recalled were the police investigation, the funeral home visiting (Mrs. A.) and the reluctance of friends to come around after the death.
When asked for recommendations, Mr. and Mrs. A. gave the following:

1) Mr. A. suggested that people would be helped to talk about the experience. "You can’t get rid of the sorrow but you can ease it a little".

2) Mrs. A. suggested that it was important that parents not blame themselves or each other and she suggested that others should reinforce this with the parents.

3) Mr. A. suggested that it was important for professionals to take time to talk with the family. "They always seem too busy".

CASE #2 (Mr. and Mrs. B.)

Mr. and Mrs. B. lived in the city at the time of their child’s death. The baby was a male who died in August, 1974 at the age of five weeks. At the time of the baby’s death, the family consisted of Mr. and Mrs. B. and a one and a half year old boy. The couple has since had another male child who was fourteen months old at the time of the interview. Mr. and Mrs. B. were pleasant throughout the interview and responded with a moderate amount of affect. Mr. B. tended to show and express more tenderness in recalling the experience than his wife and Mrs. B. tended to show and express more anger.

Mrs. B. recalled that the dead child was the most difficult of her three pregnancies, with more nausea and back pain than the other two. The baby was carried to full term, labour was not induced and the baby weighed nine pounds at birth. The pregnancy had been planned and all members of the family were happy about the pregnancy.

The baby died on a Wednesday morning. The baby was described by Mrs. B. as being "cranky". She recalled that she had been up during the night with the baby. She fed him and burped him at 7:00 A.M. but he continued to cry. She was worried that his crying would wake their other son so she brought the crib out into the living room so he could cry himself back to sleep without disturbing the other child. Mrs. B. recalled waking with a start at approximately 8:00 A.M. She stated that she knew something was wrong through what she termed "woman’s intuition". She ran into the living room and saw the baby laying motionless. She described her first reactions as "shock and a closed-in feeling". One of the first thoughts which Mrs. B. recalled having was "what did I do wrong?" She stood for what she thought was several minutes, unable to move or identify the thoughts that were running through her head. She then came to her senses, picked the baby up and ran into the bedroom yelling at her husband to get up and that the baby...
was dead. She then tried to resuscitate the baby. Mr. B. recalled being awakened by his wife and asked to "please get some help". He ran downstairs and asked someone to phone for an ambulance. Mrs. B. then came downstairs with the baby in her arms and the couple waited for the ambulance.

The ambulance came and one of the attendants picked up the baby and then left immediately for the hospital. The ambulance attendants did not ask if the parents would like to go with them. One of the people downstairs offered to look after their son while Mr. and Mrs. B. went to the hospital. Mr. B. recalled that he tried to start his van but was unable to, "maybe through nervousness". Another of the people downstairs offered Mr. and Mrs. B. a ride to the hospital. To this point, Mr. and Mrs. B. described the people downstairs as being very helpful and they felt badly that the ambulance attendants had not offered to take them to the hospital with their baby.

When Mr. and Mrs. B. arrived at the hospital, a nurse directed them to a private room to wait. Mr. B. noticed a priest with whom he was acquainted and who was on staff at the hospital. He left Mrs. B. in the room to talk to the priest. Mr. B. explained to the priest that the baby had not yet been baptized and asked if it could be done. The priest agreed to baptize the child and he also called the funeral home and eventually drove Mr. and Mrs. B. home from the hospital. He was described by Mr. B. as being very helpful. Mrs. B. sat in the room by herself for what seemed like half an hour until a nurse came in. Mrs. B. asked the nurse if she could tell her something "because it's a hospital you still have that last bit of hope, even though you know that he's dead". The nurse declined to answer and told Mrs. B. that she would have to wait for the doctor. Mrs. B. recalled being upset by this. She felt that everyone was avoiding this issue and "you just get brushed aside until the right person comes along to tell you".

The doctor came in shortly after the nurse. He explained that there was nothing they could do for the baby and asked if they would come and identify him. Mrs. B. asked what had happened and the doctor explained that he could find nothing wrong with the baby and he thought it might be a crib death. Mr. B. recalled that she felt "up in the air" with the doctor's explanation because she knew nothing at all about crib death. Both Mr. and Mrs. B. went in to identify the baby and Mr. B. remembered that it was "kind of hard to see the little thing just laying there". While Mr. and Mrs. B. were at the hospital, a policeman came in but left immediately after talking with the doctor.
The B.'s remembered the hospital experience as "confusing" and "upsetting". Mrs. B. said that the family doctor was not present and "you're dealing with a bunch of totally strange people. It all happens so fast and there is no one who just sits down and talks to you". The B.'s also recalled that there were a lot of papers to sign, most of which they did not understand at the time. The B.'s identified the priest as being the most helpful person throughout the hospital experience.

When Mr. and Mrs. B. arrived home from the hospital, they were greeted by Mr. B.'s aunt who had been packing baby things away while the couple was at the hospital. This aunt told Mr. and Mrs. B. that she would not allow them to stay in the apartment and that they would move in with her. Mr. B. found this helpful because "the place where a person dies is hard to return to". The B.'s stayed with the aunt for a week during which time the aunt made regular trips to the B.'s apartment to pack baby things. The B.'s moved out of their apartment the same week and recalled that they found it very hard to cope with moving the baby's things.

Mr. and Mrs. B. went to the funeral home the day after the death to complete the funeral arrangements. It was decided that the baby would be "laid out" for one night only and the funeral would take place on Friday. It was at the funeral home that the B.'s first received any information about S.I.D.S. when they were given a pamphlet. It was also at the funeral home that Mr. and Mrs. B. were told about the autopsy which they had apparently signed for at the hospital. Mrs. B. recalled that this didn't upset her because she wanted to know what had happened and would have approved the autopsy anyway. The funeral director advised the B.'s that the police might visit them because the baby died at home but that there was no cause for alarm as the visit would be more for statistical purposes than an investigation. The B.'s found the funeral director helpful in that he provided them with information which they previously had not received.

The B.'s most vivid recollections of the funeral experience were of the visiting at the funeral home and they made little mention of the funeral service or the burial during the interview. The B.'s described the funeral home experience as frustrating and upsetting. Mrs. B. recalled standing in the funeral home and not recognizing some of the people who came in. She recalled thinking to herself "what do they think this is, a party?". She stated that people don't know what to say to parents of a dead infant because all of the cliches about suffering etc. don't apply. She also stated that "I had to be more understanding of other people than they were of me". There was one particularly upsetting incident at the funeral home
involving some members of a religious sect who upset Mrs. B. and had to be ushered out when they refused to leave. The funeral director had to be asked to close the doors and check everyone who came in to see if they were relatives or friends. Mr. B. recalled how ridiculous it seemed to have someone standing guard to keep people out of a funeral home. The B.’s stated that the funeral service and burial were not as upsetting for them as the visiting experience.

There are several experiences which stood out for Mr. and Mrs. B. in the months following the funeral. Mr. B. was working the evening shift following the funeral and Mrs. B. found herself spending a great deal of time alone with very few visitors. She found herself feeling very closed in and she used to take her son for rides in the car. Often they would go to the cemetery. The family still visits the grave every two months. On one visit to the cemetery, Mrs. B. ran into a man who had lost a daughter at ten months of age. She found it very helpful to talk with him about their experiences. She also found out that the man’s wife had had a tubal ligation after the birth and according to Mrs. B., this broke her own resolve not to have any more children when she realized that she was fortunate to be able to have more.

Mrs. B. also recalled that she had decided to keep her appointment with her gynecologist-obstetrician which had been scheduled for six weeks after the birth. She recalled walking into a visiting room full of pregnant women and being asked by the nurse to wait in the hall. Mrs. B.’s reaction to this experience was, ”It wouldn’t have bothered me to sit there. It hurt me more to be set apart”. When she did get to see the doctor, she did not find him of much assistance. He passed off her questions about S.I.D.S. by saying that it was just one of those things. Mrs. B. stated to the researchers that she wanted the information because she still had a fear in the back of her mind that she might have done something wrong. Mrs. B. eventually received what she described as “hand me down information” from her family doctor who saw her “a few times” after the death. The coroner never called with his report and Mrs. B. didn’t know what was on the report until she called the coroner eight months before the interview. Mrs. B. found it frustrating not to hear from the coroner because “people are always asking questions about what really happened and nobody knows about crib death. You get a pamphlet and that’s all you know”. The B.’s recalled one incident where they broke off a friendship with a couple who they heard via the “grapevine” had been accusing the B.’s of being responsible for the child’s death because they gave him “too much night air”. Mrs. B. told the researchers, “if
you can't cope with the guilt yourself, you have people always pointing the finger at you. If you can't say that that isn't so, you'll go crazy". Mr. B. recalled that people at work asked him a lot of questions about the death. After a while he began to accept the questions and the death. His rationale for the acceptance was "this way he doesn't have to suffer. He's better off than I am".

The emotional strain of the death showed up throughout the family in the months following. Mrs. B. recalled that for a long time after the death, she had flashbacks at night during which she would see the baby. She was able to talk about these to her family doctor who attempted an explanation. According to Mrs. B.'s recollections, "other people turned off or tried to change the subject when it was brought up". Mrs. B. found her family doctor helpful through this experience. Mr. B. went into a "fit of depression" after the death and refused to talk about it. Both Mr. and Mrs. B. found themselves becoming irritable with each other and with their son. The son seemed to know when his parents were upset and would occasionally try to comfort them by saying it would be alright. Both Mr. and Mrs. B. said that they counted on their son for support during the period after the death because "without him, there wouldn't have been much to hold on to". The B.'s son asked about the dead child for a year after the death and would sometimes call the dead child's name at night. Mr. B. was in the process of refurbishing an old van on which he was going to print his name "and sons". After the death, he lost all interest in the project and the van eventually was junked.

One of the largest adjustments which the B.'s made following their child's death was in relation to the size of their family. They had always wanted a large family but after the death, Mrs. B. did not feel that she could handle the strain of worrying about another baby. Several months after the death, the B.'s decided to adopt a child to fit in with their original family plan but they were asked to wait in view of their experience. Both Mr. and Mrs. B. felt frustrated and disappointed at not being allowed to adopt a child. They did not find the Children's Aid Society helpful at all.

After some discussion between the partners, they planned to have another child and Mrs. B became pregnant approximately one year after the death. She recalled that the pregnancy was easier than it had been for the dead child and she wished that she could keep the baby inside her until he was past the danger point. During the pregnancy, Mrs. B. read an article about a warning system which could be placed on a newborn infant to detect any cessation of breathing. She approached her family doctor
about the system and he dismissed it as a "crackpot idea". Mrs. B. recalled feeling very lost again in terms of her knowledge about S.I.D.S. While Mrs. B. was in the hospital to deliver, the head nurse of the unit came in with some pamphlets and to talk to her about her fears for the new baby. Mrs. B. recalled that she found this frightening at first but then very helpful in that someone recognized what she was going through and was prepared to talk about it.

Both Mr. and Mrs. B. found themselves being over-protective toward the new baby but neither partner wanted the other to know. Mr. B. recalled that it got to be comical for him to pass his wife in the hall as he was coming from checking on the child and she was going to check on the child. In addition to the extra attention which was paid to the new baby, the B.'s spent a lot of time checking on their older son because he had had a respiratory problem after birth. Mrs. B. recalled one incident when she was trying to burp the new baby and he stopped breathing for a moment. After this "close call" Mrs. B. found the phone number for the Canadian Foundation for the Study of Infant Deaths and called the local representative to report the incident and ask if it was important. She received what she termed a "sarcastic" response and stated that she found the representative not understanding or helpful at all.

Mr. and Mrs. B. felt that the death had some long term and permanent effects on them. Mrs. B. reported that she still has a great fear that something will happen to her children. She also stated that every time she thinks about having another child "crib death gets in the way and kind of swallows you up. You don't know if you can go through another year of worrying every moment. Mrs. B. reported that she has adopted a different way of dealing with people. "I have to say what I want to say. If it means a friendship, too bad". Mr. B. responded by saying "to this day I still remember the way I saw him" but both partners stated that they occasionally wonder why it happened.

Mrs. B. responded to a question about the help she received during the experience by saying "you get help to get you through the day of the death and the funeral but after that, people just look at you. They expect you to just pick up and carry on. Nobody really understands all of the emotions".

When they were asked for recommendations for people dealing with S.I.D.S., the B.'s gave the following:

1) Be aware that people are going to talk about the baby.
It's a part of your life and you just can't brush it away. It hurts more not to talk about it.

2) S.I.D.S. parents need a chance to get together with other people who have been through the experience just to talk.

3) When a woman comes home with a new baby, a Public Health Nurse makes follow up visits to check on both the baby and the mother. But if the baby dies, the mother is assumed to be dead too and no one visits.

A social worker or nurse should visit after the death.

4) Mrs. B. stated "you don't need someone to solve your problems for you, just a good listener. And they have to let you cry because it helps".

5) Don't assume you know how someone feels. Find out from them first.

6) Crib death should be stipulated on the death certificate so the parents know for sure.

7) Someone at the hospital should be able to help explain what is going on, what papers are being signed and why this is necessary.

8) S.I.D.S. parents need information. More information should be made available in Canada.

CASE #3 (Mrs. C.)

Mrs. C. was a married woman who lived in an urban part of the county at the time of the interview. She and her husband lost a male child to S.I.D.S. in November, 1974. The child was approximately two and a half months old at the time of death. The family consisted of Mr. and Mrs. C., an eleven year old son and a three year old daughter at the time of the child's death. No children were born into the family after the death of the child. Mrs. C. was the only member of the family who participated in the interview. This was at her request. She was pleasant throughout the interview and answered questions with a moderate amount of affect, mostly laughter.

Mrs. C. described her pregnancy for the dead child as being "rough". She was sick a great deal of the time and also had a kidney infection. This was Mrs. C.'s sixth pregnancy. In addition to the two children born before the S.I.D.S. baby, Mrs. C. had also had three miscarriages. The baby was an induced, breach birth who was one month premature and weighed four pounds at birth. The baby was also born with a respiratory problem and was kept in hospital for a month with little chance of living. At Mrs. C.'s request, the baby was baptized while in hospital. The baby was discharged from hospital with a clean bill of health and upon visiting the doctor two days before his death, weighed nine pounds and was pronounced "just fine".
The baby was planned for and eagerly awaited by the family.

Because of Mrs. C.'s illness during the course of her pregnancy, the couple had not gone out much for close to a year. They looked forward to going to a banquet on Saturday night and Mrs. C. made special arrangements to have a nineteen year old friend of the family babysit. Mr. and Mrs. C. arrived home at approximately 2:00 A.M. Sunday and Mrs. C. asked about the baby. The babysitter had just fed the baby and put him to bed. Mrs. C. went to check on the baby while her husband drove the babysitter home. The baby was fine at that time. Mrs. C. awoke at 7:00 Sunday morning and thought it was strange that the baby hadn't cried for his 4:00 A.M. feeding. She recalled thinking to herself "good, this is the first night he's slept right through". The C.'s eleven-year old son had gotten up early for seven o'clock mass. He looked in on the baby, thought he was alright, patted him on the back and left. Mrs. C. recalled that it was her husband who got up first to check on the baby. The next thing that Mrs. C. remembered was her husband "screaming hysterically" that the baby was dead. Mrs C. recalled that she ran into the room and she and her husband screamed at each other about what to do and who to call. Mr. C. went to call the operator to get an ambulance and Mrs. C. picked up the baby and started "mouth to mouth" resuscitation. Mrs. C. checked to see if the baby had choked on vomitus but found no trace of that. She told the researchers that for a period of three or four hours, she remembers very little except running around and screaming. Mrs. C. recalled that the ambulance seemed to be taking a long time arriving and so she ran out into the street with the baby in her arms and tried to flag down a car to take her to the hospital. The ambulance arrived while Mrs. C. was running up the street. The ambulance driver took the baby out of Mrs. C.'s arms, examined the fingernails, shook his head at his partner and proceeded to take the baby into the house. This is the last time that Mrs. C. saw the baby. One of the neighbours arrived at this time as did the police. Mrs. C. did not recall what her husband or the neighbour were doing at that point but the police asked her to remain in the kitchen while they "worked on" the baby with the ambulance attendants. By this time Mrs. C.'s mother-in-law and father-in-law had arrived and "within a half hour the place was full with about a million people". The baby was taken to hospital by ambulance but no one from the family went and the ambulance attendants did not ask anyone if they wanted to go. Mrs. C. recalled that one of the ambulance attendants mentioned that the baby had been dead for at least an hour. Mrs. C. made a point of requesting an autopsy but she was not sure who she asked. The police took a statement from the C.'s about the time of the last feeding and the time when the baby was discovered
and then they left.

The C.'s son returned from church after mass and saw the ambulance and the cars in front of the house. When he found what had happened, he "went hysterical" and started crying. He was taken to the doctor and given some mild tranquilizers and then returned home. Upon returning home, he went and laid on his bed which was beside the baby's crib and cried most of the afternoon. Mrs. C. recalled that her son had always wanted a baby brother and had taken part in the care of the baby from the beginning. The C.'s daughter was taken to some friends' and remained there for three days.

The babysitter who looked after the baby on the evening before his death found out about the death from her parents who heard it announced at the 11:00 A.M. mass on the day of the death. She came over immediately upon hearing of the death and was very upset about it. Mrs. C. recalled that she told the babysitter that the death was not her fault and there was nothing for her to feel guilty about.

Mr. and Mrs. C. were waiting to hear from the coroner at the house throughout the day. Mrs. C. recalled that she was very bothered by the people in the house although she realized that their intentions were good. She remembered being made to stay upstairs in the house, watching faces that she didn't recognize walk by her, listening to people whispering all around her, and hearing the downstairs telephone ringing or being dialed constantly. She also recalled being angry at people who were telling her what to do. She felt that "they weren't giving me enough credit for what I was capable of doing". Mrs. C. finally "got mad" when her father-in-law stated that he was going to make all of the funeral arrangements. She recalled telling him "that's the one thing that I am going to do".

Mr. and Mrs. C. went to make the funeral arrangements on Sunday afternoon. She recalled that the people at the funeral home were "fantastic". The funeral director suggested all of the arrangements and Mr. and Mrs. C. agreed. The funeral director also gave the C.'s pamphlets on S.I.D.S. for themselves and the babysitter and provided Mrs. C. with a pamphlet on what to say to the babysitter. Mrs. C. found this whole experience very helpful. The funeral was arranged for the next morning with no provision for visiting. This was in accordance with Mr. C.'s wishes.

The parish priest came to the house Sunday evening to inquire about the funeral arrangements. Mrs. C. recalled
that at the time she was feeling bitter and "mad at the whole world, God - just everybody". The priest told her that she shouldn't be angry with God and Mrs. C. replied "I already am, it's not fair. I wanted six kids and now I've only got two". Mrs. C. stated that she did not find the priest's visit particularly helpful except that he did not stay long.

The coroner called on Sunday night to give some preliminary information and assure the family that the autopsy would be completed for the funeral to take place on Monday. Mrs. C. recalled that one of the first things the coroner said was "I wish I could tell you he had a million things wrong with him but there was nothing. He just quit breathing". The coroner called a total of three times on Sunday, Monday and Tuesday and Mrs. C. stated that he was one of the most helpful people throughout the experience. Mrs. C. told the coroner that she felt to blame and that she shouldn't have gone out. The coroner explained that she could have been holding the baby in her arms and it wouldn't have made any difference. Mrs. C. found it comforting to talk with the coroner and get some further explanation about S.I.D.S. S.I.D.S. appeared on the autopsy report as the cause of death.

Mrs. C. recalled that the house was still full of people on Sunday night. Some of her husband's friends went to get her some tranquilizers from a medical clinic but she refused to take them. Other people were telling her she should go to bed and this rekindled some of her anger at being told what to do. Mrs. C. stayed up all of Sunday night and talked with her mother who had come to stay overnight. Mrs. C. found this helpful.

There were approximately 250 people at the funeral. Everyone in the family went except the C.'s three year old daughter. Mrs. C. said that nothing about the funeral or the burial stands out in her mind. However, when the C.'s son came home from the funeral, he immediately went to his bedroom. When Mrs. C. went in to see him, he was laying on his bed, crying and saying "my Johnny, my Johnny". Mrs. C. sat with him for a while and then he asked to be left alone. Several of the C.'s friends had prepared food for after the funeral and Mrs. C. stated that she found this helpful because she was exhausted at the time.

Mr. C.'s reaction following the funeral was that for several days he hardly left his wife's side and was constantly holding her and telling her he loved her. Mr. C. insisted that the family go to Toronto for a week and get away, even though Mrs. C. did not want to go.
A few incidents stood out for Mrs. C. in the time following the death and the funeral. Following the family's return from the trip to Toronto, Mrs. C. took down the baby furniture. Mrs. C. recalled that this hurt the most of anything in the whole experience. Neither she nor her son wanted to take down the furniture until Mr. C. became angry and said it had to be done.

About two weeks after the baby's death, Mrs. C. began to talk with her husband about having another child. Mrs. C. told the interviewers that she did it mainly to get her husband's reaction. She felt that she had failed him by having three miscarriages and a baby that died. Mr. C.'s reaction to the possibility of having another child or adopting one was "definitely not". Mrs. C. stated that she found this response "kind of helpful". Shortly after this discussion, Mrs. C. had a tubal ligation performed and has since had a hysterectomy.

Mrs. C. recalled that in the months following the funeral, it was difficult for her to get through the day once the children left for school. She stated that "I've had some good cries when I'm home alone and no one can condemn me for it". She also found it helpful to go downstairs and throw bottles at the fireplace to get her frustration out.

The individual members of the C. family have had different reactions to the death.

The C.'s daughter occasionally tells her friends that she had a baby brother who died and then makes up a wild story about the death and the circumstances surrounding it.

The C.'s son "to this day can't even discuss it without getting really upset" although he occasionally talks with his mother about what it would be like if the baby was still alive. As late as a week before the interview, Mrs. C. stated that her son came in while she was packing the baby's clothes to give away and became very upset.

Mrs. C. stated that, Mr. C. will not talk about the baby except "when I have my little fits every once in a while and cry about it, then he has to talk". Mrs. C. feels that her husband was so deeply hurt by the death that he can't show his emotions or talk about it. She stated "I would love for him just to sit down and cry". Mr. C. will not go to the cemetery and the family has never been there. Mrs. C. stated that she would like to go but, if she came home and cried her husband would get mad at her. At the time of the interview, the family had purchased a...
Mrs. C. stated that "sometimes it gets the best of you, especially when you see your friends with a new baby. You want to tell them "hold on to your baby, don't lay him down". Mrs. C. also stated that she still feels there must have been something she could have done even though her family doctor and her husband assure her that nothing could have been done.

Mrs. C. stated that she feels the family has become closer as a result of the death and they are also more considerate of one another because they realize how quickly things can happen.

When Mrs. C. was asked what her feelings are now about the experience, she made the following comments.

"It's something you just can't believe".

"I sometimes sit and rack my brain trying to find out what happened but some things are a complete blank".

"Now I feel I didn't realize I had so many friends but then it didn't matter to me one way or the other that they were there".

"I wouldn't want to be close to anyone it happens to. I would know what they were going through each day".

In retrospect, Mrs. C. found her experiences with the coroner, the funeral director, her mother and a girlfriend with whom she talked frequently most helpful. She also found her religious beliefs helpful.

She found her husband's refusal to talk about the experience, the priest's remarks on the night of the death and having people in her house telling her what to do as being not helpful.

Mrs. C. offered the following recommendations:

1) For people dealing with S.I.D.S. parents - Don't be afraid to mention the baby. Don't pretend it never existed.

2) For S.I.D.S. parents - If you feel like crying, cry. If you feel like screaming, scream.
CASE #4 (Mrs. D.)

Mrs. D. was a young woman from a semi-rural area of Essex County. Mr. and Mrs. D. had a male child die of S.I.D.S. in February, 1977. The child was approximately three and a half months old at the time of death. At the time of the child's death, the D. family consisted of Mr. and Mrs. D., a daughter who was four years old and a son who was just slightly over one year old. No children were born after the child's death, as Mrs. D. had a tubal ligation performed one and a half weeks before the child's death. Mrs. D. was the only member of the family who participated in the interview although both other children were present. Mrs. D. answered the researchers' questions with a noticeable absence of emotion and appeared to be more confused with regard to details than the majority of the other respondents.

Mrs. D. had a difficult time emotionally with her third pregnancy. The child was unexpected as he was conceived one month after the birth of the D.'s second child and at a time when Mrs. D. was taking oral contraceptives. Mrs. D. recalled that her husband was happy with the news of the pregnancy but Mrs. D. was depressed throughout the pregnancy and was placed on medication by her doctor. The child was born one month premature and weighed five pounds, nine ounces at birth. Labour was not induced. He suffered from colic for the first three months after the birth. However, Mrs. D. recalled that the dead child had been the healthiest of her three children. Her daughter was born six and a half months into the pregnancy, weighed three pounds, nine ounces at birth and was not expected to live. The second child was born seven months into the pregnancy with a respiratory problem. Mrs. D. recalled that from the beginning, the third child "just didn't fit". The other two children were named immediately upon birth but the third child took three days to name. The third also looked physically different from the first two. The baby's colic caused some difficulty for Mrs. D. for the first three months, resulting in high blood pressure for her. The baby was kept in the D.'s bedroom until a week and a half before his death, at which time he was moved to the bedroom with the older son.

The baby died on a Monday morning. Mrs. D. recalled that the baby had awakened at 6:00 A.M. which was later than usual. Mrs. D. went in to change the baby while Mr. D. went to prepare his bottle. Mrs. D. fed and burped the baby while her husband prepared for work. Mr. D. went in and kissed the baby which, according to Mrs. D., was unusual and then went to work. Mrs. D. returned to bed. Mrs. D. arose again at 8:30 A.M., went in picked up the baby, and
then put him back in his crib. As the morning progressed, Mrs. D. realized that something was wrong because both sons were abnormally quiet. Mrs. D. went into the bedroom, checked on her older son and went to prepare his bottle. When she returned to the bedroom she gave the bottle to her son and turned to look at the baby. The baby was laying face down in the crib with his arms outstretched. She turned the baby over by his feet and found that the baby's face was purple. Mrs. D. recalled that at that moment, "I couldn't believe it, didn't want to believe it". While Mrs. D. was trying to decide what to do, her daughter kept trying to come into the baby's bedroom and Mrs. D. kept trying to prevent her from doing so.

The first person that Mrs. D. thought to call was her mother-in-law as she had dealt with her own daughter in a similar situation. Mrs. D. recalled telling her mother-in-law over the phone that the baby was dead. Mrs. D. then called her husband and told him that she needed him at home right away. Mrs. D.'s mother-in-law was the first person to arrive at the house. She told Mrs. D. to start "working on" the baby and asked if she had called the ambulance. Mrs. D. recalled that neither of these two things had crossed her mind to that point. While Mrs. D. attended to the baby, her mother-in-law called the police and several relatives. When Mr. D. arrived home, his first question was "what happened?" His mother tried to explain but Mr. D. did not wait for the entire explanation. It was Mr. D.'s mother who first mentioned crib death. Mr. D. went into the Baby's bedroom and, according to Mrs. D., went kind of hysterical too". He picked up the baby, sat on the bed and began rocking him. When he realized that the baby had not yet been baptized, he began running around the house with the baby in his arms. When the police arrived, one officer went to check on the baby and "work on" him if necessary while the other officer stayed with Mrs. D. to ask about the details surrounding the death. Mrs. D. recalled being worried by the presence of the police because "right from the start, I thought it was something that I had done. I thought that 'til I got the autopsy report". One of the police officers called the ambulance and told them to "step on it" as they thought they had detected a pulse in the baby. Mrs. D. recalled wondering if the baby would be "brain-damaged or something" if he survived. The ambulance arrived in a short period of time and the attendants went in with the police and Mr. D. while Mrs. D. stayed in the kitchen with the other children and the relatives who had arrived by that point. The ambulance took the baby to the hospital and Mr. D. went with the ambulance. The police also left at the same time as the ambulance. Mrs. D. did not recall that her husband said much about what happened at the hospital except that he had
the baby baptized there, he signed for an autopsy and he was told eventually that nothing could be done for the baby as he had been dead for about two hours when he arrived at the hospital.

While Mr. D. was at the hospital, someone from the hospital called the D. home to ask for the name of the baby's family doctor. Mrs. D.'s brother-in-law answered the phone and Mrs. D. asked him to ask the hospital how the baby was. Mrs. D. was told that that information could not be given out and she recalled that she did not find that response helpful at all. Mrs. D.'s mother-in-law told her that she would have to accept that the baby was dead. Mrs. D. recalled that she could not accept this and she "just went nuts" when her mother-in-law suggested it. Mr. D. returned from the hospital approximately twenty minutes after the hospital's phone call. He was carrying the baby's clothes and Mrs. D. recalled that she could tell immediately "from the look on his face" that the baby was dead. Mr. D. tried to comfort his wife and Mrs. D. told the researchers that "if it hadn't been for him I would have been right out of it".

Mr. and Mrs. D. went for a ride in the car that afternoon and, while they were gone, relatives packed up the baby's belongings. Mrs. D. found this helpful. The only two things left out were the basinet and the baby's teddy bear, the latter by Mrs. D.'s request. The funeral arrangements were made that evening by Mr. and Mrs. D.

Mrs. D. recalled being upset at first by the funeral director and the way he matter-of-factly said "cute baby" when he first entered the room. Later however, Mrs. D. described the funeral director as "comforting". It was decided that the baby would be "laid out" for one evening. The casket would be closed and the funeral would take place on Wednesday morning. Mrs. D. recalled that while she was at the funeral home she was restless and continually walked around looking for the baby. Mr. D. had made his wife promise that she would not look at the baby although she had wanted to. However, the funeral director asked if they would identify the baby and Mrs. D. did open the coffin and kiss the baby good-bye. The funeral director also provided the D.'s with pamphlets on S.I.D.S.

On Tuesday afternoon, the D.'s parish priest invited them to the church and they sat and talked for about an hour and then sang some hymns. Mrs. D. described both the priest and the experience as being helpful although she could not remember much of what he said or did.

Mrs. D. could not recall how many people visited at the funeral home. She did recall that most of the people
did not spend much time downstairs where the coffin was but preferred to stay in the lounge. Mrs. D. recalled that she had "a reaction" that evening and was taken to hospital "for a shot". At the hospital she had an opportunity to speak with a nurse who had herself lost a child to S.I.D.S. Mrs. D. described that experience as helpful but stated that she would rather have not had the medication because at the time "I had some feelings but they wouldn't come out".

Mrs. D. did not remember what went on the day of the funeral. She only recalled that, as the coffin was being lowered into the ground, she fell down with the thought that she could retrieve the baby. Someone picked some flowers off the coffin, gave them to her and then picked her up and escorted her back to the car.

Although only four months elapsed between the baby's death and the interview, several feelings and experiences stood out for Mrs. D. during that time. For some time after the death, Mrs. D. found that she could make it through the day by keeping busy with housework and looking after the children but nights were very difficult for her. She did not sleep well and she would go into the front room and cry and occasionally she would have flashbacks of the baby the last time she saw him alive. Because of her depression and inability to sleep, Mrs. D. went to see her family doctor and was placed on anti-depressant medication and sleeping tablets. Mrs. D. recalled that her family doctor did not spend any time talking with her about the experience. Mrs. D. was still taking the medication at the time of the interview to "hold up for the kids". She weighed 143 lbs. at the time of the death and 112 lbs. at the time of the interview.

The coroner telephoned Mrs. D. a week after the death. Mrs. D. recalled that during the five minute conversation which she had with the coroner, he explained that they were calling it a crib death because they could find no other cause of death.

Mr. and Mrs. D. talked a lot about the death at first but as time went on, Mr. D. wanted his wife to "accept it" and became less inclined to talk. Mr. and Mrs. D. have only visited the grave a few times since the death. Mrs. D. stated that she would like to go more often but she is afraid to ask her husband because of "the way he acts".

Mrs. D. stated that she did not see any change in the family after the death. Mr. D. had asked his wife if she wanted to move but she said that it wouldn't change anything. Mr. D.'s mother stated that the experience would bring the couple closer together but Mrs. D. replied that
they were already close.

The most difficult things that Mrs. D. had to cope with following the death were seeing the baby's basinet still in the bedroom and seeing her neighbour who was pregnant and had also had a tubal ligation. Mrs. D. also found that the fourteenth of each month was a difficult time and she stated that she was not looking forward to her next wedding anniversary because it is the day of the baby's death.

Mrs. D. also stated that she has had difficulty not "spoiling" her other children. At the time of the interview, Mrs. D. was still checking both children at frequent intervals.

When the researchers asked Mrs. D. what "now" feelings she had, she made the following comments:

"I automatically find that that's the first thing I talk about but some people just don't want to hear about it".

"I have a feeling I'll be doing a lot of talking about it in the future".

"It's a battle. Sometimes you want to take your life then you think you can't do that because you've got two kids".

"Sometimes you just want to put your fist through the wall".

"Why did I get pregnant? Why did he have to suffer for three months with colic? Why did he die and why did I have my tubes tied a week and a half before he died?"

Mrs. D. identified her husband as being the most helpful to her throughout the experience and outside of a few minor annoyances she could not identify anyone as being detrimental to her.

Mrs. D. declined to offer any suggestions for people dealing with S.I.D.S. families.

CASE #5 (Mrs. E.)

Mrs. E. lived in a suburban area of Essex County at the time of the interview. She and her husband lost an adopted, female child through S.I.D.S. in October, 1973. The child was six months old at the time of death and had been with the E.'s for four months. At the time of the
child's death, the E. family consisted of Mr. and Mrs. E. and a three year old adopted son. The E.'s had decided to adopt a boy first and a girl second. The entire family was in favour of the adoption, especially Mrs. E. who had always wanted a daughter. The child had been in hospital before the adoption because she had been premature. At the time of the interview, the E. family consisted of Mrs. E., her son and a daughter who had been adopted nine months after the death. Mr. E. died three years after the baby's death. Mrs. E. was pleasant throughout the interview and answered questions with a moderate amount of affect.

The baby died on a Saturday morning. Three days previous to the death, the E.'s had taken out an insurance policy on the baby with a friend of theirs. Two days before the baby's death, the social worker from the Children's Aid Society had been out for her regular visit to check on how things were progressing.

The day of the baby's death, Mrs. E. recalled that the baby was happy. She fed the baby her breakfast and put her back to bed. Mrs. E. then decided that she would wash her hair and although it was not her usual custom, she asked a neighbourhood girl to come in and keep an eye on the baby. When Mrs. E. finished washing her hair, the neighbourhood girl left and Mrs. E. called her mother to talk. After a while, Mrs. E. began to think that something was wrong because the baby was sleeping much longer than usual. She walked over to the crib and found the baby lying face down with one of the crib pads over her head. She picked the baby up and her head flopped back. Mrs. E. recalled that her first reactions were shock and panic. One of the first thoughts which she could recall was "she's not dead". Mrs. E. put the baby back in the crib and ran across the street to find someone to help. Mrs. E. would not go back into the house herself and when she asked the neighbourhood girl who had been babysitting to come back into the house, she did not want to go in either. Mrs. E. spotted a friend of hers across the street with a neighbour. They both ran into the house and while the neighbour, who was trained as a V.O.N. tried to do heart massage, Mrs. E.'s friend attempted mouth to mouth resuscitation. Mrs. E. did not go into the room with the other two women but sat in the kitchen with the neighbourhood girl who had decided to come in by that point. Mrs. E. stated that it was helpful to her to have friends around who were trying to save the baby but she couldn't shake the feeling "I should have done something for that baby".

One of Mrs. E.'s friends called the family doctor and the ambulance. The friend then called Mr. E. at work
and told him that he was needed at home immediately. In retrospect, Mrs. E. felt that it was cruel that her husband did not know what to expect when he arrived home.

The family doctor arrived first but Mrs. E. did not remember exactly what he did. The ambulance arrived shortly after the doctor and the ambulance driver picked up the baby "on the run" and was attempting resuscitation as he ran out the door. Mrs. E. recalled the doctor offered her some medication which she refused and told her that she was in no way to blame for what had happened. Mrs. E. felt in retrospect that it was very helpful for her to be told from the outset that she was not to blame and it was also helpful to not be told that the baby was dead right away.

Mr. E. was driven home by a friend. The first question he asked when he entered the house was "What the hell is going on?" The doctor and ambulance had left by that time so Mrs. E. told him that the baby had died. Mrs. E. recalled that her husband's face showed anger and disbelief. He asked "how in the hell can a six month old baby die?" By that time, some of Mrs. E.'s relatives had arrived and they sat and waited to hear from the hospital. A short while afterward, the family doctor called to say that someone would have to go to the hospital to sign for an autopsy. Mrs. E. recalled that this was the first time that she knew for certain that the baby was dead. Mr. E. went to the hospital alone. Mrs. E. recalled that her husband had described the nurse with whom he dealt as "very nice". She tried to offer an explanation of the death based on preliminary findings and when Mrs. E. heard the explanation from her husband, she recalled hoping that the nurse was right and it was "something concrete". Mr. E. did not speak with the coroner at the hospital and the E.'s attempted to contact him several times over the next four days to get the results of the autopsy.

While Mr. E. was at the hospital, Mrs. E. recalled that she waited at home and worried. She described adoption to the researchers as being more difficult than having your own child because you must wait for an indefinite period of time and she recalled thinking to herself "I'm never going to go through this again". While she was at home, one of Mrs. E.'s friends came to the house and told her "I'm here to be with you. If you want to talk that's okay, if not, that's okay too". Mrs. E. recalled that she found this very helpful.

Mr. and Mrs. E. went on Saturday afternoon to make the funeral arrangements. Mrs. E. described the funeral director as a "great person". He was very calm, helpful and easy to talk to. The funeral director suggested that the baby be "laid out" on Sunday evening with the funeral
on Monday. Mrs. E. recalled that she was torn between wanting to have the baby "laid out" longer in order to allow more chance for people to visit and wanting to "get it over with". It was decided to have the casket open and to take the funeral director's suggestions about timing.

Mrs. E. attempted to explain the baby's death to her son on Saturday and she thought he had accepted the explanation until the next day when he asked when the baby was coming home. Mrs. E. found it hard to explain that the baby wasn't coming back.

Saturday night after the friends and relatives had left was the only time that Mrs. E. recalled her husband breaking down. Mrs. E. stated that she felt comforted by the fact her husband was being so strong.

Mrs. E. recalled that she found it difficult to leave the funeral home on Sunday with the baby still there. She also remembered that it bothered her to see the funeral director carry in the casket as she would have preferred to have her husband do it but she was afraid to ask him. There were quite a few people at the funeral by Mrs. E.'s recollection but she did not remember anything in particular that they said or did.

Two of the more difficult things which Mr. E. took care of after the baby's death were calling the Children's Aid Society and calling the insurance agent. The Children's Aid Society offered to pay for the funeral but the E.'s refused. The insurance agent had a difficult time convincing the company that the E.'s claim was in order and Mrs. E. remembered feeling badly about making the claim.

According to Mrs. E., the only thing that she felt bitter about was the way the coroner acted. The E.'s had attempted to contact the coroner for four days after the death in order to get the results of the autopsy. At the suggestion of their family doctor, the E.'s finally went down to the coroner's office to wait for him. Although the waiting room was empty when they arrived, the E.'s had to wait an hour to speak to the coroner. He talked with them for approximately ten minutes and was "very impersonal" according to Mrs. E. The coroner said that he was going to put crib death down as the cause of death because he couldn't find anything else. The only information he offered about crib death was that it got its name from the fact that the baby dies in his crib. The E.'s felt that they knew no more after talking with the coroner than before. Mrs. E.'s comment about the whole experience was "why did we have to wait so long? They have to know what the parents are going through". 
There were several other experiences which stood out in Mrs. E.'s mind following the baby's death.

On Monday, after the funeral, the priest came to lunch at the E.'s house. He told Mrs. E. to be happy because she had an angel in heaven who she should pray to, not for. Mrs. E. recalled that "that made all the difference in the world, I couldn't be happy about it until the priest talked to me". During the period of time between the baby's death and the funeral, family and friends had packed up all of the baby's belongings except the bedroom furniture. After her conversation with the priest, Mrs. E. decided that she would keep the baby clothes and she and her husband talked about having another child.

Mr. and Mrs. E. stopped at the Children's Aid Society on the day which they visited the coroner's office. They were told by the social worker that they should wait until February to apply because they would be facing a bad time in the following months as a result of their experience. Mrs. E. felt badly at waiting again but she felt that the social worker knew best. The E.'s did adopt another child in August, 1974. Mrs. E. felt that she and her husband received special treatment when they did apply in February because the waiting period for the third child was much shorter.

Mr. E. took a week off work after the death and after he went back, Mrs. E. felt "lost". She had been used to caring for a baby and there seemed nothing for her to do. Mrs. E. stated "that week was the roughest for me". About a week after the baby's death, two ladies from the church came over to visit at the priest's request. When they came in, they told Mrs. E. specifically that they did not want her to talk about the baby. Mrs. E. recalled that she felt worse after they left. She stated that if she had wanted to talk about things in general, she would rather have done it with a friend.

Mrs. E. decided to do some babysitting in January following the death. She recalled that the first day the father brought the child to the house, she explained what had happened and told him that if he thought she was to blame and was not comfortable with her, then he shouldn't leave the child. The father replied that he felt she was in no way to blame and had no qualms about leaving the child with her. Mrs. E. recalled that his response was very helpful to her and she also recalled that "the hardest thing I ever had to do was put the baby down in the same crib - especially someone else's child".

Mrs. E. visited the grave more often than the other members of the family but the whole family visited
regularly. Mrs. E. had her father, sister, baby and a brother who died three weeks after the baby buried in the same cemetery. Mrs. E. stated that she believed her previous experiences with death helped her to cope with her husband's death more easily.

One day soon after the new baby was adopted, Mrs. E.'s son asked her if they would be getting another baby after this one died. Mrs. E. recalled that "this question threw me" and it led to several discussions about death between Mrs. E. and her son. Aside from checking her first thing every morning, Mrs. E. did not feel that she treated the new baby differently from the one that died. "I never thought of my new daughter as a replacement. The dead baby was her own little person." The new daughter slept in the same bedroom and in the same crib as the dead baby. The only thing which was changed was the bedroom wallpaper because the E.'s felt that "something should be different."

Mrs. E. stated that she noticed some changes in the family after the baby's death. Her husband had been somewhat of a "workaholic" before the death. After the death, he changed jobs and began to take more time off to be with his wife and children. Mr. and Mrs. E. also began to take vacations with friends. Mrs. E. stated that the family became closer after the baby's death and she also stated that the memories of the time that she and her husband shared after the baby's death helped her to cope with his death. For herself, Mrs. E. felt that she became a stronger person after her daughter's death. Mrs. E. also became good friends with the woman who first tried to revive the baby with heart massage. They spent time sharing their experiences after the death and Mrs. E. stated that they now feel very close.

Mrs. E. still finds there are times that she is reminded of the dead child. Doing things for the new baby reminds her of the dead child and looking at the other neighbourhood children who are the same age as the dead child starts her thinking what the child would be like if she were still alive. "I don't think there has been a single day that I haven't thought about her."

Mrs. E. also expressed that "there are days when I don't want to talk about it and days when I have to talk about it. Other people though, won't talk about it because they think I will get upset."

In retrospect, Mrs. E. felt that her friends and neighbours had been the most helpful to her throughout the experience. She credited their emotional support and practical help with assisting her to cope with the death. Mrs. E. also listed her family doctor, the funeral director
and the priest as being helpful.

Mrs. E. felt that the coroner was the least helpful person throughout the experience. She also found the church ladies who told her not to talk about the baby as not helping.

When she was asked for recommendations, Mrs. E. gave the following:

1) The coroner should get the information about the baby's death to the family as soon as possible. Parents need to know what happened.

2) If someone who has been through the experience would visit within a few weeks after the death, it would be helpful.

CASE #6 (Mr. and Mrs. F.)

Mr. and Mrs. F. were a young couple who lived in a suburban area of Essex County. They lost a seventeen and a half month old male child to S.I.D.S. in October, 1975. At the time of the death, the F.'s family consisted of Mr. and Mrs. F. and the child. The F.'s had another male child born approximately one year after the death of their first child. Mr. and Mrs. F. were pleasant throughout the interview and showed a high degree of emotion when talking about the experience. Both partners became tearful at times during the interview and it was noted that Mr. F. picked up his second son mid-way through the interview and resisted his wife's attempts to take him for the rest of the interview.

Mrs. F. recalled that the pregnancy was not planned. Throughout the pregnancy, she was depressed a fair amount and "sick a lot". The labour period for the delivery was approximately five to six hours and the delivery itself was fairly easy. Labour for the child was induced one and a half weeks before the due date. Mr. F. recalled that he was uncertain about the pregnancy. Both Mr. and Mrs. F. were working at the time but their financial situation was not such that Mr. F. felt they could adequately support a child. Consequently Mr. F. did not react to the pregnancy "in the elated manner that most fathers do". He recalled being "uptight" for the first month after the child was born and at one point went to the doctor for an examination because he felt "draggy".

The only plans which the F.'s recalled making for the child were that they were going to spend more time with their child then their own parents had spent with them. Mrs. F. was an only child and Mr. F. was an "only child for
eleven years". Mr. F. in particular felt that although the time his parents spent with him was good, he would have liked to have had more time with them.

The baby died on a Wednesday morning. Two days before that, the baby had spilled coffee on himself and had burned his right arm. He was taken to the doctor where a dressing was applied to the arm and Mrs. F. was given some medication for the child to help him sleep. At that time, Mrs. F. was told that the first twenty-four hours would be the critical period. Both parents recalled that they did not sleep that night out of fear for the baby's condition. Mrs. F. took the child back to the doctor the following day and he put to rest her fears about the child's safety. However that evening the F.'s noticed that the child was "not himself" in that he did not eat or talk much. The child finally fell asleep late that evening and the parents attributed that to the medication. Mr. and Mrs. F. went to bed between midnight and 1:00 A.M. Mr. F. recalled that he couldn't sleep and he got up to check on the child who seemed to be alright at 3:00 A.M. This was the last time that Mr. F. saw the child alive.

Mrs. F. got up at 7:30 A.M. and went to check on the baby who appeared to be fine at that point. She had breakfast with her husband, saw him off to school and waited for the baby to wake up. After she waited for a while, Mrs. F. decided to check on the baby. The first thing she could recall thinking when she saw the baby was "he's not breathing". She immediately ran downstairs and called a neighbour who was a registered nurse. The neighbour came over immediately, closely followed by her husband and daughter. Mrs. F. went to phone for the ambulance. While she was on the phone, her neighbour came down and told her that the baby was dead. According to Mrs. F., this confirmed what she already knew. Mrs. F. then called the school and left a message for her husband to come home right away. Mr. F. returned the call and Mrs. F. told him about the baby's death over the phone. Mr. F. recalled that his immediate reaction was disbelief. His only recollections of the next few minutes were that he couldn't hang up the phone by himself and he remembered running down the hall at the school and running into the house. The rest was a blur to him. He was driven home by the principal of the school.

The ambulance arrived approximately ten minutes after Mrs. F. phoned but to her it "seemed like a year". Mr. F. arrived shortly thereafter and both parents went to the hospital in the ambulance. Mrs. F. had no recollection of what the ambulance attendants did at the house or how she reacted to them.
When Mr. and Mrs. F. arrived at the hospital, they were sent to the general waiting room. Shortly afterward, an orderly came in and escorted them to a private room to wait. After what seemed like a long time but was apparently only about fifteen minutes, the orderly returned and told the F.'s that the baby was dead. The chaplain came into the room after the orderly left and took the F.'s for a walk outside. He explained that the baby had gone to a better place. Mr. F. recalled that he did not find much solace in what the chaplain said. Mr. F. became increasingly angry as the chaplain spoke and felt that "everything he said seemed to strike me the wrong way. It was like he was giving us his Sunday sermon". Mrs. F. did not recall much of the conversation with the chaplain but stated that she was not sure anyone talking to her would have helped at that point. Mr. F. began to cry and she talked about this experience during the interview. Both Mr. and Mrs. F. stated that they would have preferred to have been consulted as to whether or not they wanted to see the chaplain.

Mr. F. recalled that it took a long time for the doctor to come in to talk to them. While they were waiting, Mr. and Mrs. F. were very quiet and didn't say "half a dozen sentences" to each other. When the doctor came in, he said he wasn't sure what had happened and wouldn't be sure until an autopsy was performed. A nurse came in with the doctor and explained that an autopsy was automatic and "in cases like this" the coroner would have to become involved. Mr. F. stated that although it might have been that he was "supersensitive" at the time, the nurse's comments smacked of accusation. After the doctor left, Mr. and Mrs. F. were allowed to see the baby, something that they had previously not been allowed to do. Mr. F. became tearful at this point in the interview and stated that after he saw the baby he couldn't sit still and began wandering "all over the place" while waiting for the coroner. He recalled feeling that everything was de-personalized "like I was back at university getting my exam paper - number 396, come here".

The nurse who had been earlier called the funeral home for the F.'s and then returned with the coroner. She introduced the coroner and explained his function. Mr. and Mrs. F. did not recall exactly what the coroner said but they thought it was something about the autopsy.

Mr. F. stated that most of his bad feelings about the hospital experience have come in retrospect. At various points in the interview, Mr. F. stated "I didn't feel that they mishandled the situation but I didn't feel they handled it either". "The coroner handled the situation quite well but the hospital staff made me feel
like it was all my fault. That's when my guilty feelings started to set in. "I never felt like a loser before but after I left the hospital I sure felt that way". Mrs. F. stated that no one thing caused her to feel guilty and she would have had those feelings regardless of what happened. With regard to guilt feelings, Mrs. F. also stated "I'm not sure my husband and I shared the same ones".

Both Mr. and Mrs. F. stated that it was helpful that they were taken out of the general waiting room. They also stated that they felt the ambulance driver was the most helpful person throughout the hospital experience. "He was really great. He made positive comments throughout the trip to the hospital and he waited at the hospital over an hour just to talk to us".

Mr. and Mrs. F. went to make the funeral arrangements later that day. They described the funeral director as a "sensitive" person who made all of the arrangements for them. The funeral was set for Friday and it was planned that the baby would be "laid out" on Thursday night. The coffin was kept open.

Mr. F.'s recollection of the period of time between the death and the funeral was that he was anxiously awaiting the results of the autopsy report. He tried several times to reach the coroner by phone and was unable to do so.

Both Mr. and Mrs. F. were visibly upset by the discussion about the funeral and both stated that it was the hardest thing for them to cope with. Mrs. F. recalled that when she first entered the funeral home, she noticed that the baby's hair had been combed differently and he didn't look right. She mentioned it to the funeral director and he immediately gave her his comb and told her to fix the baby's hair the way she wanted it. She recalled that she really appreciated that gesture. Mr. F. recalled that throughout the experience, it was not so much what people said to him as much as the fact that they had come that he found touching. He found it especially nice that most of his students and a good number of the teaching staff came to the funeral because he had only been in town for about a month when the baby died. The one incident which Mr. F. remembered most vividly and the hardest thing for him to talk about was his first encounter with his father-in-law at the funeral home. "It was almost as if he floored me with a punch. He said 'what did you do that for'. It was the first thing he said. I'll never forget that". Mr. F. cried most of the time he recalled that particular incident.

Approximately 100 to 150 people attended the
funeral. Mr. F. recalled seeing his aunt who had lost an eight year-old child two and a half years before. He felt that she knew what he and his wife were going through and he found it helpful just to know that she had taken the time to come from out of town. Mrs. F. recalled that, for her, "the very hardest thing was when they closed the coffin".

Some of Mr. F.'s fellow teachers stayed at the F.'s home during the funeral and prepared a lunch for afterward. Mr. F. found that helpful. The funeral director was also helpful in that he "was always there but never in the way".

The coroner called on Friday after the funeral and spoke with Mr. F. Mr. F. recalled that the coroner's explanation was highly technical and difficult to understand. Mr. F. remembered that the coroner mentioned S.I.D.S. during their brief conversation but he was not sure in what context. The next day, Mr. F. went to talk with the family doctor. The doctor explained the "jargon" in the coroner's report and told Mr. F. that the baby died of "basal viral pneumonia" which he considered a form of crib death. Mr. F. spent half an hour with the doctor and found his explanation very helpful.

A great many changes occurred in the F. family during the period following the death. Mr. F. recalled that he and his wife hardly spoke to one another until the end of the school year and when they did speak, it was usually critical. Mrs. F. stated that after the death she and her husband seemed to switch personality traits. Her husband had always been "even-keeled" but became very touchy after the death. She had always been "quick to temper" but became more placid after the death. Following the death, Mr. and Mrs. F. also became more insular and completely curtailed their visits to their parents.

There were changes in the grandparents of the child as well, following the death. Both sets of grandparents of the child stopped talking to one another and Mrs. F.'s father, who had doted on the child, "shut himself from the world and rejected everyone". Both Mr. and Mrs. F. stated that their relationship with Mrs. F.'s father changed following the death. The change was particularly noticeable with Mr. F. Mrs. F.'s father had always wanted a son and had kind of adopted Mr. F. after the marriage. After the incident in the funeral home, Mr. F. could hardly bring himself to speak to his father-in-law and the relationship deteriorated.

Mr. and Mrs. F. recalled one unsettling incident which occurred while they were in their "anti-social" period with regard to friends and neighbours. Someone
telephoned the F.'s late one night and, doing a "fair imitation of the witches from MacBeth" told them that they would die like their son if they did not snap out of it.

Mrs. F. recalled that for a long time after the death, Wednesday was a bad day for her and "it still tends to be my worst day". She had no other recollections of specific times that were difficult for her.

The birth of the F.'s new baby served to further illustrate the changes which took place after the death. Mr. and Mrs. F. talked about having another child about three and a half months after the death and the baby was born thirteen months after the death. Mrs. F. recalled that she ate a good deal of liver during the second pregnancy and that she felt less ill with the pregnancy. The second child weighed eight ounces more than the first and was carried to full term. Mr. F. recalled that he was again not elated at hearing about the pregnancy because he was "petrified about losing another child". Mr. F. found it more difficult to take part in the care of the second child and "it has only been recently that I have been able to by myself with the baby". Mrs. F. stated that although she felt the death made her a better mother it also made her more protective. She recalled that when the baby was first born, she had difficulty putting him down.

The F.'s first baby was taken to visit his grandparents almost every weekend. Visiting with the second child was very infrequent. When it has occurred however, Mr. and Mrs. F. have noticed that Mrs. F.'s father has had difficulty relating to the child while Mr. F.'s father has taken on some of the doting characteristics of Mrs. F.'s father.

Mr. and Mrs. F. stated that they talked about the experience of the death at length once they began talking again and, both still felt partly responsible for the death at the time of the interview. One of the reasons given for the diminished frequency of visits with the new child is that Mr. and Mrs. F. felt the constant travelling with their first baby contributed to "his weakened condition".

Some of the long term changes which the F.'s felt had occurred were that they were less demanding on their second child in terms of acquisition of developmental skills and that both of their sleeping habits had changed. Mr. F. stated that at the time of the interview, he was still unable to sleep past 7:00 A.M. regardless of the time he went to bed and Mrs. F. stated that she did not want to get out of bed in the morning for fear of what she might find.
Both Mr. and Mrs. F. stated that they felt that they had become less dominated by their parents as a result of the death and Mr. F. stated that he had also become less conscientious about his work. At the end of the interview, Mr. F. asked the researchers about job prospects as he was planning to leave teaching at the end of the school year.

When they were asked for recommendations, the F.'s offered the following:

1) Parents want to know as much as possible as quickly as possible about the circumstances surrounding the death.
2) The subject of the autopsy should be approached with caution by the hospital staff because it is a very sensitive issue.

CASE #7 (Mr. and Mrs. G.)

Mr. and Mrs. G. lived in an urban area of Kent County at the time of the interview. The G.'s lost a four-month-old male child to S.I.D.S. in January, 1976. At the time of the child's death, the G. family consisted of Mr. and Mrs. G., a six-year-old daughter, a five-year-old daughter and a three-year-old daughter. Fourteen months after the death, the G.'s had another daughter who was three and a half months old at the time of the interview. Both parents participated in the interview but the children did not. The G.'s were pleasant throughout the interview and answered questions with a moderate amount of affect, especially Mrs. G. who expressed some anger.

Mrs. G. recalled that when she was pregnant with the child who died, she was upset because the pregnancy was unexpected and she didn't want the baby. She stated that abortion was out of the question for her so she resigned herself to having the baby. Mr. G. was not upset about the pregnancy. Mrs. G. recalled that the pregnancy was difficult but the delivery was worse. The baby was born two months premature. Twice before the delivery, Mrs. G. was told that the baby was dead but then a heartbeat was found. As Mrs. G. was being taken to the delivery room, she was told that the delivery was being done for her sake because the baby would likely not live. Due to complications in the delivery, the baby was delivered by caesarian section. The baby was born with a respiratory problem and was sent to a hospital in London and then returned home. The baby spent most of his life in and out of hospital and was returned home after a week in hospital just three days before his death. Mr. G.
recalled being happy that the baby was a boy and Mrs. G. stated that because of all the things she went through in having the baby, he was "special" to her. The baby was to have had a medical checkup on the day he died.

The baby died on a Thursday morning. Mr. G. had just returned to work after a weekend off. Mr. G. arrived home from work at 2:00 A.M. and found his wife still up. Mr. G. asked about the baby and Mrs. G. replied that he was asleep. Mr. and Mrs. G. went to check on the baby. Mrs. G. recalled that the baby was not himself in that he was trying to bury his head in the covers. Mrs. G. pulled his head out of the covers and went to bed.

At 7:00 A.M. the G.'s were awakened by the sound of the dog scratching at the door to get out. Mrs. G. recalled being worried because the baby had never slept through the night before. She knew something was wrong and she got up and ran to the baby's room. Mrs. G. recalled that she knew the baby was dead immediately. "I couldn't believe it but I knew it was real." She recalled experiencing a flood of emotions, "so many emotional feelings tied up in that one moment, emotions I had never experienced". The one emotion that Mrs. G. was able to isolate was hatred. She hated the baby for dying. Mrs. G. screamed and her husband came running into the room. Mrs. G. had picked up the baby but she gave it immediately to her husband because at the time, she didn't want to look at the baby or touch him. She didn't even want to be in the room and her first impulse was to run. Mr. G. recalled being in a state of panic. He couldn't believe that the baby was dead. After the initial shock wore off, his first thought was to see how his wife was doing. He recalled that Mrs. G. was running around the house and throwing things at that point. He went to try and comfort her but she did not want anyone to touch her. Mr. G. went and phoned the police and also the priest because Mrs. G. was very concerned that the baby had not been baptized. Mr. G. recalled that as soon as he had called the police, his wife asked if they were going to come and blame her for the death.

The first people to arrive at the G.'s house were the police. One police officer went into the baby's room to "look things over" while the other stopped to talk with Mr. G. The police officer suggested that Mr. G. "keep an eye on" his wife. He then went to call the coroner. Mrs. G. recalled that she felt overly protected. She didn't like being kept out of the bedroom while the police were in there. She wondered if they were worried that she would go in and try to correct anything that she had done wrong. She also felt that she was not free to react the way she wanted to. She recalled however that she did not
have any quarrel with the particular police officers but more with the procedure. She felt that the fact that her husband was a policeman might have influenced their reactions. Mr. G. felt that the police were "pretty good".

The priest was the next person to arrive at the house. Mrs. G. recalled that he was young and she thought "it was probably his first death". Mrs. G. had not met him before. When the priest came into the house, he immediately tried to console Mrs. G. but she yelled at him to go and baptize the baby. After he had baptized the baby, he sat in the kitchen with Mrs. G. Mrs. G. did not recall much of what the priest said to her except that she should be thankful that she had other children. Mr. G. recalled that "I wasn't thankful I had other children. At that time I didn't care". Mr. G. stated that the priest seemed lost with respect to what he should say or do. "I probably helped him but he didn't help me that day. I didn't get any consoling from anybody".

The coroner arrived at the G. house shortly after the priest. He went in to examine the baby and Mr. G. overheard him tell one of the police officers that it looked like a crib death. Although this was the first time that crib death had been mentioned, Mrs. G. stated that she had always been aware of crib death and knew that the baby had died of crib death as soon as she saw him. This knowledge did not prevent her from feeling guilty however and she recalled that her major concern was that she had placed the vaporizer too close to the crib. The coroner asked Mrs. G. for permission to perform an autopsy. Mrs. G. replied "don't you touch him". Mr. G. remembered thinking that an autopsy would not bring the baby back and "it wasn't important why he was gone, just that he was gone". While the coroner was in the house, the ambulance was called. Mrs. G. did not see the ambulance attendants as she was in another room and Mr. G. saw them but did not talk to them. In reviewing the experience, both Mr. and Mrs. G. stated that it was helpful that the coroner came to the house because they would not have wanted to go to the hospital. Mrs. G. stated that it seemed to her as if the coroner had just breezed in and out and that she felt this was cruel. Mr. G. did not agree that the coroner's actions were cruel but he stated that it would have been helpful if the coroner had taken ten minutes to sit down and talk with them about the situation.

The baby was taken to the morgue by ambulance and neither Mr. nor Mrs. G. went along.

The G.'s family doctor telephoned on the morning of the baby's death. He had apparently been contacted by the coroner. The doctor suggested some medication which Mr. G.
refused and he stressed that it was important that the parents did not blame themselves for the death. Mr. G. found the doctor's statement helpful.

After everyone had left the house, Mr. and Mrs. G. went to Mrs. G.'s sister's house "just to get out of the house". Mr. G.'s mother, who had come in to pack up some of the baby's things, took the G.'s three daughter's with her. Mr. G. recalled that while he was at his sister-in-law's house, Mrs. G.'s mother "kept after" him to go and make the funeral arrangements. Mr. G. stated that this annoyed him as he wanted to have some time to collect his thoughts before he went to make any arrangements.

Mr. and Mrs. G. went to make the funeral arrangements at noon that day. Mrs. G. described the funeral director as "very good" but recalled that she was surprised that the funeral director said it would be better to have the casket closed. Mrs. G. told the funeral director that she wanted to see the baby so the casket would be left open. It was arranged that the baby would be "laid out" on Tuesday night and the funeral would be held the next day.

When Mr. and Mrs. G. went home after lunch, family and friends came to visit. A couple of statements made to Mrs. G. that afternoon stood out in her mind. She recalled that her aunt told her that she could always have another baby. "That floored me that someone would say that at that time". Mrs. G. also recalled that a friend said that with all of the difficulties the baby had been through, he might have been retarded. Mrs. G. made the statement that "no one seemed to take an interest in the fact that he was a person". Mrs. G. also stated that "everyone had a different theory on how I should behave but it was my baby and no one who came in had ever experienced it".

The G.'s went to the funeral home that night and took their two oldest daughters. The family doctor had advised against taking the children but, in retrospect, Mrs. G. regretted that she had not also taken the youngest child because of the difficulties which she experienced after the death. No one else came to the funeral home that night.

Relatives and friends came to the funeral the next day. Mrs. G. recalled feeling as if some of the people at the funeral had come for a show. Mrs. G. "held up" well until the end of the memorial service at the cemetery. At that point she broke down and started yelling "my baby" and "it's not fair". Mr. G. held up well at the funeral and Mrs. G. recalled that it was helpful for her that her husband did not break down because the couple were not
getting any help from anyone else. Mrs. G. reported that it seemed as if "everyone wanted to keep their distance."

The day after the funeral, Mrs. G. went with her youngest daughter to her sister-in-law's in Ottawa. She recalled that she did some skiing, tried not to think about the death and did not talk about it. Mrs. G. stated that she found it helpful not to have to look at baby clothes for a while. Mr. G. recalled that it was hard for him to see his wife go to Ottawa. While she was away, he spent the time taking his daughters out.

Two days after the death, Mr. G. went to see the family doctor for an explanation of the death. The doctor explained crib death as a very deep sleep during which the portion of the brain which controls breathing over-relaxes and the baby stops breathing. Mr. G. stated that he found the doctor's explanation very helpful.

Several other experiences during the time following the death stood out in the minds of Mr. and Mrs. G.

Mr. G. recalled that about two weeks after the death, he began to allow some of his emotions to surface. By this time, Mrs. G. was beginning to "come up" and was in a position to support her husband. Mrs. G. regarded this as a lucky occurrence.

As a result of the death, the G.'s felt that they became closer to the children. They also didn't let the children out of their sight and checked on the children three or four times a night, a practice which was still continuing at the time of the interview.

The G.'s found their dealings with other people somewhat difficult. Mr. G. recalled that as much as nine months after the death, friends were telling him that the death was probably the best thing. Mr. G. recalled that he resented that statement and he said "there's no way I'll believe that it was the best thing". Mrs. G. recalled that people were either "cold and thick-skinned" or they really wanted to help. "There was nobody in between". The G.'s lost a lot of friends in the process because "they just stayed away. They must have thought we just sat around and cried all day". The family also tried to convince Mr. G. that his wife should not have another child.

The G.'s first started talking about having another child four months after the death and the baby was conceived a month later. Mrs. G. recalled that when she first learned she was pregnant, she did not care whether the baby was a boy or a girl, but as time wore on, she felt more and more that she wanted a boy. The pregnancy for and birth of the
new child was not nearly as difficult as it had been for the dead child. The new baby was included in Mr. and Mrs. G.'s protective measures. Mrs. G. recalled that she ran immediately to the doctor when the baby caught a cold. Mrs. G. stated that she felt the family doctor had changed as a result of the death in that he became more understanding.

There appeared to have been effects of the death within two of the G.'s children. The youngest child talked about death "for months" after the death and she even expressed a desire to die herself. The G.'s oldest child experienced some adjustment problems at home and school after the death. A year after the death, the daughter told Mrs. G. that she felt guilty that she had wanted to punch her mother in the stomach while she was pregnant for the dead child. Feelings of jealousy were behind that desire according to Mrs. G.

Mrs. G. stated that, as far as she and her husband were concerned "I know that we've adjusted to it. I sometimes feel guilty that I don't have some of those guilty feelings.

The G.'s "now" feelings about the experience are that the death has become much more of a religious experience. Mrs. G. stated that she now feels that she has given the baby to God—and she will someday be able to join her baby. Mr. G. asked "If you didn't have your religion, where would you look?"

When the G.'s were asked for recommendations, they offered the following:

1) Just being there helps. Let the parents do most of the talking.
2) Some explanation for the death should be given right at the time from the family doctor. The coroner is sometimes too frank.

CASE #8 (Mr. and Mrs. H.)

Mr. and Mrs. H. lived in an urban part of Essex county at the time of the interview. They lost a one month old female child to S.I.D.S. in July, 1974. This was the H.'s first child. The H.'s had another child, a male, approximately one year after the death. At the time of the interview, the H.'s had been separated for nine months. They were both pleasant throughout the interview and responded with a moderate amount of affect, Mr. H. with anger and Mrs. H. with a mixture of laughter and tears.
Mrs. H. recalled that the pregnancy for the dead child was "normal". The pregnancy was planned. She was not too sick while carrying the child. Both parents recalled that they were looking forward to having the child. The child was born six weeks premature and was not induced. The baby weighed four pounds nine ounces at birth and was kept in hospital for three weeks. She was only home one week before she died.

The baby died on a Saturday morning. Mr. and Mrs. H. had had an argument on the night before the child's death and Mr. H. had spent the evening out drinking. He arrived home at approximately 3:00 A.M. He heard the baby crying but did not go in to check on him. Mrs. H. got up an hour later and fed the baby. She recalled that the baby ate well and burped well. At 8:00 A.M., Mrs. H. awoke and felt that something was wrong. She asked her husband to go and check on the baby. Mr. H. went to check on the baby and he stated that he felt the baby was dead as soon as he touched her as she was cold. He yelled at his wife to call an ambulance immediately and he began mouth to mouth resuscitation. He also attempted heart massage from the little he knew about it. He stated "I knew there was nothing I could do but I knew I had to try". At that point he recalled that he did not want to believe that the baby was dead.

The ambulance arrived within minutes of the telephone call. When it arrived, Mr. H. was outside with the baby in his arms. The ambulance attendant immediately took the baby from Mr. H. and took her to the ambulance where he started to administer oxygen. The ambulance driver asked Mr. H. if he wanted to go in the ambulance but Mr. H. replied that he would follow in his car. Mr. H. characterized the ambulance attendants as "good guys".

Mr. and Mrs. H. followed the ambulance in their car. They were stopped by the police for running a red light but when Mr. H. explained the situation, the police escorted the car to the hospital. Mr. H. recalled that he was grateful to the police on that occasion.

When Mr. and Mrs. H. arrived at the hospital, the first person they ran into was an ambulance attendant who said "don't worry, everything's okay". Mr. H. described the hospital experience as "sweating and drinking coffee". Mr. and Mrs. H. were taken to a private waiting room. Mr. H. recalled that sitting and waiting to hear something was hard for him. Mr. H. called his sister-in-law from the hospital. At first she thought Mr. H. was joking until one of the nurses got on the phone and explained the situation. Two of Mrs. H.'s sisters came to the hospital immediately. Mr. H. recalled that throughout the experience, he was
trying not to upset his wife more by crying. Mrs. H.'s recollection of the hospital experience was that people kept coming into the room and telling her that they were working on the baby. Mr. H. characterized the nurses as "really great". One nurse brought Mr. and Mrs. H. coffee and a nurse stayed with the H.'s throughout the experience. One nurse who had been present when the baby was delivered was particularly upset at the death. Both the H.'s family doctor and the coroner were present at the hospital. Mr. and Mrs. H. found this helpful. The family doctor confirmed the death and asked permission for an autopsy which the H.'s gave readily. While at the hospital, the coroner talked with Mr. H. and the family doctor spoke with Mrs. H. Both physicians mentioned crib death at the time. The priest was also at the hospital and he baptized the baby. When the nurse asked if someone would identify the baby, Mr. H. volunteered but the nurse felt that it would be preferable not to have Mr. or Mrs. H. make the identification. Mrs. H.'s sister volunteered to make the identification. Mr. H. recalled that throughout the hospital experience, he and his wife did not leave one another's sides. Mr. H. recalled that he and his wife spent approximately an hour at the hospital and he felt that the experience was a helpful one.

Mr. H. and his brother-in-law made the funeral arrangements that same day. Mr. H. stated that he found the funeral director to be "okay" but he was happy that his brother-in-law was there. Mr. H. recalled that he was feeling very angry with God at that point and was thinking "who is He to take away a kid who hasn't had a chance to live yet?" When the funeral director suggested a cross for the casket, Mr. H. told him to "ram it up his ass". Mr. H.'s brother-in-law intervened and from that point on, helped with the making of the arrangements. It was decided that the baby would be "laid out" on Monday night and the funeral would be held on Tuesday. Mr. H. requested that the casket remain closed.

Mr. and Mrs. H. had few recollections of what happened between Saturday and Monday except that there were friends and relatives around. Mr. and Mrs. H. did not talk much about the experience together. Mrs. H. stated that right after the death, she did not want to discuss it or read about it. "I just didn't want it to exist I guess". During this time, Mr. H.'s parents, who had been vacationing in the United States, returned. They had been telephoned and returned immediately.

The families of both parents visited the funeral home on Monday evening with the exception of one of Mrs. H.'s sisters who was expecting a baby at any time. Mr. H. recalled that his wife's father asked the funeral director
to open the casket on Monday evening. Mr. H. overheard the conversation and threatened the funeral director with legal action if the casket was opened. Mr. H.'s father and father-in-law also approached him at the funeral home and told him to "act like a man". Mr. H. replied "don't tell me how to act. Have you ever had it happen to you?" Mr. H. also recalled that the priest tried to contact him at the funeral home and Mr. H. told him to get out of the way. Mrs. H. recalled that she did not want to go to the funeral home and did not want to see people. She was "angry" and "hurt" the entire time and was not aware of who was at the funeral home. She stated that "all I remember was that I wanted my mother more than I ever had before but I didn't remember her arrival or what she said to me."

Mr. and Mrs. H. did not have many recollections of the funeral itself.

During the months following the death, several experiences and incidents stood out for Mr. and Mrs. H.

On the day of the funeral, Mr. H. went to thank his family doctor and the coroner for their help. He spoke with the family doctor briefly and then went to see the coroner. The coroner's nurse told him that the coroner would not be able to see him. The coroner overheard the conversation from his office and told Mr. H. to come right in. The coroner explained S.I.D.S. to Mr. H. and told him that there was nothing he could have done to prevent the death. Mr. H. stated that both doctors were helpful. Mrs. H. also went to see the family doctor because she was not sleeping after the death. He prescribed some medication for her and talked with her briefly about the experience and reinforced the fact that there was nothing she could have done. Mrs. H. stated that she found the family doctor helpful.

Approximately a week after the death, a V.O.N. nurse telephoned Mrs. H. to ask if she could visit. Mrs. H. refused the visit. She told the researchers "it does help to talk after a while but only after you've got it straight in your own mind". Mrs. H. stated that she thought the V.O.N.'s offer was premature.

Four days after the death of the child, Mrs. H.'s sister had a baby. Mrs. H. recalled that she felt angry at her sister for having a baby until her sister confronted her about those feelings. Mrs. H. stated that the anger "went away" after the confrontation.

One of Mr. H.'s cousins also had a baby at about the time of the death. Mr. H. recalled that he offered his child's crib to his cousin's wife but she refused because a
baby had died in that crib.

Mr. and Mrs. H. recalled that there were events which brought back the memory of the dead child in the months following the death. Saturday mornings were difficult for both Mr. and Mrs. H. Mrs. H. also found bright, sunny days difficult because the baby had died on a sunny day. Mrs. H. remarked that just the sight of the sun shining through the window in the morning would be enough to make her feel badly. Mr. H. recalled that it was difficult for him to live in the same house with the memory of the dead baby. He also recalled that he was unable to look at his new niece without wondering what his own daughter would be like if she were still alive. Mrs. H. also recalled that friends and relatives seemed to stay away after the death. She stated that she felt as though people were afraid to talk to her because they thought she would be angry or upset. Mrs. H. felt that she received most of her comfort from reading about S.I.D.S. when she was ready.

Although Mrs. H. stated that she did not care to go to the cemetery, the H.'s were still visiting the grave every three months at the time of the interview and were taking their son along. Mr. H. stated "it still hurts to go there".

Mr. H. recalled that he wanted to have another child almost immediately after the death. He had been told by a friend that he should have another child right away even if it meant throwing his wife's "pills" away. The H.'s second child was conceived several months after the death of their first child. Mrs. H. recalled that she was scared from the moment that she found out she was pregnant. Mr. H. was happy but "uptight" about what might happen. Throughout the pregnancy, Mrs. H. had recurring dreams about falling down the stairs and losing the baby. She was convinced that she would not have the child. While she was in the hospital, she felt that the baby would be still-born. Mrs. H. had her second child in the same hospital, the same room and the same bed as the dead child. She recalled that being in that particular hospital reminded her of the dead child and she did not sleep well while she was in hospital. The second baby was carried to full term and was healthy. The baby slept in the H.'s bedroom for a month after he arrived home and received extra attention with regard to breathing checks from both parents.

By their own admission, Mr. and Mrs. H. went through some difficult times after the death. Mr. H. became very angry with everything and became involved in several bar-room fights. He drank quite heavily after the death and would spend most of his spare time in the bar. He
would usually stay out until the early hours of the morning, go to bed and get up and go to work. During this period, Mr. H. began seeing a psychiatrist regularly. He described the psychiatrist as "an A-1 guy" and felt that the psychiatrist helped him to feel less guilty about the death.

The death and Mr. H.'s subsequent anger and drinking caused "quite a bit of static" between Mr. and Mrs. H. By his own admission, Mr. H. was not much help to his wife during this period and she had to take care of herself. Mr. H. noticed a change in the marital relationship "sex-wise and other ways" following the death. Although it was never discussed between the partners, Mr. H. stated that "at different times I thought, was I in the wrong? Was she in the wrong? Who was in the wrong?" At the same time, Mrs. H. felt that her husband was blaming her for the death "because it was better to think that someone else was blaming me rather than me blaming myself". Mrs. H. stated that she felt she could not be a good mother after the baby died. During this time, Mrs. H. felt she would have liked to talk with her husband more, or failing that, a friend who would just be there and listen. Mr. H. stated that he did not feel that the death had any bearing on the couple's subsequent separation.

Mrs. H. stated that she felt the death had changed the way she felt about life. She stated that it made her think twice before losing her temper at someone because "you can be perfectly healthy one minute and extremely ill or dead the next".

When Mr. and Mrs. H. were asked for their "now" feelings regarding the experience, they offered the following comments:

Mrs. H. stated "I still can't see any reason for the death. It made me aware of how cruel life can be".

Mr. H. stated "I never want to have to go through it again. I still miss the kid. That will never escape from my mind".

Mrs. H. offered the following suggestion for people dealing with S.I.D.S. parents:

1) Don't try to comfort and expound on theories; just listen.

CASE #9 (Mrs. J.)

Mrs. J. lived in an urban area of Essex County at
the time of the interview. She and her husband lost an adopted female child to S.I.D.S. in October, 1975. The child was three months old when she died and had been with the J.'s for two and a half weeks. At the time of the death, the family consisted of Mr. and Mrs. J. and an adopted four year old son. The J.'s adopted another daughter nine months after the death. Several times during the interview, Mrs. J. confused the names of her new daughter and the dead child. Mrs. J. was very pleasant throughout the interview and discussed her experience with a moderate amount of affect.

Mrs. J. recalled that the adoption of the child was a happy event. Everyone in the family was in favour of the adoption and the J.'s son took special delight in introducing his baby sister to everyone he met on the street. Mrs. J. described the child as a very happy baby who ate and slept well from the beginning. Mr. and Mrs. J. had planned that the child would have "a good life" and would go on to university if she so desired. Mrs. J. recalled that in the days before the baby died, she had begun to recognize the members of the family and smile when she saw them.

The baby died on a Wednesday morning. Mrs. J. recalled that she got up that morning and fed and bathed the baby. The baby ate particularly well that morning and seemed to be having a good day. After bathing the baby, Mrs. J. took some of "those little nude pictures that you show to boyfriends" and then dressed the baby. She remembered debating whether or not she should put the baby outside in the cool air and she decided that it would be alright. She put the baby on the front porch in her carriage and went to do some housework. Sometime during the morning, Mrs. J.'s father-in-law stopped in for a few minutes and looked in at the baby who seemed to be fine. Mrs. J. began to get worried about noon that the baby was sleeping too long. She went out to check on the baby and she recalled having a "premonition" before she picked up the baby that she was dead. The baby was lying face down in the carriage and had changed positions from what Mrs. J. remembered. The baby's hair was wet with perspiration. Mrs. J. recalled that her first thought upon picking up the baby was "no, this can't be" and she started yelling and shaking the baby in an attempt to wake her up. She took the baby inside, laid her on the dishwasher and attempted resuscitation. The J.'s son was home from nursery school that day with a cold and Mrs. J. yelled at him to call his grandmother and tell her to come right over. Mrs. J. recalled that at that point, her son was "hysterical" and was unable to dial the phone. Mrs. J. ran over and dialed the number, then she went back to the baby. Although Mrs. J. had not mentioned death, when her son spoke to her mother-in-law on the phone, he told her that the baby was dead. Mrs. J. then went and phoned for
an ambulance.

Mrs. J.'s mother-in-law was the first person to arrive at the house. When she came in, she immediately started to "work on" the baby while Mrs. J. called her husband. Although it was his lunch hour, Mrs. J. was able to contact her husband at work and she told him to come home right away because the baby had suffocated.

The ambulance arrived shortly thereafter and the ambulance driver asked which hospital Mrs. J. would like to have the baby taken to. He picked up the baby and asked Mrs. J. if she wanted to go along. For reasons which she could not explain during the interview, Mrs. J. asked her mother-in-law if she wanted to go. Her mother-in-law responded that she would stay home with her grandson and would send Mr. J. over to the hospital as soon as he got home. Mrs. J. recalled that when she left, her son was still upset and crying but her mother-in-law seemed to be "in good control". Mrs. J. stated that she found it very helpful that the ambulance attendants took the baby to the hospital because the baby was already dead and the ambulance attendants did not technically have to take the baby.

When the ambulance arrived at the hospital, the baby was taken into one of the treatment rooms and Mrs. J. was asked to fill out the necessary forms. She was then asked to sit in the general waiting room. Mrs. J. recalled that as she was walking to the waiting room, she thought "what are people going to think of me?". There were two ladies sitting in the waiting room, one of whom asked Mrs. J. what had happened to the baby. Mrs. J. replied "I think he suffocated" and the lady turned to her friend and said "you hear a lot of that nowadays and you never used to". Mrs. J. recalled that she was extremely upset by this incident. A nurse came in a short while later and Mrs. J. asked if the baby was still alive. The nurse replied "it doesn't look too good" and said that the doctor would be in shortly. The nurse took Mrs. J. to a private room and began to ask her questions about the baby's last feeding and the details surrounding the death. Mrs. J. felt that the questions were implying guilt on her part. The doctor came in shortly after and said that the baby had "expired". Mrs. J. asked him if it was a crib-death and the doctor said that he didn't know. Mrs. J. asked what the cause of S.I.D.S. was and the doctor replied "it's just one of those things" and then left. Mrs. J. said that, in retrospect, it seemed like the doctor wanted to get out of the room as quickly as possible. The nurse stayed for a few minutes and explained that an autopsy would have to be performed. Mrs. J. recalled feeling that she had killed her baby. She was sure that there would be a coroner's inquest and that she would never survive the process. Mr. J. came into the
room at this point and Mrs. J. recalled that he looked "absolutely stunned". He asked what had happened and Mrs. J. replied that the baby had died of crib death. Mr. J. asked what caused it and Mrs. J. said that they didn't know. The nurse came back in and said that someone would have to identify the baby. Mrs. J. recalled that she wondered why it was necessary for someone to identify the baby when she had brought her in. She offered to make the identification in order to protect her husband from a bad memory of the baby but Mr. J. and the nurse decided that Mr. J. would make the identification. Mrs. J. signed papers for the autopsy and recalled that she had no objection to the autopsy because she wanted to know what happened.

When Mr. J. came back from identifying the baby, he mentioned to his wife that the Children's Aid Society would have to be contacted. Mrs. J. recalled that this added another source of concern for her and she wondered "what will they think of me?" Mr. J. called Children's Aid but "broke down" and was unable to speak. The J.'s regular social worker was not in, so Mrs. J. explained what had happened to the worker on duty. Mrs. J. described the social worker as "very sympathetic". Mr. and Mrs. J. then left the hospital and Mrs. J. recalled that "no one even knew when we left the hospital. They couldn't have cared less".

On the way home from the hospital, Mr. and Mrs. J. decided to stop at the funeral home. Mrs. J. said very little because at that point she was "a zombie". The J.'s had decided previously that they would be cremated when they died so they decided that the baby would also be cremated. The nearest crematorium was in Detroit so the actual burial did not take place until two weeks after the death. Based on the experience of Mrs. J.'s father's funeral the year before, the J.'s decided that: a memorial service would be held on Friday, the baby would not be "laid out", and the coffin would remain closed. Mrs. J. recalled that her father's death had been her first close experience with death and she described his funeral as "three days of hell for everyone". She stated that she did not feel like going through that experience again and she would not put anyone else through it.

When Mr. and Mrs. J. arrived home, Mr. J.'s parents were there. Mrs. J. noticed that her mother-in-law had been crying, an unusual occurrence for her. The J.'s son was asleep "from exhaustion". Mrs. J.'s father-in-law put his arms around her as soon as she came in and tried to comfort her. Mrs. J. recalled that she had a "compulsion" to phone her social worker, just so she could hear her say that Children's Aid did not blame her for the death. She
could not reach the social worker but she did talk to the nurse who had been involved in the adoption. The nurse was very supportive and said that they did not blame her for the death. Mrs. J.'s father-in-law had called her mother who lived out of town and she said that she would be there the next morning. On Wednesday night at dinner, Mrs. J. called the minister who came over to the house right away. The minister said that he honestly didn't know what to do as this was the first time he had dealt with this kind of situation but he did talk with Mrs. J. for some time and Mrs. J. stated that she found him helpful.

That same night, Mrs. J. became obsessed with putting away the baby's clothes. She remembered standing at the top of the stairs and throwing the clothes into the basement until her husband stopped her. Mr. J. took down the baby's playpen and put the carriage in the garage. In retrospect, Mrs. J. stated that she found it odd that she was so obsessed with the baby's clothes and yet did not notice the baby bottles in the refrigerator until three days later.

Mrs. J. recalled that later the same evening, she got up enough courage to ask her husband if he had any questions about what had happened. He replied that he had no questions. Mrs. J. told him that she felt she had killed the baby and her husband completely rejected that idea. Mrs. J. felt it very helpful that her husband demonstrated so much trust in her.

The next day, Mrs. J. called one of her friends to tell her what had happened. Within a matter of hours, another friend who had heard the news via the grapevine showed up at the door and she, Mr. J. and Mrs. J.'s mother spent the afternoon drinking Bloody Mary's and talking. Mrs. J. stated that "under the circumstances, we had a very nice time" and she found the experience helpful. When the friend's husband came to the J.'s to pick up his wife, he decided to stay and have a few beers with Mr. J. while his wife went home to look after the children. Mrs. J. stated that this particular couple were very helpful throughout the experience.

The night after was when the J.'s had their first discussion about adopting another child. Mrs. J. recalled feeling that she did not want to go through the experience again but she also did not want to cheat her husband out of his daughter. She also recalled wondering if the Children's Aid would ever give her another child.

The memorial service for the baby was on Friday morning. The only people in attendance were: Mr. and Mrs. J., their son, Mrs. J.'s mother, Mr. J.'s parents and sister,
and the social worker and nurse from Children's Aid. Mrs. J. recalled that the only people who didn't cry at the service were herself and her son. She remembered that her son tried to comfort his father by telling him not to cry.

After the service, the social worker went back to the J.'s for lunch and sat and talked with Mrs. J. The social worker reiterated that no blame whatsoever was placed on Mrs. J. for the death. Mrs. J. recalled feeling that "a piano had been lifted off of my shoulders". That same afternoon, a friend who had lost a child two years earlier stopped at the J.'s and gave Mrs. J. some pamphlets on S.I.D.S. Mrs. J. recalled that she found that very helpful.

There were several experiences which stood out for Mrs. J. in the period following the baby's death.

For the first two weeks after the death, Mrs. J.'s friends drew up a schedule so that one of them would have Mrs. J. over for lunch every day. Mrs. J. stated that she found this helpful. One girlfriend also came over two weeks after the death and helped Mrs. J. sort the baby clothes.

The researchers were not clear when the coroner called to give his report but Mrs. J. stated that she would have preferred if he had taken more time to explain S.I.D.S. to her.

About a month after the baby's death, the crib had to be taken out of the bedroom because it was upsetting the J.'s son. He stated that he was afraid to go to sleep because he might die. Mrs. J. explained that S.I.D.S. was a baby disease and that he did not have to worry about it.

The J.'s applied to Children's Aid to adopt another child in January following the death. They were told that because of the short duration of the first adoption, they would be given priority. The J.'s first request was for a girl between the ages of six months and a year. This request was later revised to three to six months and when the baby was finally chosen, she was two weeks old.

Mrs. J. recalled that she went through some very bad times with her new daughter. After the death, Mrs. J. recalled that Wednesdays were bad for her, but after the arrival of the new baby, every day brought something new to worry about. Both she and her husband were highly overprotective with the new baby just as they had been overprotective of their son immediately after the death. They checked the baby's breathing frequently and the baby slept in the J.'s bedroom. Mrs. J. recalled that it was a big move to put the basinet at the foot of the bed when the baby was
six months old and an even bigger move to put the baby in
the other bedroom when she was nine months old. Mrs. J.
also recalled that she worried tremendously about germs the
first time she took the baby outside and that she "was a
basket case" when the baby caught her first cold. The J.'s
son was apparently very aware of what was going on because
on one occasion when Mrs. J. asked him to check on the baby,
he returned and said "it's okay mom, she's still breathing".
At the time of the interview, Mrs. J. stated that she was
still afraid to go into the room if the baby had taken an
abnormally long nap. Mrs. J. reported that the one day she
finds difficult now is the babies' birthday. Both children
were born on the same day and Mrs. J. finds it difficult to
be putting flowers on the grave and planning her new
daughter's birthday party at the same time.

Mrs. J. stated that she felt the death had brought
the family closer together. It also seemed to have affected
the J.'s son in that after the death, his nursery school
teacher recommended that he attend group therapy because of
his relationships with other children. He was still
attending group therapy at the time of the interview.

When Mrs. J. was asked what her "now" feelings were
with respect to the incident, she replied "it's the worst
thing that ever happened to me" and "there has got to be a
reason for it (S.I.D.S.)".

Mrs. J. offered the following suggestions:

1) All S.I.D.S. babies should be sent to one hospital in
order to give the staff a chance to learn how to deal
with it.

2) The family should not be put in the general waiting room
at the hospital.

3) Some kind of personal attention is needed for parents at
the hospital.

4) Information should be given about S.I.D.S. as soon as
possible. The coroner's involvement should be explained
fully and the coroner should sit down with the parents
and explain his report.

CASE #10 (Mrs. K.)

Mrs. K. lived in a rural section of Essex County.
She and her husband lost a female child to S.I.D.S. in
February, 1973. The baby was approximately three and one
half months old at the time of death. At the time of death,
the family was made up of Mr. and Mrs. K. and the child who
died. This was the K.'s first child. The K.'s were
separated at the time of the interview. Mrs. K. spoke very
quietly with a moderate degree of affect.
Mrs. K. described her pregnancy as normal, the child weighing over seven pounds at birth. Labour was induced approximately one and a half weeks before the calculated due date. Everyone in the nuclear and extended families was happy about the birth. For Mrs. K.'s parents, this was their first grandchild.

The child died on a Wednesday about noon. Mrs. K. recalled coming home from work in the morning and talking for a few minutes with her husband, who, after telling her about the baby's morning feeding, left for work. The baby was awake at this point and Mrs. K. remembered playing with her for a while and then rocking her to sleep. Mrs. K. put the baby in a crib beside the couch in the living room. Mrs. K. then fell asleep.

Mrs. K. recalled dreaming that something was wrong with the baby. She woke with a start to check the baby and found her dead in her crib beside the couch.

Mrs. K. recalled her first reactions as being fright and shock. She grabbed the baby and shook her, yelling her name at her. She then threw the baby down on the couch, hoping to dislodge anything that might be blocking the baby's breathing. She began mouth-to-mouth resuscitation. While attempting resuscitation she called the ambulance and then her pediatrician who gave her heart massage directions over the phone. She recalled feeling confused and helpless at this point as the baby was not responding to her efforts.

The police and the ambulance arrived very closely together. The ambulance drivers made some short resuscitation efforts and gave up, quickly recognizing that the baby was dead. Mrs. K. recalled the ambulance drivers telling her that the baby was dead and that there was no use. Mrs. K. then, although "numb", managed to call her parents. She told them the situation and asked them to call Mr. K.'s parents. Mrs. K.'s parents said they would be there immediately to be with her. Mrs. K. then phoned her husband's office and a message was relayed to her husband who was out of the office at a meeting some fifty miles from the family home.

The policeman remained in the house with her after the ambulance left. The baby was left lying on the couch with a blanket over her. Mrs. K. said she didn't want the baby moved until her husband arrived. Mrs. K. recalled that she felt very alone in the house while she waited for relatives to arrive. The policeman, as she recalled, didn't say much and the house seemed eerie. She also stated that at this time she, on a couple of occasions thought she heard the baby crying. She had a feeling of wanting to run.
Although the policeman had asked her a few questions about what had happened, Mrs. K. said she found him to be very concerned and careful not to upset her. Although he was quiet while they waited for relatives, she said she was glad of his presence.

Mrs. K.'s parents arrived first, followed by Mr. K.'s parents. The grandmothers both were tearful and shaken. Mrs. K.'s father also burst into tears when he saw the baby on the couch. Mr. K.'s father, although visibly in shock, proceeded to attempt to comfort the others. Mr. K. arrived last with a friend. He came into the house and ran over to Mrs. K. Mrs. K. recalled that her husband held her for a few minutes, then went to look at the baby. Mrs. K. then recalled her husband cursing God and exhibiting further anger before being approached by his father who got him to settle down.

By this time the funeral home car had arrived and, according to Mrs. K., her husband carried the dead baby out to the car. Mr. K. then, on the advice of his father, phoned the insurance company with whom he had a life insurance policy on the baby.

At this point the K.'s drove with Mrs. K.'s parents into town to make funeral arrangements. The parents were asked if they wanted an autopsy done by the coroner who had pronounced the child dead at the house. They refused. Mrs. K. recalled little about the coroner's arrival or departure, but said he was quick about his work and did not upset her in any way.

Mrs. K. recalled that during the ride of some thirty miles to town, both she and her husband began feeling guilty and wondered if they had failed to do something for their daughter.

The people at the funeral home were very co-operative and sensitive as Mrs. K. remembered. She did not remember anything in particular that was notable, however.

The baby was "laid out" on Thursday and Friday and friends and relatives attended. Mrs. K. recalled that she and her husband talked together in bed on Wednesday and Thursday, questioning themselves about what had happened. Mrs. K. recalled her husband blaming himself and saying that the death must have had something to do with how he had fed her or burped her. The K.'s did not blame each other however, as Mrs. K. recalled.

During the funeral process, many friends and relatives came. Mrs. K. recalled thinking that some of the people seemed upset when she would go to the casket and touch her dead baby. She also recalled breaking down on a few
occasions and being helped to control herself by her husband. On Saturday, the morning of the funeral, the K.'s spent time alone with the baby and Mrs. K. recalled her husband having to almost drag her away from the casket when the time came for the service. She did not want to leave the baby. She recalled pleading to be left with the baby.

In the months after the baby's death, the K.'s found themselves restless and irritable. They went on a short trip right after the funeral and when they stopped for the night at a motel, Mrs. K. recalled seeing an old pioneer cradle and bursting into tears. She recalled that later her husband told her that one of his brothers who accompanied them for part of the trip had seen the cradle earlier and warned Mr. K. to keep her clear of it, but he forgot.

The K.'s left the baby's room untouched for a few weeks before packing up the baby's things. They did this packing together, a bit at a time, and found it brought back not only bad memories but also gave them chance to share again some of the joy of the three and a half months their daughter had been with them.

Mrs. K. found Wednesdays hard for her for a while and the baby's birthday and the anniversary of the death still bring back uncomfortable memories. Mrs. K. recalled being upset at seeing little babies for a couple of months after the baby's death. Mrs. K. also recalled that, although friends and relatives remained close and concerned, they avoided talking about the baby. Mrs. K.'s husband was never unwilling to talk about the baby. He was perhaps able to discuss the baby's death more easily than Mrs. K. herself.

It was approximately two years before the K.'s had another baby, a male, weighing between nine and ten pounds. Mrs. K. remembered both her and her husband's joy over the birth. She recalled that because the baby was so big and healthy looking, some of her fear about something happening to him was immediately alleviated. However, both she and her husband checked the baby regularly and the baby slept in their bedroom until he was about six months of age.

Mrs. K. said that she still occasionally relived the experience, especially when she hears or reads about child abuse, neglect, or an infant dying needlessly. Mrs. K. stated that as yet they had not put a grave marker in the cemetery and at times this bothers both her and her husband.

Mrs. K. felt that perhaps the experience was less frightening and devastating for her because they had lots of support from family and friends. Also they did not have to go through the hospital experience, nor were they questioned extensively by the police. However, Mrs. K. stated that the
experience was something "you never really get over, only something you learn to live with as time goes on".

When asked for recommendations, Mrs. K. suggested that:

1) People should realize that S.I.D.S. parents need to and will want to talk about their dead child.
2) People should not act as if the child never existed.
3) Mrs. K. suggested that as much information about crib death as is available should be made available through hospitals, funeral homes and churches, to parents. Parents should not have to stumble onto this material.
4) Someone to talk with about crib death, who is knowledgeable in the area and who perhaps has been close to or directly involved in a S.I.D.S. death would be helpful to many parents. Not everyone's husband or "relatives" will talk or know anything about this kind of death, she stated.
Summary of Data

All of the data collected during the interviews are presented in the case studies. However, the following section is concerned with bringing together the major data so that comparison is made easier.

Description of the Sample

Of the ten interviews which were conducted, nine were with people from Essex County and one was from Kent County. Three of the sample lived in primarily rural areas at the time of the child's death. Five of the sample lived in urban areas at the time of the child's death and two lived in suburban areas. All of the people who participated in the study were married and living together at the time of the child's death. Two couples separated subsequent to the death and the husband of one of the sample died after the death of the child. In one half of the cases, both husband and wife were interviewed, including one case where the couple was separated. In the remaining five cases, all interviews were conducted with the wife. In three of these five cases, it was specifically stated that the husband would not participate in the interview. No family members, apart from husbands and wives, were interviewed, although, in four cases, children who had been present at the time of the death were present at the interview.

Of the fifteen people actually interviewed, twelve
were considered by the researchers to have exhibited a moderate amount of affect. Two people showed considerable emotion and one person showed very little emotion in discussing the experience. The most prominent emotion noted was anger, which was clearly shown by four of the respondents. In three of the four cases where anger was detected, it was the woman who exhibited it. The remaining respondents showed mixtures of emotions, usually sadness and anger.

Pre-Death Conditions

Of the ten children who died, six were males and four were females. Two of the ten children, both females, were adopted. Four of the children died in 1974, two in 1973, two in 1975 and one each in 1976 and 1977. Three of the children died in the month of October, two died in February, and one each in January, March, July, August and November. Four of the children died on Wednesday, three died on Saturday and one died on each of Sunday, Monday and Tuesday. All of the children were found dead in the morning. In three of the ten cases, the child who died was first child born to the couple. None of these cases involved an adopted child. In one of these cases the child who died was the first born to that particular couple but both partners had had children through previous marriages. In three cases, the dead child was the last to be born and sterilization of the wives had taken place in all three
The youngest child died at the age of one month and the oldest at seventeen and a half months. The three to four month old period was the modal age of death, with deaths occurring within this period in five of the cases.

Some of the data was not available for the births of the adopted children. Both adopted children were born prematurely and spent some time in hospital before going to their adoptive homes.

Of the remaining eight children, three were not planned and, in two of these cases, the wife did not want to have the baby. The pregnancies were described as "normal" in three of the eight cases and "difficult" in the remaining five. Sickness or emotional difficulties were reported in all five cases where the pregnancy was termed "difficult".

Of the eight biologic children, seven were born prematurely, ranging from one and a half weeks to two months. The one exceptional child weighed nine pounds at birth. Three of the eight deliveries were as a result of induced labour and one was by caesarian-section.

In seven of the ten cases, both parents were happy with the arrival of the child. Of the remaining three cases, the wife was the dissatisfied partner in two instances.
The Death

In nine of the ten cases reported, the family lived in a detached dwelling at the time of the child's death. In the one remaining case, the couple lived in an upstairs apartment.

In only one of the ten cases were both partners working and in all cases, one of the partners was at home when the baby died. One babysitter was also involved but was not present when the baby was found dead.

In eight out of ten cases, it was the wife who found the baby dead. In three of these eight cases, the husband was also at home when the baby was found dead. In nine out of the ten cases, the wife reported that she knew something was wrong before the baby was found dead.

The most common first reactions which were reported were shock and disbelief. Immediate feelings of anger (Case 7) and guilt (Case 1) were also reported. In five cases, it was reported that one of the first reactions was to begin screaming. In one case (Case 3) both husband and wife began to scream when the baby was found dead. Two respondents reported being immobilized at first.

Immediate attempts were made at resuscitation of the baby by one of the parents in five out of the ten cases. In two cases (Case 5 and Case 6), a neighbour was called who attempted resuscitation and in one case (Case 4) a relative who was called immediately began resuscitation.
attempts. In both the two cases where resuscitation attempts were not made (Case 1 and Case 7), both wives reported that they did not want to touch the baby and one husband reported that he knew the baby was dead.

Reports of immediate knowledge of the baby's death were common among the respondents but those respondents who attempted resuscitation anyway stated that they still held some hope or, as one respondent stated "I knew there was nothing I could do but I knew I had to try". (Case 8).

The first person called differed from case to case. In four cases, the first to be called was a friend or relative, in four cases it was the ambulance, in one case it was the family doctor and in one case it was the police.

In two of the ten cases, (Case 1 and Case 5), the family doctor arrived at the house and in two cases (Case 7 and Case 10), the coroner visited the house before the baby was removed. The ambulance was called in all cases but in one case (Case 10) the ambulance did not transport the baby. In three cases, (Case 2, Case 3 and Case 8) one of the parents was already outside with the child when the ambulance arrived.

In eight of the ten cases, friends or relatives arrived at the house before the baby was removed. In half of these eight cases, these people had been the first ones called.

The police were involved in five of the ten cases and
in three of the remaining cases, the parents were told that the police might have to be involved.

The actions of the people who came to the house immediately following the death also varied from case to case. Resuscitation attempts were common as were attempts to comfort the family (primarily by relatives and friends). The police were primarily involved for the purpose of conducting an investigation. In all cases where the police were involved, the thought of an investigation triggered anxiety but the actual police officers were not seen in a negative light. The police were also not seen as being particularly helpful.

In the cases in which the family doctor was involved, he was seen as helpful in one case (Case 5) in that he told the wife immediately that it was not her fault that the baby had died. In both cases, recollections about what the family doctor actually did were not clear and the doctor did not stay long in either case. The family doctor was contacted by telephone in two cases (Case 7 and Case 10) and was described as helpful in both instances.

In the two cases in which the coroner became involved immediately, he was found by the respondents to be very quick about his work. He left no impression on one respondent (Case 10) and was upsetting to the other (Case 7).

In one case (Case 7) the priest was involved immediately in the situation and he was not found to be helpful.
The ambulance attendants were found to be helpful in nine of ten cases and in one case (Case 6) were considered one of the most positive things throughout the experience.

Friends and relatives who arrived at the house shortly after the death were generally considered to be helpful, especially those who made resuscitation attempts and took care of practical concerns such as making phone calls. In one case (Case 3) the friends and relatives who arrived were a source of irritation to one of the respondents.

The parents had the child's death confirmed for them by various people. In three cases, the death was confirmed by the family doctor (In Case 8 at the hospital), in two cases by the coroner, in two cases by the "on duty" doctor at the hospital and in one case by an orderly at the hospital. In one case, the husband had the death confirmed at the hospital and he confirmed it for his wife when he returned home.

In five cases, husbands were called at work. In two of these five cases, the husband was told of the death over the telephone (In Case 10, in specific response to the husband's question). In one case (Case 10) the husband was the last person to arrive before the baby was removed and in one case (Case 9) the baby had already been taken to hospital when the husband arrived home.

Of the ten cases, eight involved having the child taken to hospital. In one case (Case 7) the child was taken
to the morgue and in one case, (Case 10) the child was taken directly to the funeral home.

Autopsies were performed on seven of the ten children. In two cases (Case 7 and Case 10) the autopsy was refused and in one case (Case 1), permission was given for an autopsy but it was never performed. The subject of autopsy was raised by various people. In two cases, the autopsy was mentioned by the family doctor, in two cases it was mentioned by a nurse at the hospital, in one case it was mentioned by the "on duty" doctor at the hospital and in one case the autopsy permission was requested by the police. In one case (Case 3) the autopsy was specifically requested by the wife and in one case (Case 2) the funeral director mentioned that the parents had signed for an autopsy at the hospital and they were unaware of having done so. The autopsy was presented as a "must" in the majority of instances. In two cases (Case 6 and Case 9) the mention of the requirement of the autopsy upset the respondents, one to the point of saying that his guilt feelings started then. All of the parents who agreed to the autopsy were in favour of having one performed, primarily out of a need to know for certain what had happened to the baby. The two respondents who rejected the autopsy felt that it served no purpose.

The Hospital Experience

Of the eight children who were taken to hospital,
five were accompanied by family members. In one case (Case 5) the husband went to the hospital at the request of the family doctor to give permission for an autopsy.

Three couples went immediately with the child, one in the ambulance and two behind the ambulance. One wife went to the hospital in the ambulance and was joined there by her husband (Case 9). In one case (Case 4) the husband went by himself with the ambulance while his wife stayed at home. Detailed information was not available for the cases in which the husband went to the hospital by himself as neither husband was interviewed and he did not discuss the experience at length with his wife in either case.

Of the four cases for which detailed data was available, a nurse was the first person encountered for three of the respondents. The remaining respondent (Case 8) first encountered the ambulance driver who had taken the baby to hospital. In two instances, the respondents were asked to wait in the general waiting area and then taken to a private room. In the other two cases, the respondents were taken directly to a private room. In one case (Case 9) waiting in the general waiting room proved to be an upsetting experience.

In all four cases, the respondents were questioned by a nurse about the situation surrounding the death. These questions were described as upsetting in three instances. In one case, the nurses were described as very helpful in that they stayed with the parents throughout the
experience and brought them coffee. In the remaining three cases, the nurses came in and out of the room on different occasions. In one case (Case 6) the nurse telephoned the funeral home for the parents. The nurses were described as helpful by one respondent.

In three of the four cases where both partners were at the hospital and in the case where the husband went to the hospital alone, members of the clergy became involved. In three out of the four cases, the clergyman (priest) baptized the dead child. The clergy were described as helpful by two of the respondents. In one case (Case 2) the priest telephoned the funeral home for the parents and also drove them home from the hospital and in one case, the clergyman was described as being not helpful.

All of the respondents came in contact with a physician at the hospital. In one case (Case 8) it was the family physician and in the remaining three cases, the "on duty" physician. In two cases, the coroner was also present at the hospital.

The family doctor was considered helpful in the one case (Case 8) in which he was involved at the hospital. He offered "crib death" as a preliminary cause of death and talked with the wife at the hospital.

In the three cases in which the "on duty" hospital physician was involved, he was not considered helpful by the respondents. In these cases (Case 2, 6 and 9) the physician offered no explanation for the death except to
mention crib death in one case (Case 2). The prototype of the statement offered by the physicians was that "there was nothing they could do". In these three cases, the respondents felt that the physician was in a rush and did not wish to spend time explaining the death or comforting them.

In three of the four cases for which data was most available, the parents were asked by a member of the hospital staff to identify the baby. In the fourth case (Case 6), the parents themselves requested to see the baby after they had talked with the physician. In one case where only one parent went to the hospital (Case 4), they were asked to identify the baby at the funeral home.

Of the three cases where identification of the baby was requested at the hospital, one involved both parents making the identification (Case 2). In one case (Case 9), the wife volunteered to make the identification but it was suggested by her husband and the nurse that her husband make the identification. In the other case (Case 8), the husband volunteered to make the identification but was told by the nurse that it would be better for someone who was not a member of the immediate family to make the identification.

Of the four sets of respondents from whom detailed data was obtained about the hospital experience, one found it to be a helpful experience. In this case (Case 8), the couple credited the nursing staff primarily for making the experience the way it was.

The remaining three sets of respondents found the
hospital experience confusing and upsetting. The major contributing factors toward these feelings were: inadequate explanation of procedures, lack of personal contact, questions which were taken as implying blame, and lack of information about the death and the possible reasons for the death.

The Funeral Experience

In nine of the ten cases, Case 2 being the exception, the funeral arrangements were made on the same day as the death. Also in nine of ten cases, Case 8 being the exception, both parents went to the funeral home. The actual funeral arrangements differed from case to case.

In three cases, the funeral was held on the day following the death. In one of these cases (Case 3), no provisions were made for the child to be "laid out". In one case (Case 1), family and friends visited the funeral home the night before the funeral. The couple's children however, did not attend. In the remaining case (Case 7), only the immediate family, with the exception of the youngest child, visited the funeral home on the night before the funeral. In Cases 1 and 7, the children who did not visit the funeral home also did not attend the funeral.

Of the three cases where the funeral was held on the day following the death, two involved leaving the casket open and one involved closing the casket.

In five cases, the funeral was held two days after
the death. In one of these cases (Case 9) no provision was made for the child to be "laid out". In the remaining four cases, family and friends visited the funeral home. Other children in the family were generally not involved with the exception of Case 3. Of these five cases, three had open casket services.

In two cases, the funeral was held three days after the death. In one of these cases (Case 8) the child was "laid out" for one evening and in the other case (Case 10) the child was "laid out" for two evenings. In both cases, family and friends attended both the visiting and the funeral. Neither of these two sets of respondents had other children at the time of the death. In one of these cases, the coffin was left open.

In all of the seven cases where friends and relatives visited, the experience was upsetting for one or both partners. Several of the respondents recalled specific incidents which took place at the funeral home and which they found particularly upsetting. Two of the respondents (Case 2 and Case 8) recalled wondering why some of the people were there and most of the respondents reported that people who were visiting at the funeral home were at a loss for words when talking to the parents. In one case (Case 4) the wife had to be taken from the funeral home during visiting to receive some medication at a local hospital.

Memories of the funeral service and burial were generally not clear among the respondents. Three respondents
(Case 1, 4 and 7) recalled that the burial was a very difficult time for them. One wife (Case 4) had to be removed from the burial site and one wife (Case 7) had to be restrained during an emotional outburst. In two cases (Cases 6 and 10), the closing of the coffin was reported as a difficult time. One respondent (Case 5) recalled that leaving the funeral home the night before the burial was difficult for her and one respondent (Case 9) recalled that she and her son were the only ones not to cry at the funeral. Burials were not possible in all cases because of the season and in one case (Case 9) the child was cremated two weeks after the funeral service.

The funeral directors were considered helpful in nine of ten cases. In all cases, the funeral director suggested the arrangements and his suggestions were usually accepted. The respondents generally found the funeral directors to be comforting, sensitive and easy to talk to. In addition, the funeral directors were the first source of S.I.D.S. information in four cases. The funeral directors also performed practical services for the families and were generally sensitive to the wishes of the parents as in Case 6 and Case 10.

Through the entire funeral process, specific family members and friends were considered helpful by the respondents while others were felt to be detrimental to the emotional well-being of the respondents. With the exception of Case 8, respondents reported that their spouses were of
great help throughout the funeral experience.

Post-Death Experiences

Immediately after the funeral, two couples and one wife left for short vacations. In two cases, (Case 7 and Case 10), the wife expressed a desire to run and get away and in one case (Case 2), the couple did not return to the house where the baby had died. All respondents stated at some point that it was difficult to return to the house following the death.

Parents coped with the death in different manners. Three wives reported going to speak to the family doctor shortly after the death because of sleeplessness and emotional distress. Three husbands went to see the family doctor for information about S.I.D.S. shortly following the death. The desire for information about the death was common to most of the respondents. Of the seven cases where autopsies were performed, only one respondent reported being happy with both the speed of contact from the coroner and the adequacy of his explanation. The coroner was described as not helpful following the death in every case but two in which he was involved. In one case (Case 5) he was described as the least helpful person throughout the experience. In one case where the coroner was considered "very helpful" (Case 3), he telephoned the family three times in three days to update his report and he spent a good deal of time explaining the situation to the respond-
ents. In two cases, it was reported that the coroner did not ever telephone his report to the family.

Sleeplessness, irritability and depression were reported often by the respondents as being post-death phenomena. These problems were generally handled by the family physician. Three wives reported "flashbacks" after the death and the family doctor was considered helpful in dealing with these except in one case where the medication prescribed was not appreciated by the respondent. A psychiatrist was consulted by one husband (Case 8) and was considered helpful.

There were several things which the respondents found brought back memories of the child. In all ten cases, the respondents reported being reminded of their dead child by the presence of another child, particularly if the child belonged to a friend or a relative.

Packing the baby's belongings was reported often as a difficult experience for the respondents. In four of ten cases, a friend or relative packed the baby's belongings while the parents were out. In some of these cases, however, furniture was left out and had to be dismantled later, and baby clothes eventually had to be disposed of in one manner or another. The packing of the baby's belongings was done by both partners in three instances and in three cases, the packing of the belongings sparked family discussions. In one case (Case 5); the baby clothes acted as a catalyst for discussions about the possibility of future children.
Other "bad" times which were reported were: the day of the week on which the baby died, the baby's birthday, the anniversary of the death, Mother's Day and days when the grave was visited.

Visiting the baby's grave was found generally to be an infrequent occurrence among respondents. In five cases, visiting was reported as irregular, in four cases, visiting was reported as regular with variable frequency among respondents and in one case, it was reported that the grave had never been visited.

One change which occurred in seven of the ten families interviewed was the addition of another child to the family. In two of these seven cases, the child was adopted. No family had more than one child after the death. In both cases where the child was adopted (Case 5 and Case 9), the adoption occurred nine months after the death of the previous child. In cases of biologic children, the children were born from one to two years after the death. Discussion between the marital partners about possibility of having another child began as early as the day after the death or as late as eight months after the death.

In the five cases where the subsequent child was not adopted, the pregnancy was characterized as more comfortable than it had been for the dead child and none of these children was premature.

The pregnancies for the subsequent children were reported as points of concern for all respondents involved.
One respondent (Case 8) recalled having nightmares about the death of the baby throughout the pregnancy.

In the cases where the children were adopted, the parents did not have the concerns of the pregnancy but both sets of parents were required to wait before being given another child. In both cases, the respondents found it difficult to wait for the child but both found the Children's Aid workers helpful and both stated that they got preferential treatment from the Children's Aid Society. In one case (Case 2) where the couple applied to adopt a child before having another biologic child, they stated that they found the Children's Aid Society worker not helpful and they resented being told that they would have to wait because of their experience with the death.

In all cases, the new child received more attention from the parents than had the previous child. Frequency of breathing checks was the most common change noted but in three cases, the child was also taken into the parents bedroom and remained there from three to nine months.

Older children also received additional attention from their parents in the majority of cases, particularly in terms of night checks.

In eight out of the ten cases, the parents remarked that they felt the child's death had brought them closer together as a couple. In one case (Case 8), the behaviour of the husband alienated the couple after the death and in one case (Case 4), the respondent stated that she and her
husband had been close before the death and that the death did not change this situation. In both cases where the parents separated at some point after the death, they stated that the death had not had any bearing on the separation.

Individual reactions to the death were reported in several cases. In three cases (Case 3, Case 7 and Case 9) reactions among older children were reported and one child was receiving professional assistance.

In two cases (Case 1 and 6) particular reactions were noted in the husband and professional assistance was sought (in one case the family doctor and in one case a psychiatrist). In three other cases, the husband changed jobs after the death and exhibited more inclination to take time off from work. In one more case, the husband refused to talk about the death and also refused to visit the grave or bring out a headstone. This reluctance to talk about the experience was also present in two of the remaining husbands but to a lesser extent.

Six out of the ten wives interviewed felt that the death had changed them. These changes fell along the lines of feeling stronger, changing outlooks on life and changing interpersonal relations. In one case (Case 5) the respondent felt that the baby's death had helped her to cope better with the death of her husband when it occurred.

In all ten cases, the respondents noticed changes among their friends and relatives. In one case (Case 6) definite disturbances were noted among the child's grand-
parents. In another case (Case 1) a friend who was pregnant at the time of the baby's death became upset as a result of her own fears. In two cases (Case 2 and Case 7) the respondents noted the permanent loss of some friends and in all cases, the respondents noted a temporary loss of friends. It was generally the case that friends and relatives did not visit often after the death and did not want to talk about the baby. One respondent (Case 7) noted that the baby's death appeared to have changed her family doctor in his relations with mothers.

In addition to family doctors and coroners, the respondents dealt with several different people after the death. Three sets of respondents had dealings with social workers and two of these three found the social worker helpful.

In all ten cases, clergymen were involved. In all but three cases, the clergyman was seen as being helpful. The majority of respondents felt that their religion had been of great assistance to them throughout the experience, regardless of the actual activities of the clergyman involved.

All ten sets of respondents dealt with friends and relatives at different points throughout the experience. Generally, relatives and friends were considered to be helpful up until the funeral and not helpful after the funeral. Friends were generally considered to be more helpful than relatives. In two cases (Case 5 and Case 9)
friends were found to be the most helpful people throughout the experience. In three cases, no one outside of the spouse was considered to be helpful.

In order to illustrate some of the data contained in this section in a global manner, the following charts were prepared by the researchers.
## TABLE 2

**PERCEIVED POINTS OF STRESS**

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- 3 = High Stress  
- 2 = Moderate Stress  
- 1 = Low Stress  
- = Non Applicable, or Insufficient Information

Husband/Wife
**TABLE 3**

**PERCEIVED HELPFULNESS (DEATH TO BURIAL)**

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<th>Ambulance Attend.</th>
<th>Police</th>
<th>Attending Physician</th>
<th>Coroner</th>
<th>Nurses</th>
<th>Clergy</th>
<th>Funeral Direct.</th>
<th>Friends</th>
<th>Relatives</th>
<th>Spouse</th>
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*Husband/Wife*

1 = Helpful  
0 = Not Helpful  
- = Insufficient Information or Non-Applicable
### TABLE 4

**PERCEIVED HELPFULNESS (POST-BURIAL)**

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<th>Case</th>
<th>Family Physician</th>
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**Husband/Wife**

1 = Helpful.  0 = Not Helpful  - = Non Applicable or Insufficient Information
Discussion of Data

Points of Stress and Contributing Factors

In attempting to answer the research question "what are the critical points of stress surrounding a S.I.D.S. death?", the researchers gathered the data which is presented in Table 2 on page 153. The information presented in Table 2 represents an attempt on the part of the researchers to draw together information on the commonly identified points of stress. Specific and detailed information is contained in the case histories. Information on the research question "What might the contributing factors to these points of stress be?" is not contained in Table 2 and that information will be presented here.

Table 2 indicates that the greatest point of stress throughout the experience is the actual death and the moments immediately following the discovery of the death. The literature has suggested that the point of discovery of the death is a particularly stressful time because of the shock of finding a previously healthy baby dead and feeling completely helpless (see Bergman, 1972 and Norman, 1974). The respondents in this study expressed feelings of shock and helplessness unanimously. Frantic resuscitation efforts on the part of parents despite admitted knowledge of the child's death would appear to be attempts to deal with the tremendous stress of the moment and to cope with the
feeling of helplessness. The acute stress of the moment was also evidenced by the frequent accounts of "dancing", jumping, running and screaming by respondents. The feelings of shock and helplessness were not lessened in cases where spouses were not present at the time of the discovery of the death and were notified by telephone.

The hospital experience was not shared by all respondents, although it had been considered an integral part of the S.I.D.S. experience by the researchers at the beginning of the study. As can be seen in Table 2, male respondents considered the hospital experience to be moderately stressful while female respondents found the hospital experience to be quite stressful. The difference in scores between male and female respondents was greatest in this area. This is partially accounted for by the fact that one husband went to the hospital for the specific purpose of giving permission for an autopsy and, as such, did not have the waiting process which the other respondents went through.

The respondents attributed the stress that did occur as a result of the hospital experience to the confusion of signing a variety of forms and dealing with a variety of unknown people in most cases. The stressfulness of the hospital experience was also partly attributed to the lack of speed, lack of sensitivity and vagueness with which information was given. This was particularly true of information about the cause of death and the involvement of
the coroner. In the one case where the hospital experience was considered to be not too stressful for both parents, the parents were confronted with familiar faces and were attended to constantly by nurses.

One possible explanation for the difference in stress experienced by husbands and wives at the hospital is the contention by Parkes (1972) that hospital staff do not handle death well themselves. As such, they prefer to deal with the person they feel is less likely to become emotional. This was generally the male in this sample and the findings of this study show that the husband was given more information than was the wife.

The police investigation was also not experienced by all respondents in the study. It was again the case that husbands found the police investigation less stressful than did wives. The stress attached to the police investigation stemmed from the guilt feelings which plagued the parents and from the fear that the investigation would uncover some evidence of neglect on the part of the parents. The difference in stress between husbands and wives with regard to the police investigation might be accounted for by two factors. One of these was the small number of husbands who dealt with the police (three) and the fact that one of the husbands was himself a police officer. The other factor which might account for the difference in stress is that the majority (four of five) of wives who had dealings with the police were homemakers and were more involved in the day
to day care of the child. Fear of the police uncovering some type of neglect or wrongdoing was greater for the women in the sample.

A moderate amount of stress was experienced by the respondents in relation to the coroner's report and there was little difference between the amount of stress experienced by husbands and wives in relation to this report. In the cases where the coroner's report caused high amounts of stress, the stress was attributed to the tardiness and impersonality with which the information was given or to the use of medical terminology which was not well understood by the respondent. In cases where the coroner's report resulted in low amounts of stress, the respondents reported that either 1) the information was of little consequence to them because it had been given to them by the family physician or 2) the information was received promptly from the coroner and the circumstances of the death were explained clearly.

There was a notable lack of stress surrounding the making of funeral arrangements. The researchers speculated that there was a correlation between the low amounts of stress experienced at this point and the perceived helpfulness of the funeral directors. A brief statistical analysis was done to test this speculation but the analysis yielded a chi square of 1.75 with one degree of freedom which was not significant. It is speculated by the researchers that the low amount of stress associated with the making of
funeral arrangements is, in part, accounted for by 1) the concrete nature of the task to be performed and 2) the fact that the funeral arrangements represent the first opportunity after the confirmation of death for the parents to do something for the child in order to alleviate some of their guilt feelings. The researchers have found no support for these speculations in the available literature.

The funeral and burial were described as particularly stressful times for the respondents with little difference between husbands and wives. The stress at this point was attributed to feelings of separation and loss. This observation is supported in the literature by Bowlby (1973). There was no evidence in this study to suggest that feelings of loss were intensified in cases where the child was the first-born. Feelings of separation and loss also began to surface for the dead child's siblings at the time of the funeral and burial. It should be noted that in two cases, the respondents did not make any statements about the funeral or burial and it is not known why this was the case.

The packing of baby belongings was reported as a stressful task by the respondents from whom the information was obtained. In addition to the packing of baby belongings, returning to the house where the death had occurred was stress-inducing for the majority of the respondents. In two cases the parents moved from the place where the death had occurred and attributed the move to the effects of the death. The stress surrounding these two points of time
(i.e. packing the baby's belongings and returning to the house where the baby had died) resulted from memories of the death. In the cases where friends and relatives packed the baby's belongings shortly after the death, the stress involved in the performance of the task was delayed until the belongings had to be unpacked or repacked. The stress did not appear to have been diminished in these instances but those respondents who found it helpful to have the baby's belongings packed initially for them stated that they felt better able to cope with the stress at a later date. Husbands were less inclined to become involved in the packing of the baby's belongings than were wives but when they did become involved, they did not experience less stress than did their wives.

Visiting the grave was a notable point in the experience in that it was the only point at which wives admitted less stress than their husbands. It should be noted that the researchers interpreted a refusal to visit the grave site as an indication of high stress levels about such visiting. The researchers observed that stress levels were lower in respondents for whom visiting the cemetery involved also visiting the graves of other members of the family who had died. There is support for this observation about previous experience with death in the crisis intervention literature (see Lindemann, 1965, Rapoport, 1965, and Williams, 1973). It was noted that the desire to do something for the child which the researchers speculated as a
factor in reducing stress during the making of funeral arrangements was absent in the case of visiting the grave site. The researchers found no evidence to suggest a reason for the higher stress levels among husbands in this area.

The subsequent pregnancy or adoption was more stressful for wives than for husbands although stress was not really high for either. The stress which did occur in the cases of pregnancy was attributed to fears about the health of the new child and the possibility of another death. It is speculated by the researchers that wives showed more stress in this area than did husbands because 1) the pregnancy for the dead child had been uncomfortable in the majority of cases and 2) wives are more directly responsible for the physical health of the foetus through pre-natal care.

In the cases where the next child was adopted, stress centred around the fear that the Children's Aid Society would not permit another adoption by the family.

In cases of both pregnancy and adoption, guilt feelings about the death resurfaced at this time and added to the stress of the situation.

The care of the new child created stress in the respondents which centred around fears for the new child's life. Added to the emotional stress of these fears was the physical stress of sleeplessness and constant vigilance which occurred in the majority of cases. The stress reported as resulting from the care of the new children was second
in intensity only to the stress of the death itself and husbands and wives did not differ greatly in the amount of stress they showed. The stress of caring for and worrying about a new child following the death of the previous child is discussed in literature by Norman (1974) who cites fear of incompetence as a care-giver as a source of stress. The rise in the stress level of husbands is felt by the researchers to be accounted for in part by the change in the amount of care given to the new child. In the majority of cases, husbands took a larger part in the care of the new child but in two cases, the husband took a dramatically small role in the care of the new child.

In summary, the researchers found that stress levels varied from situation to situation and were connected to feelings of guilt and helplessness as well as feelings of separation and loss. Table 2 indicates that stress levels fluctuate from a high at the time of death to high at the time of the subsequent birth or adoption with an intermediate peak at the time of the child's funeral and burial. It should be noted however that Table 2 presents numerical representation of nominal data and as such the scores are not attached to any absolute value.

Perceptions of Helpfulness

In order to help answer the research question "What types of intervention did the families feel were helpful or would have been helpful?", the researchers have prepared
two tables (Table 3 and Table 4 on pages 154 and 155). The tables have been prepared to represent two different time frames because it was suggested by the data that certain forms of intervention and certain individuals were of varying degrees of assistance, depending upon the time period. It should be noted that in Tables 3 and 4 only those observations by people who participated in the interview are included. This was done because perceptions of helpfulness are not readily observable forms of behaviour and the opinions of those people not involved in the interviews might not be accurately represented by the respondents.

The data which appears on Tables 3 and 4 have suggested to the researchers that the perception of the helpfulness of an individual is connected with the role expectations which one has for that individual. This is particularly true with individuals who are unknown to the family and as a result, whose role expectations are defined by the particular job which they hold.

In the case of the ambulance attendants who were perceived as helpful by the majority of the respondents who dealt with them, the expectations placed on them by the respondents were that they would arrive quickly when called, transport the child to hospital and would try to revive the child with the equipment which they had at their disposal. In the majority of cases, the ambulance drivers did what was expected of them and as such were deemed helpful.
Additional helpful behaviours which were performed by the ambulance attendants included: 1) waiting for a spouse to arrive home before transporting the child, 2) transporting parents to the hospital and encouraging them on the way 3) agreeing to take the dead child when they were under no legal obligation to do so and 4) assisting in resuscitation attempts in the house. There were cases where the ambulance drivers did not fulfil their role expectations and were still perceived as helpful. It is speculated by the researchers that in the shock and confusion which immediately followed the death, any person who reacted calmly and efficiently in that situation was likely to be perceived as helpful. In the one case where the ambulance attendants were not perceived as helpful, they did not ask the parents to accompany them to the hospital and as such were considered insensitive.

The police who investigated in three cases were perceived as helpful by the majority of the respondents because they did not fulfill their role expectations. The thought of the police investigation was a source of concern for most respondents and the sensitivity of the police officers who 1) explained the purpose of their investigation and explained the procedures as they did them and, 2) asked questions of the respondents without implying any criminality. In one case, the police did not conduct an investigation but were considered helpful in that they escorted the parents to the hospital when they found them
speeding through town. In the one case where the police were not considered helpful, the complaint against them was that they excluded the respondent from their investigation and gave her no information as to what they were doing.

The physicians (excluding coroners) who were involved in the experience were found to be not helpful by the majority of the respondents who came into contact with them up until the time of the burial (Table 3). The physicians were, however found to be helpful by the majority of respondents in the period of time following the burial (Table 4).

The respondents reported several reasons for their changes in perception with regard to the helpfulness of the physician: 1) the majority of respondents dealt with an "on duty" physician at the hospital but with their family physician following the burial. The respondents felt that familiarity with the physician was an important factor in their change of perceptions. 2) Before the burial, the physician was vague and impersonal but the family physician was able to be more explicit in his explanation of the death following the burial. 3) The physician was more in a rush at the hospital than in his office following the burial.

Role expectation also appears to have influenced the respondents' perception of the helpfulness of the physician. When the physician is first contacted it is hoped that he will somehow be able to save the child with
his skill and there is a certain amount of disappointment when the child is unable to be revived. The physician, with his medical knowledge, is expected to have an explanation for the child's death and in the case of S.I.D.S. where an explanation is not immediately possible, disappointment again sets in. When the parent visits the family physician after the burial, the focus of the physician shifts from the dead child whom he was examining at the house or the hospital to the parent in his office, and as such, the parent feels more attended to. The physician after the burial also has access to the autopsy information and is in a better position to explain the circumstances of the death than he or the attending physician was prior to the autopsy.

This speculation is supported by the respondents who identified the family physician's ability to explain the death after the burial as helpful. Preliminary explanations at the hospital, when they were attempted, were also found helpful by the respondents.

The coroner was found to be not helpful to a small majority of respondents who dealt with him prior to the burial and a larger majority of those respondents who dealt with him after the burial. In terms of expectations, the coroner is the person who is the final authority on the cause of death and it is he who has the most detailed information on the death. As such, he should be the one who is able to provide the best explanation for the death.
In the cases where the coroner was perceived not to be helpful he: 1) "breezed in and out" without talking to the parents, 2) did not provide the information from the autopsy report within a "reasonable" period of time, or 3) provided information that was deemed to be inadequate or difficult to understand.

In the cases where the coroner was perceived as helpful, none of the above behaviours occurred and the coroner was perceived as less impersonal.

One explanation for the perception of the coroner as less helpful after the burial is that by the time the burial has taken place, several days have elapsed and anxiety in the family has increased about obtaining the facts about death.

Nurses were perceived by the majority of respondents to be not helpful. Nurses were perceived to be not helpful when they: 1) reacted impersonally or insensitively to the respondent, 2) gave little or no explanation for the forms which they were filling out or the procedures they were conducting, 3) did not spend any time with the parents and 4) declined to offer any information about the condition of the baby.

The expectation placed on a nurse is that she: 1) has some medical knowledge but is "closer to the common man" than the physician and, as such, is able to provide down to earth explanations of medical matters and 2) is a warm and compassionate person who provides "tender loving care".
When these expectations were not met, nurses were perceived as not helpful by the respondents.

Respondents' recommendations around hospital procedures reflect the expectations outlined above.

Members of the clergy were perceived as helpful by a small majority of the respondents during the time period from the death to the burial. After the burial, only two respondents recalled any particular dealings with their clergyman. The major expectation of the clergyman is spiritual guidance and comfort. In cases of death of an infant, concerns of baptism and funeral rites are also directed to the clergyman.

In the cases where the clergyman was perceived to be helpful, he: 1) baptized the dead child, 2) provided practical assistance with the funeral arrangements, 3) made comforting remarks about the "life after death" of the child and 4) attended to the emotional and spiritual needs of the parents by listening and, in one case, leading the parents in a hymn sing.

The behaviour of the clergyman did not differ much from case to case but the perception of his helpfulness did. Based on comments from the respondents, the researchers developed two possible explanations for this phenomenon.

1) The respondents, in the midst of angry feelings about God, were not in a position to be comforted with spiritual guidance.

2) The clergyman was seen not as a person but as a
representative of a particular system of beliefs, a system not subscribed to by the respondents.

The funeral director was viewed as helpful by a large majority of the respondents. One respondent identified as an expectation of the funeral director that he would try to sell him elaborate accessories that he did not want and in one case where the funeral director was not considered helpful, this did occur.

In the cases where the funeral director was perceived as helpful he 1) suggested funeral arrangements for respondents who were unfamiliar with the process (see Morrice, 1976), 2) made all arrangements including contact with the clergy in most cases, 3) allowed for special requests of the family (e.g. private visitation before the funeral), and 4) provided information on S.I.D.S. in the form of pamphlets. The providing of S.I.D.S. information was unexpected to most respondents and was greatly appreciated by all. The funeral directors were described as sensitive, understanding and comforting. The researchers have speculated that the funeral directors' attitudes toward and experience with death were partly responsible for the perceptions of the respondents.

Friends and relatives of the respondents were perceived to be helpful by a large majority of the respondents from the death through to the burial. After the burial however, friends and relatives were considered not helpful by a small majority of the respondents.
Up to the point of the burial, friends and relatives performed practical tasks for the family such as: driving parents to or from the hospital, packing baby clothes, notifying other friends and relatives, preparing food for visitors, babysitting younger children and, as has previously been reported, attempting to resuscitate the child in three cases. Friends and relatives also provided emotional support for the family either by "just being there" or by talking and listening to the parents. In the cases where friends and relatives were considered not to be helpful, this feeling was attributed to "callous" or accusatory remarks which they made to the respondents (see for example Case 6).

After the burial however, respondents reported that friends and relatives: 1) stayed away, 2) visited but avoided any discussion of the dead child, 3) engaged in speculation about the parents' involvement in the death (one case), or 4) asked questions about the circumstances surrounding the death and made comments which the respondents considered upsetting.

In the cases where friends and relatives were deemed to be helpful, they continued visiting and socializing with the family and felt free to discuss any topic which the respondents introduced.

It should be noted that several respondents made the remark that they felt that they had to be more understanding of their friends than their friends were of them after the
death. It is the researchers' opinion that this is a further indication that the effects of a S.I.D.S. death extend beyond the boundaries of the nuclear or even the extended family.

Spouses were considered helpful by all respondents during the time period from the death to the funeral. Helpful behaviours were identified by the respondents as:
1) being emotionally supportive, 2) helping to alleviate guilt feelings, 3) talking about the experience and 4) performing tasks when one partner or the other was "not up to it". Where these behaviours were continued after the burial, perception of the spouse as helpful also continued.

Two spouses (both husbands) were not considered helpful following the burial and in both cases, this perception was attributed to an unwillingness on the part of the husband to engage in conversation about the death or the dead child. In one of these cases, the husband also engaged in behaviour (i.e. drinking) which caused him to be absent from home much of the time and this was not considered to be helpful.

Social workers were involved in only three cases and all of these cases involved the question of adoption. In all three cases, the social worker told the parents to wait before deciding to adopt because of their experience with the dead child. In two cases, this was found to be helpful in retrospect. In one case this was found not to be helpful and the respondents decided against adopting.
The two respondents who perceived the social worker to be helpful also felt that the waiting period was shortened once they did apply to adopt a child because of their experiences. They reported that they found this extra consideration helpful.

In summary, perceptions of helpfulness were dependent on 1) the expectation of the respondent of the helping person, 2) the behaviour of the helping person and 3) the attitude of the helping person. In the period of time following the burial, attitude became a primary concern for the respondents and those helpers who were able to react with sensitivity to the respondents were perceived to be helpful. The respondents' feelings on what would have been helpful are contained both in the text of the case histories and in their recommendations.

Perceptions of helpfulness also had a bearing on the total impact of the experience on the family.

Impact of S.I.D.S.

The question of the impact of a S.I.D.S. death is multi-faceted and complex. The results of this study have indicated that there is an immediate impact as well as a long term impact. In actuality, there are a variety of impacts of a S.I.D.S. death, both short term and long term. The researchers therefore have chosen to discuss the data on the impact of a S.I.D.S. death on a family in two sections. Throughout these sections, the results obtained
in this study have been compared with information which the researchers found in the available literature.

Short Term Impact

The full impact of finding a previously healthy child suddenly dead is extremely difficult to determine and the results of this study have only superficially answered the question. All respondents noted an acute rise in their stress levels as the death triggered an alarm reaction. Among the reactions reported by the respondents who initially discovered the dead child were: complete immobility for a few moments, emotional flooding with no one emotion standing out, instantaneous denial of the death followed by frantic efforts at reviving the child through yelling, shaking or other forms of resuscitation. In addition to these responses, many of the respondents screamed and it was common for them to become hyperkinetic, run or dance wildly about the house. One respondent reported that his wife gave him the dead child immediately and began running about the house throwing anything she could lay her hands on. Some respondents reported that they picked up the child immediately, while others (two cases) reported that they were unable to touch the child.

The two husbands who were told of the baby's death over the telephone tended to exhibit the same type of response as those of the respondents who had been present
when the child was found dead. Attempts to deny the death and a desire to run were reported.

Those husbands who had not been told specifically of the death began to think of the possibility of death while they were travelling home.

In cases where the husband was not present when the dead child was discovered, he tended to ask questions immediately upon entering the house and was generally more able to function than those people who were present at the time the child was found. This finding might lend additional credence to Lindemann's (1965) concept of "anticipatory grief".

The results of this study would indicate that the initial impact of a S.I.D.S. death is most often not the triggering of feelings of guilt. Immediate feelings of guilt were reported in only one case. The guilt response which is mentioned in the S.I.D.S. literature (see Bergman, 1972, Norman, 1974 and Pomeroy, 1969) appears to set in after the initial feelings of shock and disbelief.

Following the initial period which lasted from a few moments to several hours for the respondents, feelings of "numbness" set in in several cases. This numbness was characterized by confusion (one respondent did not think to call the ambulance or the doctor until she was told to do so) and uncommunicativeness. The respondents generally said very little to anyone during this time and did not seem to be aware of what was taking place around them. This
is evidenced by the lack of recollection about what happened shortly after the death was discovered. Female respondents noted a period of numbness more than did male respondents. The feeling of numbness lasted varying lengths of time for the respondents. Some respondents recalled recovering from this feeling rather quickly while others recalled feeling numb up to and through the funeral. It was also reported that feelings of numbness surfaced from time to time throughout the experience. In one case the numbness appeared to the researchers to have lasted for five months following the death but this was difficult to determine accurately because the respondent was still on medication at the time of the interview.

Feelings of guilt surfaced at some point after the death for all respondents but the circumstances surrounding the surfacing of these feelings varied considerably. In some cases, the guilt feelings surfaced soon after the discovery of the death and without any precipitating events other than the death. In other cases guilt feelings were triggered by the phoning or arrival of the police, the introduction of the topic of autopsy, casual statements by relatives or hospital staff, questions by the police, doctor or hospital staff about the condition of the baby prior to the death, or the involvement of the coroner. These findings appear to be consistent with the description of the experience by Bergman (1974). One respondent stated that her guilt feelings would have surfaced regardless of what
anyone said or did and the researchers cannot speculate as to what effect more sensitivity on the part of people involved with the family would have had with regard to guilt feelings.

Anger is also frequently reported in the literature (see Pomeroy, 1969). Immediate anger was reported by one respondent and anger surfaced shortly after the death in three other cases. In these four cases, the anger was usually directed at no one and everyone. God was often mentioned as the recipient of initial anger. No one group of people who dealt with the family was untouched by their anger. Angry feelings were reported in relation to the activities or statements of ambulance attendants, doctors, nurses, police, funeral directors, clergy, social workers, friends and relatives. Most commonly, the respondents reported feeling angry at what they considered to be an impersonal attitude or insensitivity.

The arrival of the various people who came to the house immediately following the death resulted in confusion for the family. In the majority of cases, the parents were not directly involved in the activities of those people who came into the house. The baby was taken from the parents and, if not directly transported to hospital, taken to another room of the house. If this was not the case, then the parents were ushered to another room of the house. In the cases where the husband was home, he tended to become more involved in the activities of those people who came into the
house, asking questions and assisting in resuscitation attempts. In virtually every case where the wife did not go immediately with the child in the ambulance, she sat in the kitchen and was not involved in any of the activity. The researchers have wondered about the significance of the room chosen by the wives.

The confusion experienced by the respondents appeared to be tied into 1) the number of people entering and leaving the house, 2) the rapidity with which some people performed their functions and left, and 3) the lack of information provided to parents about what was being done and why it was being done.

In the four cases where detailed information was available about the hospital experience, it was found by the majority of the respondents (three of four) to be a confusing and frustrating experience. The respondents expressed some expectations of the hospital staff that they would be understanding and would be able to explain what had happened to the baby. One respondent commented that the hospital was the last hope for him that the baby might be saved.

It was in these areas of understanding and explanation that the respondents found the hospital staff most lacking. No respondent felt that the child did not receive adequate care and attention. In only one case however, the respondents felt that they had received adequate attention to their needs and sufficient explanation about the circumstances of the child's death. It should be noted that this
was also the only case in which the family physician was present at the hospital.

For the remaining three sets of respondents, the hospital experience consisted of a confusing array of documents to be signed, nurses who declined to divulge the condition of the child, doctors who stated that they could find nothing which caused the death and waits of various lengths in general and private waiting rooms. The result of these experiences was that the parents 1) were left bewildered about what had taken place, 2) felt at a loss for a reason for the child's death and 3) felt disappointed about the help that they had received. Two respondents identified hospital experiences as a source of guilt feelings. Both of these incidents centred around the subjects of the coroner's involvement and the autopsy. The hospital experience was the source of a great many of the recommendations which were made by the respondents. In the one case where the respondents reported that the hospital experience did not have a great impact on them, a nurse was continually with the parents and both the family doctor and the coroner talked with the parents.

The funeral process was handled well by the majority of respondents. The short term impact included a rise in level of stress, as illustrated by Table 2. Individual respondents reacted in most cases with the stoicism expected by our society, particularly among males (see Williams, 1973). In other cases, parents responded with
anger (see Cases 7 and 8) and in one case, a respondent had to be taken to hospital for tranquilizing medication. The results of this study indicate that where visitation took place at the funeral home, this had a greater impact on the family than the actual funeral. It should be noted that although Morrice (1976) stated that the making of funeral arrangements can be an upsetting experience, this was not found to be the case in this study. One wife was still in a state of confusion at the funeral home and could not remember what had gone on around her.

The incidents surrounding the funeral process which had the greatest impact involved visiting friends and family members who were unable to be of any comfort or were insensitive in their remarks. These incidents resulted in bitter feelings and anger on the part of the parents and in one case, a severe disturbance in the relationship between a husband and his father-in-law. In another case, a previous experience with funeral home visitation resulted in the decision to avoid having the child "laid out".

The funeral service brought few recollections from the respondents. In one case the child's parents spent half an hour alone with the coffin and delayed the funeral service. In another case a husband had to take his wife away from the coffin prior to the funeral service.

The burial resulted in an emotional outburst on the part of two wives, one of whom had to be ushered away from the grave site. The burial also resulted in a delayed
reaction on the part of a child who returned home and cried for most of the afternoon.

Post-burial reactions will be dealt with in the following section under the heading Long Term Impact.

Long Term Impact

Long term impact is taken by the researchers to include those reactions which did not occur as an immediate response to an occurrence from the time of the child's death to the burial.

One of the most common reactions to the death as reported by the respondents was sleeplessness. All couples reported some amount of this. The family doctor was contacted by three respondents because of problems with sleeping. In one case sleep disturbances were reported to be occurring 1½ years after the death. Sleep disturbances were reported in two children as well and the respondents reported the presence of the dead baby's crib as the source of the problem in one instance. In the other instance the sleeplessness was considered by the parents to be a reaction to the loss. These findings are in agreement with those reported by Pomeroy (1969) and Segal (1974).

Respondents reacted to their spouses in one of two ways. Although nine respondents stated that they felt that they became closer as a result of the death, this was not so in every case. In three cases, the marital couple spoke to each other only minimally for some months after the death.
In all three cases, it was the husband who admitted to irritable behaviour. In one case, the death produced an intensification of previous pugnacious and drinking behaviours. To varying degrees, irascibility was reported by all respondents.

In the cases where the couple did become closer following the death, there was a dependency exhibited as expressed in statements such as "he wouldn't leave my side" or "we realized we only had each other". In two cases, the parents also spent a great deal of time with their children and admitted to overprotective behaviour beyond what they knew was reasonable.

Couples who began by hardly speaking to one another gradually became communicative as time wore on. It was the rule rather than the exception that discussions about the death did not take place until several months after the death. In the nine cases where it was possible to determine, it appeared that all couples had re-established an equilibrium within a year of the death. According to the couples, the level and type of functioning was similar to the pre-death level. No respondent reported a permanent disturbance in the marital relationship as a result of the death.

It should be noted that both of the separated couples who were interviewed were on friendly terms at the time of the interview although one separated husband did not participate in the interview. The researchers found little evidence which would support any contention that the death
was directly responsible for the separation of these two couples. In one case (Case 8) blaming of one parent by the other did occur and this might be taken as a source of marital discord (see Hill, 1965, on intra-family events and Williams, 1973).

The impact of the death on individual members of the families also varied considerably. Husbands went into "fits of depression", isolated themselves from friends and family, clung to their wives and children, drank excessively and fought with everyone, or tried to continue as before. Three husbands changed jobs following the death (one frequently) and one husband was in the process of changing careers at the time of the interview. Loss of interest in work was reported by the majority of husbands and in three cases, permanent reappraisals of the importance of work were made.

It was reported that two husbands refused to visit the grave site and in two other cases, husbands were the most persistent visitors to the cemetery.

There were no reports of relationship disturbances at work but two husbands reported that they were disturbed by questions about the death which they received from fellow workers. This was part of a reported sensitivity with regard to the lack of an adequate explanation for the child's death on the part of all respondents.

It has been reported in the literature (see Pomeroy, 1969) that there is a "typical" male response to a S.I.D.S.
death which involves "closing the book" on the experience. This was found by the researchers not to be the case. There was evidence in only three cases that the husband would not have participated in the interview if it was possible. There were seven cases where it was reported that the husband refused to discuss the death with his wife but in the majority of these cases, the refusal was temporary.

Wives responded to the death with a mixture of sadness and anger. They spent more time attending to their other children when this was possible and tried to keep busy around the house to avoid thinking about the dead child. In two cases increased contact with friends was reported and in one case it was reported that a great deal of time was spent driving around town and visiting the cemetery.

Memories of the child resulted in reactions to situations such as 1) pregnancies of friends and relatives, 2) packing baby belongings and 3) dealing with friends and relatives around the subject of the death. Wives also reported more often than husbands that the day of the week on which the child died and birth and death anniversaries bothered them.

The majority of the women respondents reported that they had undergone attitudinal changes. These changes took the form of "living more for today" or "dealing differently with people". One respondent reacted to the death and the subsequent refusal on the part of her husband to talk about
the death by spending time crying to herself and throwing
glasses into the fireplace to drain off some of the anger.

The mother of the child who died most recently re-
ported periods of depression during which she contemplated
suicide. Those wives who displayed little overt emotional-
ity following the death stated unanimously that they felt
they should "hold up" for the sake of the other children.

The wives who fared worst in terms of their own
assessment of their adjustment to the death were those who
attempted to cope with the situation without the help of
outside resources. These attempts to cope with the situ-
tion alone were either by choice (see, for example, Case 8)
or by default (see, for example, Case 2):

The researchers received information on the react-
ions of nine children to the death. This information was
based on parental observation.

In Case 1, the children did not ask much about the
death but they did advance the dead child's birthday three
days so that their brother and baby Jesus could celebrate
the same birthday.

In Case 2, the son asked about the dead child for a
year after the death and occasionally called the child's name
in the night. He also reacted to his parents' moods by
attempting to comfort them when they were feeling depressed.

In case 3, the oldest child reacted strongly to the
death. He refused to talk about the child for a long time
and he became very upset when his mother decided to give away
the baby's belongings. The younger child in this family reflected the lack of information which she had been given about the death in that she would make up stories about the circumstances surrounding it so she could tell her friends.

The son in Case 5 reflected his lack of information about death in that he asked his mother after the new child had been adopted if he could have another sister after "this" child died. This response prompted further discussion between mother and son about death.

Two of the three children in Case 7 reacted to the death in manners that were observable to the parents. The older child developed problems at school and in her relationships with family and friends. A year after the death, she admitted to her mother that she felt very guilty because of the jealousy she experienced when her mother became pregnant for the dead baby. The youngest child in this family also reacted to the death by preoccupying herself with the baby's death and expressing a desire to die herself. Her mother attributed part of this behaviour to the fact that she was the only child who was not included in the funeral process.

In Case 8, the son reacted to his sister's death with sleeplessness and fears that he would also die. He also developed a relationship problem at nursery school which required professional intervention in the form of group therapy.
Norman (1974) described many of the reactions of children which the researchers discovered in this study. The point has also been made in the literature that children will take their cues on how to react to death from their parents. This is also evident from the findings of this study.

The impact of the death had several common elements for both parents. The most notable of these elements is guilt. In two out of the ten cases, a respondent reported a complete absense of guilt feelings. In one of these cases however, the respondent followed up this statement by saying "I just wish I had checked the baby sooner". The guilt experienced by the parents manifested itself strongly in the form of overcompensation with the remaining or subsequent children.

Guilt feelings also prompted virtually every respondent to state at some point in the interview that they felt partly responsible for the child's death. The respondents realized that the guilt feelings were not grounded in fact and the majority of them had been told often that they were not to blame for the death, but as one respondent put it: "It's a difficult feeling to shake".

Another common reaction to the death was the desire to have another child. Of the ten couples, only three did not add another child to the family after the death and of these three, only one respondent was completely satisfied with the decision not to have another child.
The death of the child had an impact which spread beyond the boundaries of the nuclear family. The findings of this study would indicate that in every case, relatives and friends of the family also had immediate and long term reactions to the death. In one case, disturbances in the extended family were clearly noted and in all cases, friends and relatives reacted to the death by either avoiding the couple or avoiding any mention of the dead child. There were also two cases where blame for the death was placed on the parents by friends or relatives. These phenomena have been described in the literature by Norman (1974).

In summary, the findings of this study indicate that the impact of a S.I.D.S. death on a family is not confined simply to the nuclear family and reactions to the death are highly individual. Guilt feelings are almost universal as is the quest for information about the nature of S.I.D.S. Other reactions are dependent on the nature of intra-family and extra-family support systems more than on professional support systems. The only findings which severely contradict information in the available literature are those surrounding the male response to a S.I.D.S. death.

The findings of this study have led the researchers to develop some conclusions and recommendations which are presented in the following chapter.
CHAPTER V

LIMITATIONS, CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

This study was undertaken for the purpose of gaining insight into the effects of a Sudden Infant Death Syndrome death on the family in which the death occurred and to develop priorities for future research into this area.

In order to accomplish these purposes, the researchers developed the following research questions:

1) What are the readily observable points of stress surrounding a S.I.D.S. death?
2) What might the contributing factors to these points of stress be?
3) What types of intervention did the families feel were helpful or would have been helpful?
4) What is the impact of a S.I.D.S. death and subsequent interventions on the family?

In order to answer these questions, an interview schedule was developed and ten families were interviewed in person by the researchers.

This chapter will be used to present the limitations of the findings of the study, to draw some conclusions from the findings, to discuss the implications of the findings for social work and to present recommendations for consideration. Because of the stated purposes of the study, recommendations for further research will also constitute conclusions of the study.
Limitations of the Study

Because the stated purposes of the study included the establishment of priorities for further research, the conclusions drawn from the findings of the study can be considered of no more importance than the recommendations for further research.

The small size of the sample limits the generalizability of the findings. Conclusions which are drawn from the findings of the study can only legitimately apply to those S.I.D.S. families who participated in the study.

The purposive nature of the sample also limits the generalizability of the findings in that no claims can be made for the representativeness of the sample.

The voluntary nature of the sample may tend to bias the findings in that it may be argued that those families who volunteered to be interviewed would show better adjustment to a S.I.D.S. death than the population and would therefore not accurately represent the situation within the population.

The use of self-reporting, where respondents were called upon to give their own accounts of the experience and their feelings about it, may limit the findings of the study in that some of the respondents might have chosen not to divulge information which was too painful or which was felt not to be relevant or important.

Finally, although the prejudices of the researchers
were explicitly stated from the beginning of the study and attempts were made to control for them (see Chapter III), they may have biased the findings in a manner that is unknown to the researchers.

Conclusions

From the findings of this study, the researchers have arrived at some conclusions. These conclusions represent hunches which will require testing under more rigorous scientific conditions than were attempted here.

Stress Points and Contributing Factors

There is evidence from the findings of this study to suggest that there are three critical points of stress throughout the S.I.D.S. experience of a family and there are other points of lesser stress.

The three points of most stress which were indicated by the findings of the study are 1) the discovery of the death itself, 2) the funeral and burial period and 3) the introduction of a new child into the family. These points of stress for the respondents were associated with feelings of guilt, helplessness and loss. The amount of stress which stemmed from these three points within the experience did not appear to be affected by the perceived helplessness of any person who came in contact with the family.

Points of lesser stress throughout the experience were identified as 1) the police investigation, 2) the
hospital experience, 3) the coroner's report, 4) the funeral arrangements, 5) the return to the house and the packing of baby belongings, 6) the visitation of the grave site and 7) the pregnancy or adoption plans for the next child. There was also stress surrounding various individual memory-inducing events such as anniversaries of the birth or death of the child, the day of the week on which the child died or contact with pregnant friends or friends with small children. There was some evidence to suggest that these lesser points of stress were somehow amenable to mediation by helpful behaviour on the part of other persons, both inside and outside the family, but this requires further testing.

Perceived Helpfulness

The findings of the study indicate that perceptions of helpfulness for the same person may vary from point to point in the experience. People who are perceived as helpful from the point of death to the funeral and burial may not be perceived as such following the burial.

There was evidence from the study to suggest that perceptions of helpfulness were in part related to the expectations which were placed on the helping person. That is to say, people who met or exceeded the expectations of the family tended to be perceived as helpful.

Helpfulness was perceived by the respondents of this study in terms of behaviour and attitude. Both of these factors were considered to be important up to the point of
the burial and attitude was of primary importance during the
time following the burial.

This feeling on the part of the respondents resulted
in friends and relatives being perceived as helpful up until
the burial and not helpful after the burial. Friends and
relatives tended to be more comfortable in dealing with the
family when they were able to perform concrete tasks for
family members. They were less comfortable in dealing with
the emotional impact of the death on the family and tended
to avoid dealing with this. This was also true of hospital
personnel.

Respondents in this study expressed a great desire
for information about the nature of the death and people
who were able and willing to provide this information were
perceived as helpful. This resulted in the physician being
perceived as not helpful before the autopsy but helpful
following the autopsy. This also resulted in the funeral
director being perceived as helpful and the coroner being
perceived as helpful only in cases where he was able to
explain the nature of S.L.D.S. quickly and clearly. Through-
out the experience, families tended to rely on their own
members and significant others for support rather than on
outside agencies.

Where strong religious beliefs were held by the
respondents, they were found to be helpful on a long term
basis. Strong religious beliefs did not however, necessarily
lead to perceptions of helpfulness for the clergy who became
involved with the family.

Impact

The most notable conclusion which the researchers have arrived at as the result of the study is that the impact of a S.I.D.S. death extends far beyond the boundaries of the family. A S.I.D.S. death results in shock waves which reverberate throughout the family system, the extended family systems, "significant other" systems and professional systems. Non nuclear family members may in fact react more strongly to the death than the family.

Guilt feelings develop as a result of a S.I.D.S. death and although they are lessened by information about S.I.D.S., they are not amenable to eradication. Guilt feelings for the respondents of this study did not disappear over the course of time (up to three years in the case of this study).

Feelings of anger diminished with the passage of time but also did not disappear.

Helpful behaviour and attitudes on the part of friends and relatives during the S.I.D.S. experience resulted in the strengthening of bonds between the family and the helpful person. The reverse of this was also found to be the case.

Despite the emotional impact of the death, the families in this study were not "devastated" as Norman (1974) suggested. The researchers found little evidence of gross
long term behavioural or emotional disturbances among the families. Reticence on the part of family and friends to deal with the family appeared to be based more on assumption than on actual fact. Children of the families also coped with the death without being devastated and this coping was enhanced by the inclusion of the children in the grief process. Little evidence was uncovered to suggest that males do not wish to talk about the experience. Expectations placed on husbands that they should not grieve resulted in more of a tendency toward "closing the book" than expectations that husbands should react like anyone else.

There was evidence in the study to suggest that the impact of the death was diminished by: 1) previous experience with death at close range and 2) permission on the part of family members and outside helpers for the family to grieve.

Recommendations

The conclusions arrived at in the study have led the researchers to propose the following recommendations:

1. People who come into contact with families who have just experienced a S.I.D.S. death should approach them with sensitivity but not with fear. S.I.D.S. families are not fragile and they do want to talk about their dead child. People dealing with
S.I.D.S. families should take their cues from the family members on what topics are suitable for discussion. It hurts more to have the dead child ignored than to have him mentioned.

2. Families who have just experienced a S.I.D.S. death often appreciate help with practical concerns. It should not be assumed however, that these families can do nothing for themselves. Before doing anything for the family, helpers should inform the family of what they would like to do and check to see if the family members would rather do it themselves.

3. Children should be included in the total experience of the death. Children also need to grieve for the lost child and exclusion from the bereavement process may result in greater emotional disturbance than inclusion in family bereavement. It should not be assumed that funerals and burials are too traumatic for children to be involved.

4. The events surrounding the death of a child at home can be confusing to families. Attempts should be made to explain what is taking place and why it is taking place. Autopsies and investigations may need to
be performed, forms may need to be signed and special procedures may need to be carried out. An explanation of the necessity of these procedures would help to diminish feelings of confusion and guilt which surround the death. The subject of autopsies especially needs to be approached with care and sensitivity.

5. Hospitals can be foreboding places for the parents of a dead child. Parents should not be made to wait in the general waiting area. The family doctor should try to be in attendance whenever possible and hospital staff should attempt to telephone a friend or relative of the family to provide them with a friendly face. If this is not possible, a hospital staff member should be assigned to attend to the family and should attempt to explain what is happening. A staff member who has had a similar experience may prove helpful to the family. Upon departing from the hospital, parents should be told what will take place in their absence and when the child will be released to the funeral home.

6. S.I.D.S. families want and need information about the death quickly. Preliminary ex-
planations of the death as soon as possible with the promise of more detailed information as soon as it is available are helpful. Printed information on S.I.D.S. should be made available to families as soon as possible and extra copies for friends and relatives would also be helpful.

7. Information about the death should come from a physician whenever possible. Coroners and family doctors are the most likely candidates to give detailed explanations after the autopsy but emergency room physicians should take time to offer some type of explanation immediately after their preliminary examination. S.I.D.S. families find it helpful to discuss the death with a physician and to ask questions. Five minutes on the telephone is not sufficient.

8. S.I.D.S. parents need to be told immediately that they were not to blame for the death and this should be reinforced by everyone who comes in contact with the parents throughout the experience.

9. Follow-up with S.I.D.S. families is an area which is in desperate need of attention. A crisis team consisting of a public health
nurse (preferably the one who visited shortly after the birth), a social worker and a S.I.D.S. parent could provide a valuable service to S.I.D.S. families. This team would contact the parents shortly after the death and offer to visit at the family's convenience. The family should make the decision about the timing of the follow-up visit. The number of follow-up visits would vary from family to family but any serious problems would be referred to an appropriate agency (including self-help groups).

10. Public education about S.I.D.S. is desperately needed. Families who experience a S.I.D.S. death are often not aware of S.I.D.S. and friends and relatives can often be hurtful to the family because they also are not aware of S.I.D.S. Much confusion could be avoided if a common name for S.I.D.S. could be arrived at.

11. Self-help groups should be formed so that they are available to all families who require an opportunity to talk with people who have been through the experience.
Implications for Social Work

Although the implications discussed in this section are directed primarily at social workers, many of them apply equally to any helping person who comes in contact with a S.I.D.S. family.

Many of the stress-producing situations which S.I.D.S. families experienced resulted from a lack of good communication. It occurs to the researchers that social workers, with their expertise in interpersonal communication, would be the obvious people to involve themselves in cases of S.I.D.S.

Feelings of guilt and confusion often arise for S.I.D.S. families when they are not notified of what is being done or the reason for a particular procedure. Acting as advocates for the family, social workers can work to improve methods of communicating information so that other helpers will keep families posted on what is happening at all times. It would also guarantee that parents rights were not ignored in the interest of expediency or out of discomfort on the part of helping professionals. Mediating between families and other professionals would also seem to be an appropriate role for social workers.

Education of other professionals with regard to the impact of S.I.D.S. on a family is another role for social workers. This information would prove to be a valuable addition to the medical knowledge of hospital staff and
physicians. It might also help to diminish the frequency of casual remarks which respondents in this study found upsetting.

Dealing with S.I.D.S. families requires a certain amount of introspection on the part of helping persons with respect to their own feelings on death. The introspection which is a part of the social work education process gives social workers an advantage in dealing with S.I.D.S. families and hopefully makes them more sensitive to family needs.

Clinically, social work skills in fostering better communication between people and teaching alternate methods of coping with crisis would seem to be of great value in assisting S.I.D.S. families to continue functioning smoothly after the death. Where breakdowns do occur in the wake of a S.I.D.S. death, they usually do so as a result of faulty communication or inadequate intrapersonal coping skills.

Whether they are acting as members of a crisis team following up on S.I.D.S. families or as primary therapists in a family counselling situation (extended family-counselling is indicated in cases of S.I.D.S.), social workers possess the training and skills to assist S.I.D.S. families to cope better with the S.I.D.S. experience. Sensitivity, above all, is the major prerequisite.

Recommendations for Further Research

From the findings obtained from the study and the
experiences of the researchers in conducting the study, the following suggestions for further research have been arrived at:

1. Further studies are needed to explore the impact of a S.I.D.S. death on extended family members, friends and professionals.

2. Research is needed to determine the emotional effects of a S.I.D.S. death on surviving and subsequent children with a view toward establishing intervention procedures to assist these children.

3. The findings of this study indicated a possible link between stress and the helpful behaviour of professionals and others. Testing this link might be a fruitful area for research.

4. The effect of previous death experiences as a determinant of coping with a S.I.D.S. death is another area in which the researchers would like to see research conducted.

5. A carefully controlled study to compare the effects of a S.I.D.S. death with the effects of other deaths on a family is definitely in order.

6. The area of maternal premonitions in S.I.D.S. deaths may offer some clues to professionals who wish to study causation.
7. Evaluation studies which would lead to suggestions for the improvement of the transmission of information from medical examinations would be helpful to parents.

8. An evaluation study to assess the effectiveness of a S.I.D.S. crisis team such as is suggested in this study would further help to determine the most effective type of professional intervention for S.I.D.S. families.

Summary

In this chapter, the researchers have presented what they consider to be the limitations of the study. They have also drawn some conclusions based on the findings of the study and have made recommendations for people dealing with S.I.D.S. families.

A section was included in this chapter which discussed the implications of the results of the study for social workers and the chapter was concluded with some recommendations for further research, based on the experiences of this study.
INTERVIEW SCHEDULE

1. When did the child die? Day Month Year

2. Who was in the family when the child died? 
   sex and age of family members 
   relationship 
   name age and sex of the child

3.a Was the pregnancy planned?

b Was the pregnancy expected?

4. How did the family members feel about the pregnancy? 
   did they want a boy/girl?

5. What was the pregnancy like? Special problems

6. After the child was born, were there any long-range plans for him/her? 
   education (savings accounts; insurance policies) 
   occupation

7. How old was the child when he/she died?

8. What was the sequence of events the day the child died? 
   where? - what time of day?
   who was present at the time of death? 
   what did they do? - who was contacted first? 
   who arrived at the house (place) first? - what did they do? 
   did anyone else come into the house? - what did they do?

9. How did each family member react to these events? to the outside people who became involved?

10. What were the initial feelings toward - the death? other family members? the child? the other people involved?

11. Who or what was most helpful up to this point? - how?

12. Who or what was least helpful up to this point? - how?

13. What do you feel would have been most helpful?

14. Where was the child taken? by whom?

15. Which family members went with the child? where were the other family members?
16. If the child was taken to hospital, what happened there?
   who was first encountered? - what did they do?
   which doctor (family or other) saw the child?
   where were the family members physically located?
   who told the present family members that the child
   had died? where?
   what explanation was given for the death?
   was anyone else involved? what did they do?
   how long did the family stay at the hospital?

17. How did the present family members react to this situation?

18. How did they feel about each of the people with whom
   they came in contact?

19. Who or what was most helpful at the hospital? - how?

20. Who or what was least helpful at the hospital? - how?

21. What could have been done, if anything, to be more
   helpful?

22. Was the subject of autopsy mentioned? how did the
   family members feel about it?

23. In the time between the death and the funeral, how did
   each of the family members behave?
   disruption in routine?
   who did what daily tasks? did this differ from the
   normal pattern?
   what were the predominant feelings of each family
   member?
   were these feelings directed toward anyone?
   was anyone from outside the family called in to help?
   what did they do?

24. What funeral arrangements were made? who made them?
   how long between death and funeral?
   was there visiting at the funeral home?
   what family members were there? open or closed
   casket?
   where was the service held? large or small service?
   where was the burial? who officiated at the service
   and burial?
   who attended? (from the family and outside)

25. How did each family member react to - the preparations?
   the visitation? the service? the burial?

26. What were the family members feelings toward - the
   arrangements? the service? the burial? the funeral
director(s)? the other family members? the people who visited and attended the funeral? the minister, priest or rabbi?

27. a Which part of the funeral process was most difficult to handle? why?

b Which part of the funeral process was easiest to handle? why?

28. Who or what was most helpful during the time of the funeral? how?

29. Who or what was least helpful during the time of the funeral? how?

30. What could have been done if anything, to be more helpful?

31. Did the family visit the grave? which members usually went?
   how often? is the grave still visited? how often?
   by whom?
   who in the family has stopped visiting the grave and when did they stop?

32. What happened within the family during the months following the burial?
   how did family members act?
   did the normal pattern of activity change? how?
   did relationships with other family members change?
   other non-family members? how?
   what were the predominant feelings for each member?
   were these feelings directed toward anything or anyone?
   was anyone called on for help? what did they do?
   when did things return to "normal" for the family?
   what if any "permanent" changes have occurred within the family?
   were there any really crucial points in time in the months following the burial?

33. Was there any discussion between the marital partners about having more children? what was decided?
   how did each partner feel about having more children?
   how long after the death did this decision come?
   was anyone outside the family consulted?

34. How did the family members feel when it was discovered that the wife was pregnant again?

35. Was the subsequent (to the death) pregnancy handled differently? if so how? what were the predominant
feelings during the pregnancy?

36. a Was the delivery handled differently for the subsequent child? method? hospital? doctor?
   b Name and sex of new child?

37. Was the new child treated differently when he/she returned home? feeding? medical check-ups? physical location of child? frequency of observation?

38. What are the family members predominant "now" feelings about the death?
   the death?
   the subsequent experiences?
   the family members (including subsequent children)?
   the people they dealt with at the time of the death?

39. a Which times were most difficult to handle?
   b Which times were easiest to handle?
      what contributed to making these times easy or difficult?

40. What do families who have experienced a S.I.D.S. death need to help them cope with the death? what, if any, changes in the health care and social systems are required to meet these needs?

ATTENTION. If you have lost a child within the last 5 years due to "Crib Death" we would like to talk with you for the purposes of a research project. Please write: S.I.D.S. Research, c/o School of Social Work, University of Windsor, Windsor, Ontario. We need your help! Anonymity Guaranteed.
BIBLIOGRAPHY


VITA

David A. Bennett was born in Ottawa, Ontario on May 12, 1947. He attended elementary school at Ottawa and Brockville, Ontario and High School at Thousand Islands Secondary School in Brockville, Ontario. He graduated from the University of Windsor with a Bachelor of Arts degree in 1972 and a Bachelor of Social Work degree in 1975. Mr. Bennett has worked as an Executive Director with the Kent County Mental Health Branch and as a program director with the Windsor Association for the Mentally Retarded in their community residence program. His B.S.W. field placement was with the Windsor Roman Catholic School Board where he acted as an elementary school social worker. His M.S.W. placement was at Hotel Dieu Hospital in the Social Work Department where he did marriage and family counselling. Mr. Bennett was admitted to the University of Windsor School of Social Work in September, 1976 and expects to graduate in October, 1977.
VITA

Richard Gordon Bough was born on December 5, 1950 in Cornwall, Ontario. He received his secondary school education at Cornwall Collegiate Institute and Vocational School.

Mr. Bough graduated with a Bachelor of Arts degree with a major in Psychology from the University of Windsor in 1971, after which he accepted a position in the Department of Social Work at the Cornwall General Hospital.

Mr. Bough returned to the University of Windsor in July, 1975 to continue his studies and graduated with a Bachelor of Social Work degree in May, 1976. He began the Master of Social Work programme at the University of Windsor in September, 1976 and he expects to graduate in October, 1977.

Mr. Bough's field placement during his M.S.W. candidate year was with the Salvation Army Grace Hospital in Windsor.

During his M.S.W. candidate year, Mr. Bough was a teaching assistant in the School of Social Work and was also a representative to the School's Assembly.