STILLBIRTH : A PSYCHOSOCIAL CRISIS

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ABSTRACT

This study is an investigation of the psychosocial trauma of stillbirth and the implications of that trauma for case management. Stillbirth is considered a crisis for parents that calls for immediate intervention and constructive management. It strains family coping mechanisms and can overwhelm them if not properly handled. Additionally, a grief response follows a stillbirth which must be recognised, accepted, and treated therapeutically if needed.

Parents' problems and needs have not been adequately met by medical, social or community services. There is also little recognition of the training needed by medical personnel in the management of stillbirths. Stillbirth is also a crisis for medical personnel as the delivery of a dead baby evokes feelings of confusion and stress for those dealing with the confinement and aftercare. By highlighting the psychological and emotional sequelae of stillbirths for parents, the needs of parents after the event, and the needs of personnel providing care, the writer intended to contribute to an improved understanding of the issues related to stillbirth and, ultimately, to more compassionate care for those who experience this unhappy event.

Issues analyzed and recorded are as follows: The emotional and physical reactions of mothers following a stillbirth; the assistance that parents need in order to adjust constructively; the impact that the stillbirth has upon the family; the mothers' interpretation of their management in hospital; and the hospital and community services rendered and needed to assist with constructive adjustment.

Study data was collected over a six month period.

Subjects were selected from one hospital and were residents of the municipal areas of Cape Town. Two face-to-face interviews were conducted with each respondent using a semi-structured interview schedule. The first interview, which took place within a week of the mothers' discharge from hospital, gathered data on the reactions of the respondents to stillbirth, the impact of stillbirth on the family, and respondents' interpretation of their management in hospital. This interview was tape-recorded. The second interview followed the interview schedule and obtained information on the needs of families after a stillbirth. Data was coded on the interview schedules and statistical analysis was done by computer.

The findings of this study agreed with previous ones, that mothers display typical grief reactions after a stillbirth. The stillbirth was experienced as a disappointment that caused significant distress for the majority of mothers. Management was found to be satisfactory with the exception of post-natal placement. The need for options in this area became evident. A lack of social and psychological services, both within the hospital and in the community, was found. Using knowledge gained from this study, a support organization for parents experiencing stillbirths has been organized with the writer's assistance.

A breakdown in communication between the hospital and the local authority health nursing services, in terms of knowledge about the stillbirth, was apparent, and improvement in this area is needed.

Recommended guidelines for management based on the research findings and literature review have been proposed. The role of the social worker, doctor and nursing sister have been outlined.

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When a person is born we rejoice,
and when they're married we jubilate,
but when they die we pretend nothing has happened.

Margaret Mead

CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1 : INTRODUCTION

Statement of the Problem

Objectives of the Study

Significance of the Study

Limitation

INTRODUCTION

The needs of families, mothers in particular, experiencing stillbirths, are not being adequately met by medical personnel or other community services. This deficit was highlighted by the writer's social work experience in the maternity section of a large provincial hospital. The writer came to believe that the most effective manner to draw attention to the issue of stillbirths, with its concomitant emotional reactions and impact on the family, was to undertake a research study that would investigate the pertinent issues involved. The writer also wished to acquire sufficient knowledge of the problem, to initiate the formation of a community service for families afflicted by the loss of their babies.

Previous publications have documented that the delivery of a stillborn infant has specific ramifications for the parents involved and for the staff that deal with the delivery. There is limited understanding of the gravity of the loss for the mother, and little appreciation for the mourning process that follows. Society in general does not consider a stillborn infant as a "person" with whom the parents have bonded since conception, have grown to love, and for whom they have dreams and aspirations. Rather, a stillborn is seen as a "non-event", a baby who never lived, therefore one need not grieve for someone who never existed. Because this is the general attitude of society, the families are usually left to cope on their own, with no formal plan of management and no aftercare being arranged or offered.

A specific problem in the management of these families is the lack of insight and understanding that medical personnel have into the emotions surrounding a stillbirth. In medical schools, the curriculum does not focus on the psychosocial issues involved in the deliv-

ery of stillbirths and therefore doctors, be they medical students, general practitioners or specialists, are not trained to deal adequately with the family and to offer constructive help, compassion and care. If one is not aware of a problem, one is unable to offer help with it. There is, therefore, lack of formal training in the field of perinatal death.

The emotional problems of stillbirths are related to society's general attitude toward death, ie the inability to talk openly and comfortably about death. One thus finds that friends and family, along with medical personnel, do not know how to deal with the situation and so avoid the issue or make inappropriate remarks that are painful to parents.

A stillbirth is a crisis for the medical personnel involved with the delivery and postnatal management. They must deal with feelings of disappointment and failure at delivering dead infants. An unexpected stillbirth is a shock to the parents and the medical staff in attendance. By highlighting the problems and needs that families experience after such an event and the crisis entailed for the medical personnel, the writer hopes that a more thorough comprehension of the problems will evolve, and that this will lead to greater compassion and care by those dealing with the families.

STATEMENT OF THE PROBLEM

The delivery of a stillborn infant is a traumatic experience for parents and for professional personnel. The parents need guidance and support, and the professionals need training to develop skills in dealing with such families. There is no recorded information on the emotional and psychological sequelae of stillbirths in South Africa. Only in the past decade have the issues concerning stillbirths been documented in countries overseas. Stillbirths, thus, tend to be seen and treated solely as medical problems. As a result of this perspective, parents are often unsupported from a psychosocial point of view, both in hospital and at home. Additionally, the importance of mourning the stillborn child has only recently been recorded in the literature. The research done by Lewis (1979) shows that in order to assist parents in coming to terms with the death, the mourning process should be facilitated and parents supported throughout this time. Resolution of grief can be impeded if parents are not given adequate opportunities for release of these feelings.

This study will discuss the mourning process and grief responses of parents experiencing a stillbirth and make recommendations by which social workers can facilitate the parents' mourning. The hospital social worker plays an important role as an integral member of the health team in the management of the mothers, both in hospital and in arranging aftercare. The social worker's role will be discussed and guidelines proposed for the overall management of families experiencing a stillbirth.

OBJECTIVES OF THE STUDY

The writer conceptualizes stillbirth as a crises which requires a comprehensive plan of management and psychosocial care for the family. In accordance with this conceptualization, this investigation studied the issues outlined below. Based on the findings, recommendations for improved services are made.

(a) The physical and emotional reactions of mothers following a stillbirth;

(b) the assistance that families require in order to adjust constructively;

(c) the positive and negative impact that the stillbirth may have on the mother and her family;

(d) the hospital and community services (i) rendered and (ii) needed with the intent of assisting constructive adjustment to the event; and

(e) the mother's interpretation of her management in hospital.

SIGNIFICANCE OF THE STUDY

A study of this nature is important as it focuses on the pitfalls in management of families experiencing a stillbirth. It is essential to describe the reactions that parents experience, in order for the medical personnel involved in the management to gain a better understanding of the reactions and emotions that follow after the loss of a baby.

Furthermore, the needs of parents ought to be highlighted so that a more constructive plan of action can be implemented. The guidelines for management which will be proposed, should be of benefit to medical, nursing and social work staff working in maternity settings.

As a result of this study, a more comprehensive understanding of the topic of perinatal death should develop. This increased awareness and understanding should be of benefit to those health care professionals involved in the field of perinatal loss and death.

LIMITATION

This study is restricted to interviews with mothers from one general hospital in which the majority of stillborn infants in the municipal areas of Cape Town are delivered. The study population was restricted to one racial group - namely persons classified as "Coloured". This restriction made the study manageable, but it also suggests that generalization of results should be done advisedly and with the possibility in mind that racial differences might influence psychosocial reactions to stillbirth and duration of the grief process.

CHAPTER II : BACKGROUND LITERATURE

The Theoretical Background to the Concept of Crisis

Stillbirth : Past and Present Views
Medical Aspects
Legal Aspects
Religious Aspects
Funeral/Burial and Memorial Services

Aftermath : Personal
The Family : Husband, Children, Grandparents,
Medical Staff and Caregivers

Grief and Bereavement

Subsequent Pregnancy and the "Replacement Child"

Perinatal Management

BACKGROUND LITERATURE

THE THEORETICAL BACKGROUND TO THE CONCEPT OF CRISIS

The researcher has stated that a stillbirth is a psychosocial crisis, a blow to personal and family integrity, requiring intervention and constructive management.

Psychosocial crises are times when one reassesses one's relationship with the world and emerges with what Parkes calls "major changes in the heartland of self".[1] After a stillbirth, there is pain and confusion caused by the death not only of the wished-for child, but of the parents' dreams and hopes for that child and for themselves as well. Although their lives will never be the same, there can be growth and a new compassion as a result of the crisis situation. The term "crisis" as it is used in the framework of this investigation, is important and should be clarified.

Crisis refers to the psychological and physiological state of the individual who finds himself in a hazardous situation. A state of crisis is not an illness. Whereas the concept of stress tends to have negative connotations, a state of crisis is conceived as having a growth-promoting potential (Rapoport)[2]. A crisis is described as a call to new action. The challenge it provokes can elicit new coping mechanisms which serve to strengthen the individual's adaptive capacity and thereby raise his level of mental health. Crisis, in its simplest terms, is defined as "an upset in a steady state"[3]. Thus, in a state of crisis, it is postulated that the habitual problem-solving activities are not adequate and do not lead rapidly to the previously achieved balanced state.

The hazardous event, in this case, death of one's baby, creates for the mother a problem in her life situation. The problem is considered a loss and is met with grief reactions and depression.

Characteristics of the State of Crisis (Rapoport, 1962)

(1) The crisis is self-limiting in a temporal sense. In other words, the crisis does not continue indefinitely and some solution is sought to restore the state of equilibrium.

(2) There are certain typical phases which characterize the period of upset. Lindemann[4] observed the phases of the state of crisis, and of coping mechanisms linked with it, in acute grief following bereavement. He noted that the duration of the grief reaction seemed to be dependent on the success with which a person did his "grief work". A normal course of grief reaction begins when the bereaved (i) starts to emancipate himself from the bondage of the deceased; (ii) makes a readjustment to the environment in which the deceased is missing; (iii) forms new relationships or patterns of interaction that bring rewards and satisfactions.

(3) There is a rise in tension that may push toward a peak.

(4) There is a general feeling of helplessness.

(5) Some disorganisation and lack of effective functioning may ensue.

(6) Various characteristic coping patterns have been described which may be adaptive or maladaptive in nature.

In general, the patterns of responses of an individual or family necessary for healthy crisis resolution may be described as follows:

> "correct cognitive perception of the situation, which is furthered by seeking new knowledge and by keeping the problem in consciousness management of affect through awareness of feelings and appropriate verbalization leading toward tension discharge and mastery; development of patterns of seeking and using help with actual tasks, and feelings by using interpersonal and institutional resources".[5]

The implications for management and guidelines for intervention can be based on these patterns of response. The example to be used is that for the expression and management of feelings, quoted as number two above. There needs to be an explicit acceptance by the helping person of the disordered affect, irrational attitudes, and negative responses. These responses need to be placed in a rational context by understanding and by clarifying the natural history of such reactions. This is particularly evident in mothers who, in a state of shock and disbelief after a stillbirth, often do react irrationally, display anger and hostility, although not always intended. It often happens that the doctors or nurses are the targets of the mother's hostility and these are the very people she needs to help her cope with her feelings and reactions. It is important for the medical personnel to comprehend this factor and to realize that parents often have a need to blame somebody for what has happened to them. Rapoport concludes that "a little help, rationally directed and purposefully focussed at a strategic time is more effective than more extensive help given at a period of less emotional accessibility".[6]

The delivery of a stillborn infant is a crisis that calls for immediate and constructive intervention. By rendering help at a time of need and crisis, one could possibly prevent more serious disorders from developing at a later stage, and thereby ensure positive mental health and healthy family functioning.

In summary, a crisis, in a hospital context such as a labour ward, is beset with complexities specific to the setting. These influence the abilities of doctors, nurses and other team members to function effectively in helping parents get through the crisis.

> "A coordinated set of agreements and understandings among the staff must be developed early to include the personal philosophy and professional orientation of each team member. This element is essential in elucidating and sharing the facts, and it is crucial to mobilizing staff strengths in the plan for helping".[7]

STILLBIRTH

Past and Present Views

Many myths about stillbirths existed in the past. In the fourteenth century, in Medieval Europe, stillbirths were believed to be caused by the midwife. Pope Innocent III, during the Inquisition, declared these women to be witches. They were thought to use long fingernails to puncture the fontanels, thus killing babies before they could be baptized.[8]

Joseph DeLee, the "father of modern obstetrics", wrote in 1913 that sea-bathing was used by some women to bring on an abortion and he thus cautioned his patients to avoid the sea if they wished to continue their pregnancies. Dr DeLee also was concerned about baths and commented that hot and cold baths would excite uterine contractions, possibly resulting in spontaneous abortion.[9]

The following myths surrounding miscarriage and stillbirth have existed for many years :

"(i) Accidents and emotional fright are common causes of miscarriage

(ii) Horse-back riding during pregnancy will cause a miscarriage or premature birth

(iii) Babies born in the seventh month have a greater chance of surviving than babies born in the eighth month".[10]

Due to a lack of openness and general knowledge about stillbirths, many women who experience them have totally incorrect views and ideas of why they lost their babies. A common notion many women express is that they did something during their pregnancy that caused their infants to die in utero, or that they did not follow strict orders in terms of diet, exercise and so on. The consequent guilt that this view has is debilitating to grieving mothers.

Stillbirth has been described poignantly as a shattered dream. The child that was to have been, is no more. A stillbirth triggers emotional reactions in all those involved, but the reactions vary from person to person in intensity and meaning. Whether the baby was anxiously awaited, unexpected, or reluctantly accepted, feelings of loss occur as a result of this sudden and unforeseen change. The loss is a universal experience but different for each parent. The response parents have differs and the impact will evoke different reactions and results.

In order to comprehend the impact that a stillbirth has on the family, it is important to realize what pregnancy means to the mother. For most parents, pregnancy is a time of hopes, fantasies, and preparations for the future. As mothers anticipate their babies' arrival, they psychologically prepare themselves for what their futures will be like as parents. Besides the psychological adjustments, parents also make concrete preparations. For most people, pregnancies are experienced as major life events. Whatever symbolic meaning a pregnancy has, it is likely that losing a foetus will influence one's life cycle.

> "For many couples, having a baby is part of a larger larger life plan. Whether their goal was to bring a child into their lives, create a family, carry on a bloodline, or strengthen a relationship, the loss of a pregnancy deprives them of the possibility of achieving their goal this time. This leaves many couples feeling they are in limbo ..." [11]

Much has been written in the literature on the theories of maternal-foetal attachment and bonding. It is not within the scope of this study to cover attachment theory, but mention will briefly be made in relation to attachment or bonding and loss.

Deciding to have a baby is the first step in the process of attachment. When a woman becomes pregnant, her dreams and hopes promise to come true and she permits herself to become even more attached to a vision of the child she is carrying. The bond that a mother forms to her unborn child is unique. "The pregnant mother brings a lifetime of experience knowing, loving, and caring for others to this new and unique relationship".[12] Initially the mother's attachment is to a fantasy image of her future child but as pregnancy progresses, the mother forms an actual acquaintance with her child through physical sensations. As the foetus grows and becomes more active, the mother experiences it as becoming separate from herself.

> "When the birth process proceeds normally, the mother loses the child inside her while gaining an "outside" real baby. When a stillbirth occurs, there is both the loss of the child the mother had grown to know and love and the loss of the one she imagined it would someday become. In addition, there will be no baby to compensate for the loss of the internally experienced child".[13]

The nature of loss, grief and mourning will be elaborated upon in this chapter.

The tragedy of stillbirth is a quiet tragedy as the loss of an infant at birth and the resultant grief are seldom acknowledged in our culture. Others cannot see the attachment that existed between parent and child before birth.[14]

Lewis captures the essence of what a stillbirth is when he writes that:

> "Stillbirth is a common tragedy; yet it is an event which, by common consent, is cloaked in secrecy and which by its very nature seems unreal ... A stillborn is someone who did not exist, a non-person with no name. It is an empty tragedy and a painful emptiness is difficult to talk about. After a stillbirth there is a double sense of loss for the bereaved mother who now has a void where there was so was so evidently a fullness".[15]

Bourne is one of the few researchers who investigated the psychological effects of stillbirths on doctors as well as on mothers. Bourne found that family doctors were reluctant to know or remember anything about the patient who has a stillbirth.[16]

Generally, maternity units and hospitals are geared towards producing life and their staff are therefore not generally trained to cope with the emotional distress and reactions that accompany death. Consequently, parents are often left unsupported in dealing with their loss and feelings accompanying this.

Over the past decade the topic of death has become an area of scientific investigation and discussion. The subject of grief and bereavement has been extensively analyzed and described. Yet the death of a foetus is not being recognised as a significant loss. For the mother the loss is very real and can have profound effects on her emotional, psychological, social and physical well-being for a long period afterwards.

Medical Aspects, Definition and Causes

In a discussion of this topic, it is important for the reader to understand clearly the causes of stillbirth and the differences between miscarriage and stillbirth.

The topic of stillbirth does not appear to be a significant section in many obstetrical, gynaecological or midwifery reference works. In general, a few lines or pages may be devoted to this topic. There seems to be a deficiency also in the literature on the management of parents delivering stillborn infants. The issue of management will be discussed in detail in Chapter V.

Defining Stillbirth

In order to understand the difference between a miscarriage and stillbirth, a definition of each will be discussed. An abortion or miscarriage (these terms are used interchangeably) means the termination of pregnancy before the foetus is viable. A stillbirth is defined as:

> "... any child which has issued forth from its mother after the twenty eighth week of pregnancy and which did not at any time, after being completely expelled from its mother, breathe or show any other sign of life".[17]

The most recent attempt by the World Health Organisation (1950) to secure some uniformity in definition seeks to do so by distinguishing live births and foetal deaths and grouping each according to whether the gestation period is less than 20 weeks, less than 28 weeks, 28 weeks or more, or uncertain. "The stillbirth rate in most countries is under 25 per 1000 total births, but wide variations from 20 weeks to full term in the required period of gestation and in the evidence of survival still make valid international comparisons impossible.[18]

Causes of Stillbirth

At present it is difficult to compare results from different countries as there is little uniformity in classification of causes. As this investigation is restricted to Cape Town, a local classification of causes will be described.

According to Woods and Draper, the stillbirth rate in 1978 in the Peninsula Maternity and Newborn Services area was 12,56 per 1000. According to these authors, the high stillbirth rate is typical of most developing countries.[19] The following causes of stillbirth were proposed and analyzed.

Causes of stillbirth:

(a) abruptio placenta; (b) placenta praevia; (c) amniotic fluid infection; (d) gross congenital abnormalities; (e) congenital syphillis; (f) maternal diabetes; (g) eclampsia; (h) pre-eclampsia; (i) prolapsed or knotted umbilical cord; (j) placental insufficiency; (k) mechanical causes; (l) miscellaneous causes, and (m) unknown causes.[20]

For a more detailed analysis of the causes and medical aspects, the reader may consult the reference works quoted above.

At this stage it is important to mention that when referring to stillbirth, two types of events may be delineated. The first type is that of foetal death in utero. Here the baby's death is diagnosed days or weeks before delivery. The resultant grief that follows when the mother has been forewarned of her baby's death, is classified as anticipatory grief. However, in many cases, the mother may deny this knowledge and hold on to the remote hope that her infant is still alive. The second and more common type of stillbirth involves no prior knowledge. In other words, the infant's death is diagnosed during labour and delivery. While it is important to recognise the difference in these events medically, the grieving processes that follow are similar, as both result from the simultaneous birth and death of the expected baby.

Autopsy

The performance of an autopsy is important in that it can provide useful information and causes of death for the medical personnel involved, as well as for the parents themselves. However, many parents, after the trauma of delivering a stillborn infant, feel they cannot consent to an autopsy. The reasons given are varied. Whether they be rooted in religious belief, a personal value system, or a wish not to violate their infant's tiny body, parent's wishes should be respected. When consent is to be obtained, it is important for the doctor concerned to recognise the parents' current situation, their emotional state, and to be well prepared beforehand for this unpleasant task. The doctors involved may often require team support and guidance in discharging this duty.

If parents are approached cautiously and with understanding of their feelings, the initial request for an autopsy can be the beginning of discussions about what happened to the baby.
Autopsy results can form the basis for further discussion during a follow-up interview.[21]

Legal Aspects

The author has already discussed autopsy in the previous section. However, it should again be mentioned here as parental consent has to be obtained in order for an autopsy to be performed.

According to the Births, Marriages and Deaths Registration Amendment Act, No. 51 of 1974, "stillborn means that it was viable but showed

no sign of life after complete birth", and "viable" is defined as having had at least "six months of intrauterine existence".[22] In Chapter III of the Act, reference is made to the registration of a stillborn child.

> "Section 20 (Duty of medical practitioner or midwife in case of stillborn child).
>
> (1) In the case of any stillborn child, any medical practitioner or registered midwife who was in attendance at the birth, or any medical practitioner who has examined the body of the child shall forthwith sign and give, without fee or reward, either to a person required by this Act to give information concerning a death, or the undertaker or other person who causes the body to be buried, a certificate stating that the child was stillborn.
>
> (2) The person to whom a certificate is given ... shall forthwith ... deliver such certificate to the registrar or assistant registrar concerned for the registration of a death.
>
> (3) If no medical practitioner or registered midwife was present at the stillbirth ... any person who is under this Act required to give notice concerning a death shall make a solemn declaration that the child was not born alive and deliver such declaration ...
>
> (4) Whenever a person not registered as a midwife assisted at the birth, the information to be furnished shall include the name and address of such person." [23]

In Section 21 of the Act, issue of a burial order is described. The registrar or assistant registrar upon receiving the relevant certificate or declaration mentioned above, gives an order authorizing burial of the stillborn child. However, if the registrar is not satisfied that the child was stillborn, he may report this to a magistrate for further investigation.

It is important for the medical staff to discuss burial and funeral arrangements with the parents. The options available should be explained. Many parents are not in a state to make rational decisions and may therefore wish that the hospital organise the burial. However, parents should not be pressurized into making a decision about the disposal of the body and may need some time to think about such an important decision.

Religious Aspects

In this section, the author will discuss funeral arrangements, memorial services and some of the various religious beliefs and practices surrounding stillbirths.

Parents need to make decisions regarding religious ceremonies and arrangements for their stillborn infant's body. Some parents ask the hospital to take care of all arrangements as they may not want to face the additional stress of organising a burial or cremation ceremony. Others may request to have a ceremony, burial or cremation and thus face the reality of their loss more overtly.

Whether parents request a funeral service, memorial service or grave side service where the body or ashes are interned, is a decision that they need to make and they should not be forced into taking hasty actions that they may later regret. Many parents, after the shock of having a stillbirth, request the hospital to organise disposal of the body, and, at a later stage, have regrets that they did not organise a proper burial and ceremony in which they could have been involved.

Some parents derive great comfort from a religious service, whereas others may feel it is an ordeal to be suffered. Whatever decision parents make, their wishes must be respected. They may need guidance and direction in these arrangements.

Traditional expressions of grief and rituals remain an important part of the religious process in many of the major religions. It is important that the health team members working in this field become aware of the significance of religious beliefs and traditions which may be different from their own, so that they may help to initiate the involvement of the family with their own religious group or tradition at the time of the death in the family.[24]

A review of the beliefs and traditions of some of the major religions follows.

(A) Protestant

There are marked differences in Protestant religious traditions and rituals regarding funerals and mourning.

> "In the fundamentalist groups, such as the Baptists, Pentecostals, and other evangelical sects, the families often have an intense and long-standing involvement in a particular church or religious congregation. Usually the pastor has been involved with the family before the death and the church group has already moved in to offer support to the family, with help in the arrangements for the funeral and services ... These groups believe in the actual physical resurrection of their loved one on the Day of Judgement. Sometimes autopsy permission is denied because of the fantasy of resurrection with disfigurement ..."[25]

Grieving is often open and intense and families believe in a literal heaven for those who have been saved through the acceptance of Christ as a "personal saviour" by a process known as "vicarious atonement". On the other hand, if one has not been saved, he will surely go to eternal damnation and punishment for his sins.[26]

In families who belong to the more liberal Protestant groups, including the Methodists, Presbyterians, Congregationalists and others, there is often a less involved relationship with their church and their minister. The minister may come only if called upon by the family. The church will provide the necessary facilities for the funeral service, but often the relationship of the members of the congregation with each other is informal. Proceedings for funeral and religious rituals are simple, quiet and dignified. Grief is not expressed openly and mourning is quiet.

(B) Roman Catholic

Catholic families usually have been deeply involved in a particular parish church. Roman Catholics believe that the final sacrament of burial will release the soul into heaven. The ritual is well known to all family members and helps to organise their behaviour during the acute grief phase. After a death, a wake is held for 24 - 48 hours. The older and more traditional the culture, the longer the wake. A requiem mass is held in the church ...[27]
According to Hollingsworth and Pasnau, Catholics do not have an elaborate ritual for mourning. Mourning is left to parents and close family members. An annual Mass is usually held in honour of the deceased on the date of his/her death. According to the Catholic religion, a stillborn infant is recognised as a full human person. There appears to be discrepancy with regard to baptism of a still-

born infant. Some religious leaders feel that a "conditional baptism" can be done if the infant died during labour but would not perform a normal baptism if the baby had been dead for a day or longer. This matter would be left to the priest and parents concerned.

Cremation is acceptable if the parents so desire or an ordinary burial service and prayers are held. Autopsies are permitted and accepted if they are necessary from a medical point of view.

(C) Jewish Tradition

The Jewish tradition confronts death directly. Jews do not believe in a life hereafter. There are a number of rituals carried out. The deceased must be buried as soon as possible after death. The body is not viewed after death. After the funeral, the nuclear family sits "shivah" - for seven days - an intense period of mourning. The family do not visit the graveside for a year and on the anniversary of the burial, close relatives and friends go there for the unveiling of the tombstone. The Rabbi must be present for the unveiling. Each year on the anniversary of the death, a candle is lit in the home.

Jewish tradition contains a positive pattern of observance through which the individual is enabled to confront the crisis of bereavement. All aspects of funeral arrangements are governed by principles of simplicity and the acceptance of the reality of death. It is forbidden to carry out an autopsy unless the civil authorities order this.

Traditional Judaism is unequivocally opposed to cremation. However, when it comes to the burial of a stillborn infant, there is no formal mourning or ceremony carried out. Because the baby has not lived, or sinned, it would not require mercy from God. The infant is given a Jewish name; there is no funeral shroud; a male infant would be circumcized and all of this would be organized by the Jewish Burial Society. A formal burial ceremony is held when a baby has lived for a period of one month. The parents' mourning would thus be a private one within the family setting.

(D) Islam/Muslim Faith

The Islamic belief in man's freedom and responsibility and the immortality of the soul is expressed in its doctrine of the afterlife. For the Muslim, life on earth is the seedbed of an eternal future. It will be followed by a day of reckoning which is foreshadowed in the most awesome terms. The belief that unites all Muslims concerning the afterlife, is that each soul will be held accountable for his actions on earth. Burial procedures are as follows: Islam prohibits undignified behaviour or excessive grieving, though natural weeping and mourning is to be expected and understood. Strong grief reactions are regarded as signs of dissatisfaction with the Will of Allah. The corpse should be bathed and shrouded according to the customary methods and should be handled gently and with due respect. The entire funeral is simple in spirit and procedure and has remained so for 1400 years. No innovation may be tolerated. Elaborate mourning rituals and funeral feasts are stongly discouraged. Post-mortems are prohibited as they are seen as acts of mutilation and may only be performed where there has been commitment of a crime.[28] Muslims are encouraged to offer their care and sympathy to the bereaved in the true spirit of Islamic brotherhood.

The burial procedure of a stillborn infant is the same as for any other deceased person.

The overview presented above is a concise description and does not elaborate the complexity of varying religious beliefs on the subject. However, it is not within the scope of this study to describe elaborately the many details involved.

> "The enigma of religious variations must be appreciated by all of those who attempt to understand and treat families in mourning".[29]

Funeral/Burial and Memorial Services

When birth and death occur together, as in a stillbirth, there is seldom any formal ritual. It is precisely at such a time that a family may find religious beliefs and practices and the assistance of clergy and funeral directors to be valuable.

When an infant dies before birth, there is usually no baptism or other ceremony. The exception here is in the Catholic Church where a dead foetus may be baptized. Different religious ministers may perform varying ceremonies for the parents and give them the opportunity to say goodbye to their baby with the help of a supportive pastor.

Parents are usually in a state of shock from the unexpected loss of an infant. Because of their bewilderment, and the apparent lack of any clear direction from most religious denominations, the majority

of stillborn infants are buried or cremated by the hospital.[30] At a later stage parents may wonder what was done with their baby, but may be afraid to ask. They may also regret not having had the chance to bury their own baby and to have a ceremony performed at the burial.

Funerals are a source of psychological aid for the family rather than a benefit to the deceased. They "help promote a healthy recovery from grief by bringing family and community together to provide support for the bereaved".[31] Funerals enable mourners to express their feelings of sorrow, anger and guilt and help make the fact of death a reality. They also give the bereaved something concrete to do in a time of bewilderment. However, despite these benefits, there are reasons other than the lack of usual religious practice, why a family would not have a funeral for an infant.

> "... one reason is that the mother who is still hospitalized would not be able to attend ... If the parents are young and possibly newly settled in a community or considering moving somewhere else later, they are often unaffiliated with a church. For any of these reasons, the young couple may not own or wish to purchase a burial plot ... Many parents agree to have a funeral director place the baby in a corner of the local cemetry ..."[32]

It is important to remember that every couple has different needs. Some may prefer the usual practice of a brief gravesite ceremony for only the immediate family; some parents may request cremation for their infant; while others may wish to create their own ceremony and to bury their infant's remains in a special place without any formal religious ritual.

One problem that is often evident is the exclusion of the mother and her desires in the planning of a service or burial. Well-meaning husbands usually wish to protect their wives from further trauma and the ordeal of burial and therefore make arrangements without her. This often leads to conflict between parents at a later stage and open, constructive communication between them is vital in overcoming these issues and in resolving grievances.

The role of the clergy is important in helping the bereaved family deal with their loss and their many confused feelings that accompany loss. The clergy can assist families to draw on their own spiritual resources and beliefs in an attempt to reconcile themselves to a tragic and senseless event.[33]

> "Religion and ritual can help many families in their search for peace of mind. Even those who have no religious affiliations or beliefs can use welcoming and farewell ceremonies to mark the importance of their child's existence".[34]

AFTERMATH

Personal

In the centre of my body
she wove her warm cocoon
My precious tiny daughter
born to die too soon.
Did I forget to say my prayers
or perhaps I told a lie?
Dear God, I ask these questions;
give me a reason - "WHY?"

You in infinite wisdom, said,
"Go forth and multiply".
Why then, when we tried so hard,
did you let our efforts die?
Couldn't you have taken someone older,
A life maybe not so new?
This child was everything to us;
What does she mean to you? ...

"Unanswered Questions"
Nanette Wagner, 1984

For the woman who experiences a stillbirth, the loss occurs when she is physically and psychologically vulnerable.

Many factors influence the way in which women experience the loss of their infants. Among these are whether or not the pregnancy was planned and consciously desired, whether or not there are other children, the mother's age, the length of time the mother has been trying to have a baby, and whether or not the mother has had previous losses. The pain that is experienced with the loss occurs at many levels. Firstly, there is the loss of one's beloved child; there is the loss of one's pregnancy; the frustration of one's hopes and plans; and the denial of one's wish to be a parent. The woman who loses a pregnancy goes through a grief process similar to that which accompanies the loss of a significant person one has loved. However, the mourning following the loss of a pregnancy is different from that which occurs after other deaths. When a foetus is lost, there is no tangible person to mourn, and usually no shared life experiences or memories of that foetus. Consequently the loss often seems unreal. Mourning someone who has not been physically present is difficult.

The mother faces the additional problem of making the loss real because the attachment she feels to her lost infant is not shared by others. The father's attachment to the infant usually develops much later than the mother's and the loss is not as significant for him as for the mother. Few people seem to understand what the loss means to a mother and, therefore, are unable to appreciate her pain. It follows that little support will be offered to the bereaved mother.

> "The loss of a pregnancy is a life crisis that is largely ignored by modern society. The fetus is regarded as a nonperson, and its loss as a non-event. Society denies the importance of what has happened and discourages the expression of grief by letting the woman know that she didn't really lose anything; she can always try again soon".[35]

Several studies have investigated the reactions of parents to the loss of their stillborn infants.

Benfield et al, found that fathers, as well as mothers, experienced profound emotional reactions to the deaths of their infants. Although the maternal response was generally more intense, in eleven out of fifty couples studied (22 percent) the father's "grief score" exceeded that of his wife.[36]

Cooper studied the reactions of parents to the experience of a stillbirth in hospital. The information was gathered during three social work visits made during a six month period after discharge from hospital.[37] The outstanding emotional reaction was shock and anger. The stillbirth was felt as an outrage. Early after the stillbirth, partners discussed their guilt over any incident which could possibly have contributed to the stillbirth. Another reaction was shame at not being able to fulfil biological functions as a woman. In general, stillbirth was seen as an acute disappointment, a disaster, a frustrated hope and a crisis affecting marriage, status and role. Although this was a small study, the findings concur with those of other studies analyzing parental reactions.

Giles looked at the emotional and physical reactions of forty women who had lost babies in the perinatal period. His findings of the reactions are described as follows: the initial reaction was most commonly a feeling of emptiness and numbness; other common reactions were guilt; feelings of failure as a woman and self-blame or blaming of others. Physical symptoms included fatigue, insomnia, dizziness, no appetite, headaches and indigestion.[38] These are typical of grief reactions.

Jensen and Zahourek undertook a study to determine if women who lose newborn babies or have a stillbirth are a "high-risk group", ie one in which a high incidence of depression occurs following the loss. They found that a significant number of mothers were depressed after a year, and that they were still preoccupied with the loss of the infant and the problems surrounding that loss.[39] This article is relevant, in that the authors make suggestions for preventive measures that can be of help to women in these situations.

Cullberg, in a study of fifty-six Swedish women experiencing perinatal death, found a variety of serious psychological symptoms in nineteen of the women one to two years after their babies' deaths.[40] These symptoms included anxiety attacks, severe phobias, deep depressions, obsessive thought and psychotic reactions.

Lewis looked at some specific areas that caused distress to parents following a stillbirth.[41] Eighty couples participated. Some of the salient points made are as follows: for the women whose babies had died some time before delivery, the greatest difficulty for them was waiting for labour to begin. These mothers felt that the worst part of their experience was carrying a dead baby inside them. Comments such as "felt very cold", "awful", "unclean", "walking coffin", were expressed. A large number (67 percent) had nightmares after delivery

of their dead babies. Another distressing experience was producing milk for their dead babies. Although medication had been prescribed to inhibit lactation, many women still produced milk. Additional reactions of significance were feelings of inadequacy as women and guilt at "failing my baby where it should have been most safe".[42]

In the aftermath of losing a pregnancy, some women experience feelings of inadequacy and are concerned about their femininity, their bodily functioning, and their capacity to have children. This is especially evident in women suffering the loss of their first infant.

Many women experience anxiety about their ability to become pregnant again and this may escalate as attempts to conceive again are not met with success. The sense of inadequacy may spread beyond the realm of biological functioning for some women. Friedman and Gradstein comment that these women experience the loss as evidence of their more generalized inferiority and worthlessness. Feelings of inadequacy, loss of attractiveness, physical inferiority, and lack of productiveness can overshadow their previously sound sense of self-worth.[43]

> "When pregnancy ends in tragedy, there is profound disappointment ... The bereaved parents experience the pain of putting away the crib and clothes and shower presents. They have lost not only a fantasy, not only the infant who lived as an image in their minds, but a part of themselves ... their stake in the future".[44]

The Family : Husband; Children; Grandparents

When a couple suffers a pregnancy loss the husband is often faced with special burdens. He must help his wife cope with the trauma, physically and emotionally; he must deal with the medical personnel; and break the news to family and friends. While handling all this, he must deal with his own emotions of shock, anger and grief.

It is important to acknowledge that the husband, too, has lost a child and his hopes and dreams for that child. He may feel deeply sad but find it difficult to express his feelings. In our society, men are supposed to be strong and composed and not show their emotions too strongly. The husband often finds himself in the situation where he has to be strong for his wife's sake and consequently has to suppress his feelings. The wife is the key recipient of expressions of sympathy and concern and the husband may feel either neglected and in need of support, or relieved that nobody is probing his feelings since he prefers to keep them under control.

The wife's stay in hospital is usually a tense time for both partners. One of the most unpleasant tasks the husband has to face is the question of arrangements for burial. The husband should include the wife in decisions regarding burial. Failure to do so may lead to conflict in the future.

Marital Conflicts

The experience of a stillbirth causes stress to each marital partner. Couples who have stable relationships may find themselves arguing, feeling misunderstood, and experiencing tremendous strain. Because the parents are going through a crisis, there is often a break-down in communication. It is important to realize that men and women do grieve differently. Berezin explains that although the prospective father may have a strong psychological investment in the unborn child, his knowledge of that child is secondhand. The changes of pregnancy affect him only indirectly.[45] The manner in which a couple deals with the myriad of problems they are likely to encounter can have a lasting effect on their marriage.

If a relationship is already strained and the pregnancy was planned to save it or as an incentive for marriage, the stillbirth creates further serious problems. If one partner did not really want a child but agreed reluctantly to please the other, there is likely to be bitterness and animosity. While every case has its unique characteristics, it appears that incongruent bonding and incongruent grieving, in combination with each other, underlie many marital conflicts following infant death. It is essential for the couple to share their feelings, communicate openly and to resolve their misunderstanding and conflicts.

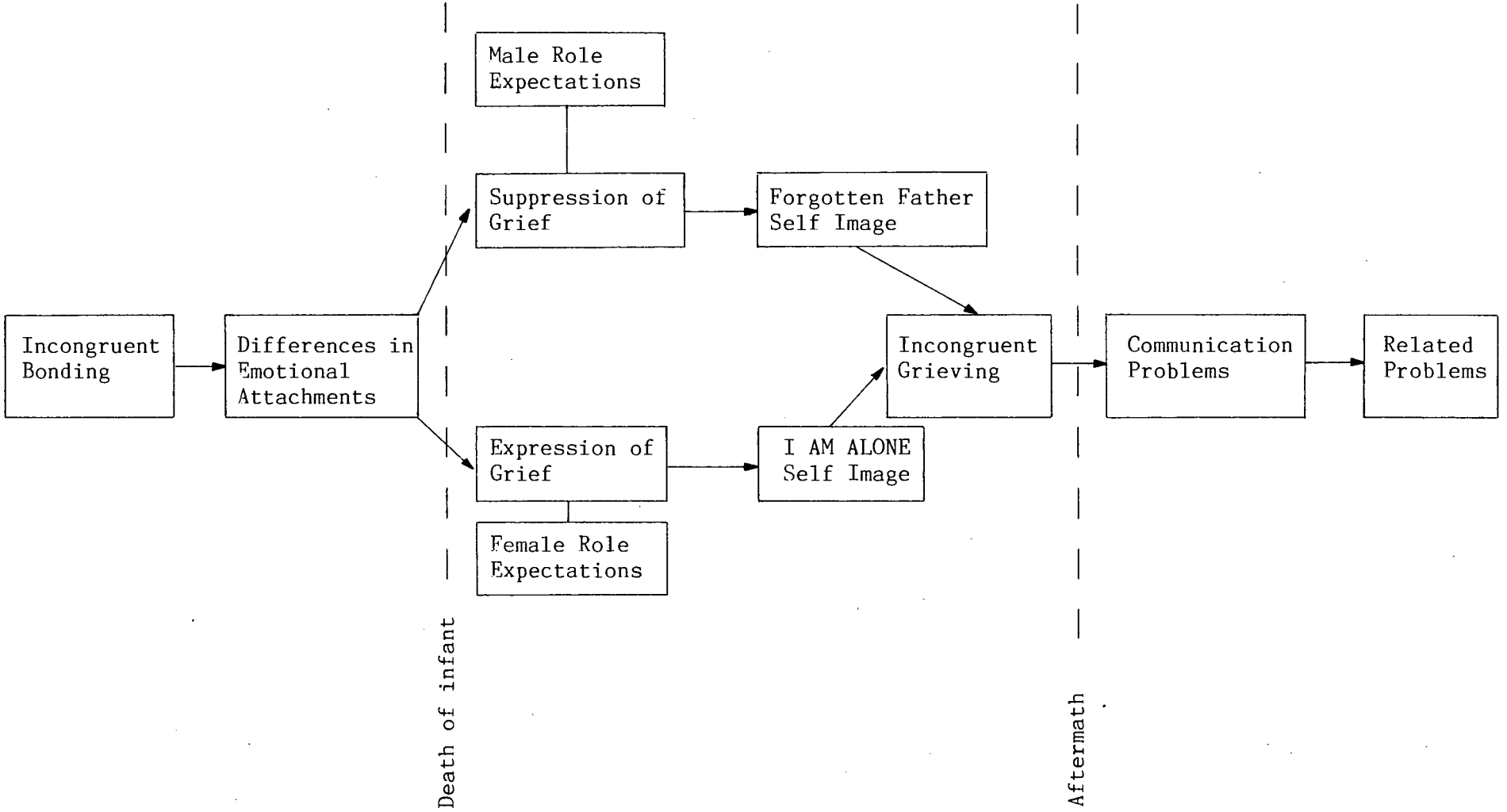
An area of special vulnerability is the couple's sexuality. "Because the relationship between sexual activity and procreation can hardly be avoided, the act itself became a repository of painful memories".[46] There may be arguments over when to resume sexual activity. The couple's feelings of depression usually produce a loss of libido and this is felt more deeply by the wife in most cases. Berezin states that whereas the husband may wish to resume sexual relations at the

earliest opportunity, the wife may resent, resenting the intrusion into her space and fearful of the link between sexuality and conception.

> "What a woman may perceive as callousness and insensitivity to her needs may at least in part be based on her husband's desire to resume emotional communication, which for some men is expressed more easily physically than verbally. In her preoccupation with mourning, she may ignore his signals of grief and loneliness and appear to abandon her former role as wife, mother ... "[47]

Figure 1 represents a model of husband/wife conflict.

Figure 1 : A Model of Husband/Wife Conflict



Larry G Peppers and Ronald J Knapp. Motherhood and Mourning. New York: Praeger Publishers, 1980 : 67

Peppers and Knapp examine the most common alterations that occur in the sexual activity of grieving parents due to the wife's conflict. They summarize these changes as follows: [48]

Type of Change	Reasons for Change
Positive (increase in sexual response and activity)	Expression of affection and intimacy Compensation for the loss Desire to conceive another child
Negative (decrease in sexual response and activity)	Fear of pregnancy Obsession with getting pregnant Loss of self-confidence Disallowance of personal pleasure Loss of sex drive

If the couple are able to approach the crisis of stillbirth in a mutually supportive manner, are flexible, communicate openly, and receive sensitive treatment, it is likely that they will emerge from the experience as stronger individuals and that the marriage will endure. However, if conditions are unfavourable for healthy resolution of grief, a negative outcome, in whatever form, can be expected.

Borg and Lasker include a section in their book on how pregnancy loss affects single women, both teenagers and adults. These women have additional problems to face as there is no husband or partner to share the decisions and to provide the needed support through delivery and the grief period that follows.

In the situation where a woman who was married at the time of conception and is then divorced or widowed during pregnancy there are unique problems. There is a great deal of ambivalence mixed with grief and anger during the time the baby is anticipated. When the pregnancy ends in failure, the woman is likely to be overwhelmed by an array of emotions such as relief, despair, quiet and renewed grief for the loss she has recently experienced. The teenager whose pregnancy ends in tragedy needs support and understanding especially from her parents and her boyfriend. This is not the time for alienation and conflicts to exist between parent and daughter. Counselling can assist these girls to understand their feelings, their needs and themselves and to help them resolve family conflicts and plan for the future.

Children

- A simple child,
That lightly draws its breath,
And feels its life in every limb,
What should it know of death?

- William Woodsworth
"We are Seven"

It is important to understand how the tragic outcome of pregnancy affects siblings in the family. Although attitudes about death become more sophisticated and involved as the child matures, one finds that even the youngest preschooler may be strongly affected by the loss of an anticipated sibling.

Berezin explains that the reason for this is: (1) There are inescapable changes in the adults around him such as depression, irritability and self-preoccupation which he does not comprehend and (2) the child's place in the family has permanently changed - he is now a survivor and must learn to cope with the complex implications of that role.[49]

The impact of bereavement on children is important to their development. The siblings of the anticipated baby react to the family disequilibrium caused by the stillbirth, and are sensitive to the mother's grief and mourning. Various authors have categorized childrens' reactions to death according to age. Melvin Lewis divided children into the following age groups:

0 - 5 years	:	The child reacts to changes in the parents. He senses withdrawal and fears loss of love.
5 - 10 years	:	The concern is in regard to implications of the death and the fear for himself.
10 - 12 years	:	The child is generally supportive, but may have survival guilt.[50]

Hollingsworth and Pasnau describe the different phases that a child passes through in his ideas about death:

3 - 5 years	:	Child denies death as a natural and final process. To him, death is like sleep : you are dead, then alive again.

5 - 9 years : Child appears to be able to accept the idea that someone has died, but does not accept it as something that eventually happens to everyone.

10 years and over : Child begins to recognise death as inevitable for all persons and as something that can come to him.[51]

How a child will experience the stillbirth event is determined by many factors: his age, his personality, his past experiences of death; his awareness of the pregnancy, how the mother reacted to the loss, and how the parents responded to the child during that period. In order to understand how children respond to a death in the family "it is necessary to consider not only their chronological age and developmental level, but also the social and cultural climate or framework in which they are raised".[52]

Initially, most childrens' reactions are confusion and puzzlement. They want to know what happened, why it happened and how. In dealing with these questions, parents should try and remember that their child's understanding is limited by his current level of development The child may not be able to comprehend what parents tell him about the death of a potential sibling, but the discussion of it will set a pattern of openness and sharing. Parents need to know that the death of an infant, once it has been explained, should not be a closed topic. The information is likely to surface in the future, often or at awkward times.

Young children faced with the death of an infant need all the help that parents can offer: special time alone with the parents, reassurances that they have not lost their place in the family; and opportunities to help them express and comprehend their feelings. Children also need to know that mourning for the dead baby and feelings of sadness are appropriate. Hereby, the child learns that mourning the loss of a loved one is normal.[53]

It is important to realize that children grieve differently to adults and express feelings of grief in their actions rather than verbally. The parents, teachers and medical personnel dealing with the family should be alert to any signs that indicate distress or a disturbed reaction in the child.

As parents are deeply affected by the stillbirth, it is impossible for other children in the family to be shielded from it.

> "Parents who find ways of coping well with their own grief are providing the best possible atmosphere in which their children can also come to accept and grow from the experience. More important perhaps than the specific words they say to a child are the love and security they provide ... "[54]

Grandparents

Goodbye,
my beautiful grandson, goodbye.
So brief a visit
Yet stillborn
No chance to meet sister and brother,
yet touched our hearts and minds
with your soul,
just enough to linger - forever.
So hard it was to separate,
what quiet knowledge to bring
What did you tell mother and father?
So sweet a smile, so sad a glance
with love you brought us all together
Now time to go
You know, not I
decision made by master plan
I try to feel a breath - not ever, no more
I kiss you softly
It's time to say goodbye.
A lifetime yet to learn.
Shalom our little Cherub
Now you may rest with the angels.

Untitled: Written by a grandfather 1986

Discussion about grandparents' grief at the loss of a potential grandchild is almost non-existent in the literature on perinatal death. Perhaps this is a general reflection of society's ignorance about stillbirth and how it affects family members.

For grandparents, the delivery of a stillborn baby is a double blow and double burden: the disappointment of their expectations for a grandchild and the pain of seeing their own children suffering; the hurt because their anticipated grandchild is dead and the hurt because their own child is desolate.

Grandparents, knowing their own children are suffering, wish they could protect them from the hurt. They feel helplessness, frustration and pain. If there are no other grandchildren in the family, they have to adjust to the reality of not being grandparents. Borg and Lasker, who succinctly describe the reactions of grandparents, quote one woman who described herself as a "grandmother-not-to-be".[55]

For grandparents who live far away from their children there are added frustrations as they are unable to be with them to offer consolation, comfort and care.

The grandparents' grief may be expressed in various ways. They may be extremely angry - at the doctor, son-in-law, daughter-in-law, or at the baby - at the source of the parents' pain. They may also feel guilt. If the baby had a genetic problem, they may feel responsible. Where there is a history of reproductive problems or infant loss in the grandparents' generation, the grandmother may wonder if she has passed on to her daughter a propensity for tragic pregnancies.[56]

Some grandparents express their grief openly and share their feelings. This can give the bereaved parents a feeling of understanding and sharing. Others may conceal their feelings to avoid upsetting the parents and reassure them that someone in the family is in control and will take care of matters.

For grandparents who wish to help their children, it is important to know that there is no timetable for grief, that their children must be allowed to grieve in their own way and that understanding, comfort and support can help them through their bereavement.

Medical Staff

A stillbirth is a stressful experience for the parents as well as the medical staff involved. When a mother delivers a stillborn infant, the reaction of others, especially doctors and nurses may influence the process of grief. Until recently, the view held by society and medical personnel was that mothers need not grieve for a stillbirth. This view has changed and so has the attitude of medical personnel working in this field of perinatal death.

Jiménez states that for the maternal health professional, foetal death is the ultimate defeat. "When the breath of life is not present at birth, all the gleaming up-to-date equipment and the modern miracle drugs stand waiting and useless".[57]

Reactions : While some authors explain that the professional experiences the same stages of grief as the parents do after a stillbirth - denial, anger, bargaining, depression and acceptance, others have found the reactions to be avoidance and inability to deal effectively with the situation.

Bourne studied the psychological effects of stillbirths on the mother and her family by comparing 100 cases of stillbirth with 100 live births. He was surprised to find clear evidence of disturbed doctor-patient relationship characterized by the doctor's strong reluctance to notice or remember anything about the patient who had had a stillbirth.[58]

Culberg observed that stillbirth and neonatal death evoke a sense of guilt in the staff on a maternity ward and mentioned three ways in which staff members handle the anxiety associated with a death: (1) avoidance of the situation; (2) projection of personal feelings onto the patient in the form of aggressive or accusing behaviour; and (3) denial and "magical repair" (" ... forget it ... get a new child ... give heavy doses of sedatives"). He commented that most doctors are not theoretically or emotionally prepared to act in a more realistic and conscious manner, and often they feel inadequate and awkward in these situations.[59] Giles noted that physicians managed bereaved mothers by treating physical symptoms only, by liberally prescribing sedatives, and by avoiding discussion of the baby's death in half the cases.[60] Evidence of the emotional unavailability of medical personnel has been provided by Wolff and colleagues in a longitudinal study of mothers who experienced a stillbirth. More than 50 percent perceived their doctors as cold and indifferent to them during their bereavement, and over 60 percent characterized their nurses similarly.[61] Rowe et al in a retrospective study of twenty-six families found that 60 percent of mothers interviewed felt dissatisfied with the information offered them about the stillbirth, and the manner in which the information was communicated.[62]

Kirkley-Best comments that while staff members may have a detrimental influence on the mother's well-being, their supportive intervention may have a facilitating effect on the grieving process.[63] Rowe et al found that mothers who received follow-up care after their stillbirths were considerably more satisfied with their treatment. Schreiner, Gresham and Green found that "a simple, caring phone call from a physician accounted for a reduction in reports of major problems in the intervention group when compared with stillbirth mothers who received no phone call".[64]

Kennell and Klaus attempted to explain why physicians react the way they do when a perinatal death occurs. At the time of the infant's death, a number of strong emotions well up in the physician. He may wonder if the result would have been the same if a different procedure had been used, and, like the parents, may be plagued by guilt. He also has the difficult task of facing the parents with the news of the baby's death. He may also feel that he is a failure at his job. These authors emphasize that in contrast to feelings of uselessness, the caretaker has a "singular opportunity to make an important contribution to the health of the parents and to the integrity of the whole family".[65] The physician or caretaker must encourage the grief process, meet the individual needs of the parents, encourage parents to communicate their feelings to each other and offer assistance with dealing with siblings in the family.

Bruce described the reactions of nurses and mothers to stillbirths and made a significant statement: "Until the nurse can handle her own response to grief she cannot meet the mother's great needs".[66] Therefore it has been stated that a nurse cannot function effectively in a patient relationship when her own anxieties limit her awareness of her patient's emotional response.

> "Hospital staff members are the first people present when a death occurs. It is in their power, through their reactions and the quality of care they provide, to control the enormous difference between a tragedy that is bearable and one made worse by insensitivity, error, or inattention to need".[67]

In some hospitals, staff are trained to meet the needs of bereaved parents. The parents benefit greatly from an understanding of their emotional needs and the giving of information relevant to the cause of the stillbirth and other related aspects. In many hospitals staff members are not trained to deal with these parents and therefore do

not have the skills to handle the many sensitive issues involved. One of the controversial issues is whether the mother should see or hold the baby. Many authors agree that seeing and holding the infant is helpful in successful grief resolution. When a mother has not seen her infant, momentos such as photographs, footprints, name tags and clothing become critically important to her. These have been observed to have beneficial effects.

A major issue for any mother after the stillbirth is the location of her hospital bed and room. Most mothers wish to be as far away as possible from healthy babies and do not want to be reminded of their emptiness and failure. Some mothers may want to remain on the maternity floor in a private room while others may feel out of place there.

Another sensitive issue to be dealt with is permission for an autopsy. The request occurs soon after a death and comes as a jolt to the parents, who may not yet be prepared to make such a decision. According to some authors in the field of perinatal death, "the autopsy seems to allay guilt and anxiety in parents of stillborns".[68] Even when no definite cause of death is found, emphasis on the baby's normality seems to alleviate much of the parents' concern.

Parents of stillborn infants desperately want information from the medical staff. Providing an explanation is not an easy task. Often there is no known cause and therefore no explanation. When an explanation is given, the parents may not take in what has been said as they may be in a state of shock. They may misunderstand or misinterpret what is said. To prevent this from happening, the doctor may have to explain what has happened several times and be available for questions that may arise at a later stage.

Berezin makes noteworthy comments, when she states that parental anger and resentment are generally least likely to occur when (1) the parents are permitted to take part in critical decisions; and (2) when physicians, nurses and other staff members allow human compassion to surface and, instead of turning away from the family, openly display their own sadness.[69]

In conclusion, it is important to acknowledge that the medical personnel involved in delivery of stillborn infants face many difficulties and emotional issues. They have to cope with their own feelings, disappointments and failure, as well as the parents' grief and specific needs and problems.

GRIEF AND BEREAVEMENT

> Blessed are those who mourn, for they shall be comforted.
>
> Matt. 5:4 RSV

Parents who experience a stillbirth are subject to the same psycho-physiological process of grieving as those who suffer the loss of any other close family member.

There are several theories about and descriptions of grief and bereavement in the literature. Much of the information presented by different authors overlaps. In recent years some authors have adopted classic descriptions of grief to fit into the realm of perinatal death.

Before discussing the grief process that follows stillbirths, it is important to define grief and related concepts.

Definitions

Bereavement has been defined as the act of separation or loss that results in the experience of grief. It has also been described as the complex series of responses which follows a loss. It is divided into two components - grief and mourning.[70]

Grief is defined as "intense emotional suffering caused by loss ..." a succession of painful feelings in response to a loss.

Anticipatory grief is the term applied to grief expressed in advance of a loss when the loss is perceived as inevitable.

Acute grief is the intense psychological pain that follows a loss. Mourning is sometimes used interchangeably with grief but is also regarded as the lengthy process following loss, of which grief is a part. It extends beyond the first reactions into the period of reorganisation. Averill regards mourning as the conventional behaviour determined by the mores and customs of a given society, dictating the way in which a person should conduct himself following the death of an individual.[71] The reactions of grief are physiological and psychological rather than cultural as in mourning and there is evidence according to Bowlby that there is a biological base to grief.

Grief and mourning may occur simultaneously in situations where feelings are supported by social customs such as funeral rites. At a time of disorganisation these rites give structure to the bereaved and also reinforce social and religious behaviour. Mourning can take place when death has produced no grief and mourning without grief can also take place where grief is inhibited, aborted, or denied.

Grief, a normal life process, can produce profound physical, emotional and mental changes and may thus be misdiagnosed as maladjustment.

Simos presents an analogy between grief and physical illness:

> "Both states take time for healing. Both include emotional and physical aspects. Both may be self-limiting or require intervention by others ... recovery can range from a complete return to the pre-existing state of health and well-being, to partial recovery, to improved growth and creativity, or both can inflict permanent damage, progressive decline and even death".[72]

Averill gives an in-depth review of grief when he analyzed bereavement behaviour from cultural, biological and psychological perspectives. He divides bereavement behaviour stating: "The complex series of responses following the loss of a significant object, is divided into two components : mourning and grief".[73] Bereavement behaviour refers to the "total response pattern, psychological and physiological, displayed by an individual following the loss of a significant object, normally a loved one".[74]

The types of grief that Averill discusses are based upon Lindemann and Parkes analyses, namely, (i) normal grief - a stereotyped set of psychological and physiological reactions in which the three stages of shock, despair and recovery can be delineated; (ii) exaggerated grief - an abnormally prolonged grief reaction; (iii) abbreviated grief - a shortlived but genuine grief reaction due to an immediate replacement of the lost object or to an insufficient attachment to the lost object; (iv) inhibited grief - a lasting inhibition of many of the manifestations of normal grief but with the appearance of other symptoms in their place; (v) anticipatory grief - symptoms of normal grief occur from an expected loss; and (vi) delayed grief - normal or exaggerated grief may be delayed for an extended period of time. The parents experiencing a stillbirth may display any of the above variations of grief.

The grieving process following a stillbirth resembles the classic descriptions of Lindemann and Parkes. The grief reaction described by Lindemann has five points:

(a) Somatic distress
(b) Preoccupation with the image of the deceased
(c) Guilt
(d) Hostility
(e) Disintegration of habitual patterns of conduct or changes in daily living routine.

He also observed that the clinical signs of acute grief in adults are remarkably uniform (Table 1). These reactions, which are more intense soon after the loss, will gradually diminish as the grief work is accomplished.[75]

Table 1 : Clinical Signs of Acute Grief

Sensations of somatic distress occurring in waves lasting 20 - 60 minutes
Feelings of tightness in the throat, choking and shortness of breath
Feelings of emptiness or loneliness
Feelings of increased emotional distance from other people
Slight sense of unreality
Need for sighing
Complaints about weakness and general exhaustion.

Lindemann also describes pathological grieving and states that when the normal course of mourning, which often takes six to twelve months, is impeded, pathological grief is likely to ensure. The characteristics of pathological grief are:

(a) Over-reaction without a sense of loss
(b) Acquisition of symptoms of the deceased's last illness
(c) Psychosomatic reactions (eg ulcerative colitis, asthma, or rheumatoid arthritis)
(d) Serious changes in relationships with friends and relatives
(e) Furious hostility against specific persons
(f) Repression of hostility leading to an overtly formal or "wooden" manner resembling schizophrenia
(g) Permanent impairment of patterns of social interaction
(h) Activities detrimental to one's own social and economic existence
(i) Agitated depression.

The research studies investigating emotional response to a pregnancy loss are few but make important contributions to the field of perinatal death. Giles, previously mentioned, studied women who had experienced perinatal loss and found that they showed emotional and physical reactions similar to those commonly displayed following the death of an older loved person.[76]

A valuable contribution to the literature on perinatal death is a study in which Benfield et al devised a parent grief score to determine the grief response of parents to neonatal death. The following seven items were considered to represent a measure of parental grief: feelings of sadness, loss of appetite, inability to sleep, increased irritability, preoccupation thinking about the baby, guilt and feelings of anger. In addition to these, five questions were

included to further measure parents' reactions. The items, requiring a positive or negative response were: episodes of crying, praying for the baby, depression, disbelief, and wanting to be left alone.[77] It was found that paternal grief scores are lower than maternal but that fathers did experience grief. The data suggested that a parent's grief response may depend more on the compassionate concern of caregivers than any other single factor, and that the attitudes and behaviour of family, friends, and health care personnel in the hospital often adversely influence parent grieving. This has important implications for management.

Dunlop analyses the process of mourning as it applies to stillbirth and presents each stage with its accompanying symptoms.[78]

1. Stage of Shock:

   This is most pronounced when the parents are suddenly confronted with the knowledge of their baby's death and when the mother may be physically shocked from a difficult labour. Shock may take the form of actual pain, numbness, complete apathy, withdrawal or abnormal calm.

2. Denial:

   This may occur with intrauterine death where the mother may suspect something is wrong, but hopes that she is mistaken. Denial may occur where the mother believes her pregnancy to be continuing. After bereavement and during the stage of denial, many parents feel intense yearning and display seeking behaviours for the dead baby.

3. Depression:

This is a natural stage and the mother should be permitted and encouraged to work through her grief.

4. Guilt:

With stillbirth guilt or self-blame is a prominant feature. Parents blame various incidents and themselves for their baby dying. Mothers' guilt may be viewed on two levels: (a) they could not produce a healthy baby and (b) they have failed in their sexual function.

5. Anxiety:

After a stillbirth, parents often experience intense anxiety and may feel they are "losing their reason" because they are unable to sleep, eat, concentrate, have panic attacks and so on.

6. Aggression:

This is a common reaction and may be directed at doctors, midwives, spouses or God. Parents may be especially angry with the hospital for not producing a live baby.

7. Re-integration:

For this to occur, it is necessary for the lost object to be relinquished and laid to rest and the emotional reactions extinguished so that the mother can start a new way of life with which the lost baby does not interfere.

Although many authors have assigned names to "stages of grief", there appears to be no step-by-step progression through stages. Rather, oscillation from intense mourning to periods of acceptance occurs.

Hildebrand and Schreiner list many of the problems that parents may experience after a perinatal death. These problems and reactions are typical grief reactions and are listed in Table 2.[79]

Table 2 : Common Reactions and Problems of Parents After a Perinatal Death

Somatic complaints (tightness in the throat, choking, shortness of breath, weakness, loss of appetite, insomnia)
Feelings of unreality
Loneliness, depression
Guilt
Anger, hostility (toward family, friends, physicians and nurses)
Irritability
Loss of routine patterns
Preoccupation with an image of the infant
Difficulties with friends and relatives.

These authors comment that the grieving process lasts six months to a year. Anniversary dates are known to be traumatic times for parents. One can therefore recommend that parents be counselled so that they are prepared for their reactions, for the length of time it may take to reach the acceptance stage, and are aware of the anxiety surrounding the anniversary date of the stillbirth. One cannot generalize about the length of the grieving process.

Each parent is unique, and has his/her own way of dealing with grief. It is therefore difficult to gauge a specific time period. Peretz also comments that the duration of grief is variable and may range from six months to a year. The acute phase should be over within one to two months.

> "The progress of grief can be judged in terms of whether there is a gradual return to the level of functioning prior to the loss ... another indication of recovery from grief includes whether new relationships are being established ... and the return of full capacity for pleasure without shame or guilt".[80]

A stillbirth may be expected by the parents where there is prior knowledge that the foetus has died; it may be suspected where the mother senses something is wrong and this leads her to have the matter investigated; or it may come as a complete shock, sudden and unexpected. In the former two instances the parents may go through the anticipatory grieving process and therefore be better prepared for what is to come. In the latter instance parents are totally unprepared. The importance of seeing, touching and holding the infant has been widely recognised and recommended in the literature. Many women are heavily sedated during the delivery and this not only interferes with opportunities for seeing the baby but may also suppress the grieving response.

The grief that follows a stillbirth is likely to show "in intense yearning and longing for the baby, in the need to see, touch, and bury it before the finality of its loss can be expected".[81] The mourning process that follows may take weeks, months or even years.

Raphael succinctly sums up problems that may follow stillbirths when she states that the risk of poor outcome may be increased if the mother is heavily sedated; if she is prevented from seeing the baby; if the parents are unable to communicate and share grief or recognize its different patterns for each other; if the mother's previous self-image was poor; and if support is lacking.[82]

The unique nature of mourning a stillbirth has been described by Lewis and many other researchers concur with his recommendations and findings. Lewis encourages the health care personnel to facilitate the mourning process of the parents. Thereby, they are encouraged to see, touch, hold and name their baby, and also to make the funeral memorable. "Memory facilitates the normal mourning processes essential for recovery".[83]

Healing and recovery from loss is a process that takes time. Although time is no guarantee of recovery, parents should be made aware of the stages of grief and be supported during this period.

He that lacks time to mourn,
lacks time to mend.

Sir Henry Taylor (1834)

SUBSEQUENT PREGNANCY AND THE "REPLACEMENT CHILD"

The "replacement child" syndrome refers to a child who is used by the parents as a substitute for a sibling who has died. "Sometimes a child is specially conceived for this purpose, at other times another sibling ... is assigned this role".[84] This syndrome has received little attention in the psychiatric literature and was first commented on by Cain and Cain in 1964 in an article on the psychological difficulties of replacing a child. They reported that replacement children tend to be overprotected by fearful parents and to be raised in homes dominated by images of the dead child. "Replacement children are often expected to emulate the idealized image of a dead child and are thereby not allowed to develop their own identity".[85] Parental attitudes toward the replacement child are a major source of difficulty. Cain and Cain described the mothers of these children as being guilt ridden, depressive, phobic or compulsive prior to the death of a child in the family.[86]

This syndrome has relevance for the parents of stillborn infants. Parents are often advised or decide on their own to have another baby as soon as possible after the stillbirth, without adequately mourning or completing their "griefwork". The subsequent or replacement infant is therefore at risk of not being able to develop his/her own personality. The parents and medical personnel should recognise the danger in mothers of stillborn infants having another child before they have grieved and resolved that grief.

> "Replacing a child with another allows the parents partially to deny the first child's death. The replacement child then acts as a barrier to the parental acknowledgement of death since a real child exists who is a substitute. Thus the first stages of bereavement are prematurely arrested and the process of mourning continues indefinitely with the replacement child acting as the continuing vehicle of parental grief".[87]

PERINATAL MANAGEMENT

Dealing with perinatal death is not easy for parents or health care professionals. Understanding the grief process, recognising the potential stress situations for parents, and being aware of the additional resources to deal with the situation may make the professional more comfortable with the task.

Morrison discusses professional intervention and comments that when perinatal death occurs, the health care providers involved with the family must first recognise their own response to the baby's death. Their next task is to decide whether they are personally able to help the family. Awareness of additional resources such as the special skills of other health care providers and parent groups can increase the clinician's options for care giving. He makes the following general recommendations which may guide the clinician's actions.[88]

(a) Express sorrow over the death
(b) Recognise the family's need to make decisions which are appropriate to them.
(c) Allow and support mourning
(d) Provide consistent information
(e) Encourage communication between family members and support group
(f) Explain the grief process to the family
(g) Alleviate guilt.

The critical junctures where appropriate intervention and dissemination of information are necessary occur at the following times:

(a) At the first indication that there may be a serious problem
(b) At the time of death
(c) During the decision-making period which precedes disposition of the body
(d) During the period between the woman's release from the hospital and the follow-up visit from the health care provider involved
(e) At the time of the follow-up visit(s) between the parents and the health care provider.

When foetal death occurs, the parents' needs are many. The doctor and medical team can help fill these needs by supplying medical and other information about the cause and circumstances of the death and by being aware of and sensitive to the emotional state of the parents during the initial phase of the grieving process.

Parents, in particular mothers, often feel guilty when a stillbirth occurs. The doctor can supply the kind of information necessary to relieve the guilt. Knapp and Peppers comment that parents want to know what went wrong, why and how it happened. They turn to the persons who can best answer these questions, ie professional personnel.

> "Being there, giving comfort and support, conveying information and autopsy results in a compassionate and understanding manner, and telling the parents how this tragedy might affect the family in the weeks and months to come are all included in the functions of counsellor-consoler".[89]

These authors found that the parents they interviewed expressed their most desperate need as the need to talk to someone about their experience. Bergman has stated that the "art of therapeutic listening" is one of the best techniques that the physician-consoler can master. "When families are in the shock of grief, one should not attempt to impart much information. 'Being there', physically and spiritually is more important than what is said".[90]

Health care professionals involved in the events surrounding a still birth can contribute to the resolution of the mother's grief and the father's sadness "only by recognising that if they can truly maintain an interest, they can be sympathetic and compassionate listeners for as long as the parents have the need to talk about the tragedy".[91]

In the past few years, a number of intervention programmes have arisen to offer information and support to the families experiencing a stillbirth. Most of these programmes include in-hospital visits and follow-up of parents at regular intervals. These programmes seem to help families cope with their loss and their grief and are run by parents themselves, by individuals (such as psychiatric nurses), or by bereavement teams. Most of the programmes involve the following: the mother is supported and encouraged to express her feelings, she is offered full options in regard to her baby (seeing, holding the baby, photographs etc), and she is followed up throughout the bereavement period.

Various authors have advocated different times of meeting with bereaved parents. The following has been described by a group of paediatricians in Cleveland, USA: The first meeting should take place directly following the event; the second, two to three days afterward; and the third, from three to six months after the baby's

death. Initially, the mourning process can be described to the parents in general terms. During this time the couple should expect to feel guilty and/or angry at one another and outsiders - reactions which are normal under the circumstances. The second meeting provides an opportunity to go over the same material in greater detail now that the parents have had some time to absorb the news and have begun the grieving process. Arrangements for a third follow-up meeting can be made at the end of the second interview. Autopsy data can be discussed at this time and the doctor can check that parental grief has begun to abate. He must also be aware of any signs of distorted or pathologic grief that may be evident.

Jiménez has summed up the basic components of effective counselling that pertain to the nurse, the doctor, childbirth educator and any other health professional who deals with grieving parents. They are as follows:[92]

1. Comfort

   Before the grieving parent can focus on his/her emotional recovery, it is imperative that the health care professional meet all the needs for physical comfort. The mother's physical discomforts must be attended to and alleviated where possible and the father's physical needs must also be attended to (for example, fatigue and hunger).

2. Caring

   While attending to the parent's physical comfort, a climate of caring can be set through touch, through expressions of concern and by just being there. After the mother has gone home, a telephone call once or twice a week will be welcomed by the

parents. The family should be told that the health care professional is available should they need him/her.

3. Communication

The rule in counselling is to encourage frank expression of feelings and concerns and to deal openly with whatever is mentioned. The parents must be encouraged to make their own decisions.

4. Continuity

Specialization in health care has many advantages but a distinct disadvantage is the fragmenting of care which is specially harmful to the grieving parents.

Many hospitals transfer mothers to a general medical-surgical floor which is intended to help her reduce her pain. But it could also lead to her isolation. It is important that the mother be placed in an area where the staff has special training in the emotional and physical care of the grieving, postpartal woman. Continuity involves participation of all members of the health-care team: doctor, nurses, social worker and childbirth educator. Each member is responsible for giving the others any information that will help in fostering healthy grief work. Referral to a self-help group can be of great benefit to the parents.

Jiménez concludes that,

> "ending the conspiracy of silence should begin with those best equipped to do so - the health professionals. By recognising birth and death as integral parts of the natural life cycle of the family, we can take the first, and most important step toward healing the wounds of grief".[93]

When a stillbirth occurs, doctors and nurses may respond in one of three ways which have been identified by bereaved parents as damaging. These are (1) avoidance of the death or saying very little; (2) confronting hostility from the parents with hostility or negative behaviour of their own; and (3) use of "magical thinking" saying "you can always have another baby", or "you are lucky you have other children".[94]

Lockwood and Lewis offer helpful advice for telling parents about the death of their baby. They comment that the art of helping couples who have suffered stillbirth lies principally in avoiding making thoughtless remarks. "Where there is no 'right' thing to say, it becomes doubly important not to say the 'wrong' thing".[95] The following hints have been proposed.

(a) Almost all babies have either a name or a list of possible names prepared before they are born. Parents may be encouraged to refer to their babies by their chosen names, and professionals should follow the parents' example.

(b) Parents of stillborn infants are hurt not only by perceived thoughtlessness and insensitivity but also by evasiveness and avoidance of contact.

(c) Parents are hurt rather than helped by reference to it being "for the best" in cases of actual or presumed congenital abnormality.[96]

These same authors recommend that parents of a stillborn infant should be followed up at intervals of six weeks, six months and a little over a year. In the first few weeks after the loss, there are a number of social and gynaecological "critical incidents" to be negotiated.

The three gynaecological crises to be faced are: (i) the let-down of the milk supply; (ii) the first postnatal menstrual period; and (iii) the resumption, or non-resumption of sexual intercourse. Patients who are warned in advance that these crises may cause distress are better prepared to cope with them.

The three major social crises confronting the parents are: (i) facing relatives and friends, especially for the first time; (ii) disposing of baby clothes, nursery furniture and things that had been intended for the new baby; and (iii) learning, often painfully and slowly, to live with the sight of casually encountered pregnant women, babies, and young children.

The purpose of the first postnatal follow-up, apart from obstetric concerns, is twofold: the first objective is to convey where possible the results of the postmortem examination and to explain what went wrong where a likely cause is identified. The second objective is to ensure that nothing dangerous is taking place: marital and family relationships should be touched upon and assurance sought that there is no prolonged denial of the reality of the loss or inhibition of appropriate grief. The objective at six months is to ensure that the most painful phase of grief is at least passing. The follow-up at about thirteen months is recommended as there is often a resurgence of grief at the first anniversary after the stillbirth. "Grief work" should be completed by this stage.[97]

The goals of a grief support team can be described as follows:

(i) to provide basic human comfort and support;
(ii) to encourage the expression of grief, and
(iii) to promote the mourning process as appropriate to each individual.

The following table has been proposed by Lake et al in their programme of grief crisis intervention and follow-up.
Table 3 summarizes perinatal management in general and provides a guide for others working in the field of perinatal death.[98]

Table 3 : Objectives of Perinatal Grief Crisis Intervention

Prior to discharge	4-6 week postpartum	4-6 months postpartum	1 year anniversary
1 Provide basic human comfort and support	1 Share preliminary autopsy report	1 Share final autopsy results	1 Facilitate expression of sadness at anniversary
2 Help make loss real	2 Assess patient's progress	2 Reassess emotional progress	2 Refer for psychotherapeutic support if pathologic reaction evident
3 Encourage expression of emotion	3 Facilitate emotional release	3 Reassess social support	3 Provide support if subsequent pregnancy planned or undertaken
4 Encourage open communication among family	4 Describe incongruent grieving	4 Explore possible problems in marital or sexual relationship	
5 Prepare for encounters in community	5 Assess couple's progress	5 Schedule anniversary visit	
6 Assess response in preparation future meetings	6 Discuss local support groups		
7 Record information	7 Assess social report		
8 Schedule 4-6 week appointment	8 Discuss plans for subsequent pregnancies		
	9 Schedule 4-6 month appointment		

The Perinatal Mortality Couselling Programme at Shands Teaching Hospital, Gainsville, Florida describes the role of its team members as follows: [99]

Obstetrician

(i) coordinates in-house management of the patient to see that appropriate medical care is given along with facilitations of grieving;

(ii) acts as a central source of information for the rest of the team regarding the status of the patient and her management;

(iii) provides information for the patient regarding her medical concerns related to the present and future pregnancies;

(iv) plans future medical management and arranges for appropriate follow-up;

(v) serves as consultant and educator of other hospital staff and students regarding management of patients experiencing perinatal death; and

(vi) can influence the establishment of hospital policies and protocol that will aid the patient and her family in grieving.

Social Worker

(i) helps the patient and her family ventilate feelings about the loss;

(ii) encourages communication between the mother and significant others regarding the infant's death;

(iii) secures social history information from the mother and her family;

(iv) informs the patient of available community resources that may be of help to her and her family;

(v) serves as liaison between service agencies and the patient when necessary;

(vi) makes contact with patients who fail to return for their postpartum visits;

(vii) provides feedback to the patient throughout the counselling contacts regarding the appropriateness of her grieving responses; and

(viii) refers the patient to appropriate counselling resources when signs of pathological grief are evident.

Pathologist

(i) provides information about the autopsy report to the patient and other family members;

(ii) provides appropriate pictures of the infant and interprets reasons for any abnormal features.

Psychologist

(i) helps to develop methods to determine the effectiveness of the present programme and related aspects;

(ii) assists in information - counselling aspects of the programme; and

(iii) gathers research articles on perinatal death psychology.

The tragedy of stillbirth does not end when the mother leaves hospital. Therefore, a programme of follow-up should be undertaken for these families. Social work follow-up ought to be done in conjunction with the doctor or team. Where this does not exist, the social worker can proceed independently. Besides offering support on a one-to-one basis, the social worker should refer such families to self-help groups and organisations specifically formed to deal with families experiencing perinatal death. Self-help groups can give mothers an opportunity to share their feelings in an atmosphere of understanding and acceptance, to realize that their grief is not unusual or abnormal, and to meet others who have resolved their loss.

The social worker can also play an important role in encouraging discussion groups amongst staff members.

Open discussion of feelings, attitudes and differences leads to improvement of interstaff communication and awareness and can increase the staff's ability to assist parents in the handling of their grief.

In terms of management, the following statement by Peppers and Knapp highlights the problems that can occur in the situation of a perinatal death.

> "... at times the mother who delivers a stillborn infant finds herself in a medical limbo. The obstetrician ... views most of his job as finished; the pediatrician has no infant with which to concern himself; thus the mother is sometimes left without responsible medical care ... " [100]

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CHAPTER III : METHOD OF INVESTIGATION

Sample Selection and Size

Data Collection

Consent Form

Data Analysis

Pilot Study

Definition of Terms

METHOD OF INVESTIGATION

This study is an investigation of the psychosocial aspects of stillbirths. A stillbirth is considered a crisis that calls for immediate intervention and follow-up management.

This chapter describes the size and method of selection of the study sample, the procedure for collection of data, and the instruments employed in the collection and analysis of data. The pilot study, conducted previously, is also discussed. The study is descriptive in nature and was designed to answer the research questions articulated in Chapter One.

SAMPLE SELECTION AND SIZE

For practical reasons, the sample was selected from one hospital. That hospital is the largest in the municipal area of Cape Town and the catchment hospital for the majority of stillbirths delivered within the region.

The sample consisted of Coloured mothers who delivered stillborn infants at Groote Schuur Hospital and who reside in the municipal area of Cape Town. The time period for collection of the sample was six months, from 1st October 1983 to 31st March 1984. It was anticipated that approximately fifty respondents would be collected in the sample, because hospital records indicate that the number of Coloured stillborn infants delivered over a six month period is approximately fifty.

The following procedure was employed for sample selection.

Subjects were collected from Monday mornings at 00.01 hours until Friday mornings at 8.00 a.m. hours. Due to skeleton staffing over weekends, it was decided not to collect subjects during these periods. The subjects' names and details were reported to the writer by a staff member from the Neonatalogy Department at Groote Schuur Hospital. This person was a consultant specialist. When he was not available, a registrar doctor replaced him who had been given relevant instructions for notification of cases to the writer. Each morning of the week, the staff member also collaborated with the writer, checked in Labour Ward to see if there had been stillbirths during the previous 24 hour period. If so, and if the subject resided in the defined area and fitted the criteria, her details were given to the writer.

Cases were limited to the first five per week for the first five weeks, and thereafter to the first three cases per week. The reason for this was to allow the writer time to do six-week follow-up visits at the time prescribed in the study protocol. With these procedures, thirty cases were collected. There was a drop out figure of ten due to the writer not being able to trace these respondents. The characteristics of these ten cases did not differ significantly from the rest of the sample.

DATA COLLECTION

Medical data was gathered from maternal records after consent had been obtained from the subjects.

The following information was recorded:

(a) Information on the mother:
obstetrical history
relevant medical history
period of hospitalization

(b) Information on the stillborn infant:
birthweight
sex
gestational age
whether an autopsy was performed
probable cause of death
burial arrangements

Psychosocial data were acquired in two stages. In stage one, the writer conducted an interview with mothers following a pre-determined interview schedule. These interviews were tape recorded. In stage two, use was made of an interview schedule but interviews were not recorded. The interview schedules were semi-structured. The first interview, ie stage one, was conducted within one week of the respondent being discharged from hospital. The second interview, ie stage two, was conducted approximately six weeks after the first interview. Interviews were conducted at the homes of the respondents, once consent had been obtained from each respondent.

See Appendix V for Interview Schedule.

The following data was gathered and recorded during each of the interviews:-

Interview 1

(a) Reactions of respondents to the stillbirth:

This phase of the first interview consisted of open-ended questions, and in addition also recorded specific grief reactions.

(b) Initial effect of stillbirth on the family:

This phase analyzed the impact that the stillbirth had on the mother, father, other children and other significant family members, as well as on the family as a whole. Effect refers to the influence and consequences that the stillbirth causes within the family in terms of their reactions, adjustment and coping behaviour, as well as the general family functioning.

(c) Mother's interpretation of management in hospital:

This included questions related to the following issues:-
Whether an explanation was given about what a stillbirth is;
whether the cause or possible cause was discussed;
whether mothers were given the opportunity to ask questions about the stillbirth;
whether mothers were given an opportunity to see, touch, and hold their infants;
whether mothers were given emotional support by hospital staff;

whether mothers were referred to a social worker or elsewhere for follow-up;
whether a post-mortem was discussed and performed;
whether medication was prescribed; and
whether desires concerning funeral arrangements were respected.

Interview 11

(a) Short-term effects of stillbirth on the family:

This phase consisted of open-ended questions and focused on the impact of the stillbirth on individual family members, the marital relationship, parent-child relationships and general family functioning. This information allowed the writer to compare effects seen at one week with those observable at six weeks.

(b) Stated needs of the family:

This discussion focused on problems within the family that resulted from the stillbirth and analyzed areas where assistance for guidance was needed. It consisted of open-ended and close-ended questions.

(c) Mother's interpretation of management in hospital:

This section was similar to Part (c) in Interview 1 and consisted of closed-ended questions. The purpose of repeating this section was to compare mother's responses with those in the first interview and thus obtain a more reliable description of their management in hospital.

After completion of the first interview, an appointment was made with each respondent for the second interview at approximately six weeks after the stillbirth.

CONSENT FORM

A consent form was signed by all respondents taking part in this study prior to the start of the first interview. See Appendix I for copy of consent form.

DATA ANALYSIS

Data was coded on the interview schedules and statistical analysis was done on computer. The assistance of a computer analyst from the Department of Paediatrics and Child Health, University of Cape Town, was used in data analysis. The taped interviews were transcribed to facilitate analysis. See Appendix II for Confidentiality Form signed by the typist.

PILOT STUDY

A pilot study was conducted on five respondents in June/July 1983. The purpose of the pilot study was to test the efficacy of the interview schedule. Additional aims were to evaluate the most suitable time for visiting mothers at home, and to obtain some guidelines on

the stated needs of mothers and family members following the stillbirth.

DEFINITION OF TERMS

Stillbirth : This is defined as any infant who is born dead with a birthweight equal to or over 1000 grams.

Family : This refers to respondents' immediate family residing in the same home as the respondents.

Municipal Area of Cape Town : This implies the City Council Area or the City of Cape Town municipality. See Appendix III for map of defined area.

Respondents : This term is used interchangeably with sample subjects.

Psychosocial Reaction to Stillbirth : This refers to the emotional, psychological and physical symptoms and social responses that women experience in consequence to a stillbirth.

Pregnancy Loss : This term refers to the loss of a foetus or infant and is used interchangeably in reference to stillbirth.

Lactation : This means the production of breast milk.

CHAPTER IV : RESULTS

Section One:
Results from Transcribed Interviews

Section Two:
Findings from the Interview Schedules

RESULTS

This chapter reports the findings of this study and is divided into two sections. Section One reports findings from the transcribed interviews, and in Section Two, the findings from interview schedules are presented.

SECTION 1

Results from the transcribed interviews which were conducted one week after the respondents' discharge from hospital are presented. The researcher asked each respondent specific questions during a tape-recorded interview. The questions asked and answers provided are as follows:

Question 1:

Was the stillbirth event the respondent's first experience of loss of a significant person?

For nine of the thirty respondents, the death of their baby had been their first experience of loss and consequent grief. Many of the respondents were young, thus one would not expect many previous stillbirths or family losses by natural means.

Question 2:

Who provided the most important emotional support for the respondents following the stillbirth?

The husband provided the main emotional support in seventeen cases, and the boyfriend was the main source of emotional support in ten cases. Several of the unmarried couples had planned to get married after the birth of their expected baby. The maternal mother was the chief emotional support system in two cases. In the one, the husband had deserted his wife, and in the other, the father of the stillborn infant was a married man who was not interested in the respondent's pregnancy or delivery. One respondent had a psychiatric history and could not recall who the father of the stillborn infant had been. In this case, the respondent lived with her sister and brother-in-law and they provided the emotional support.

Question 3:

What was the reaction of the husband or partner to the stillbirth event?

In a clear majority of cases, the husbands or partners were upset and disappointed about the stillbirth. This was true in 26 of the 30 cases. Of those who did not express sorrow or disappointment, the following factors were evident. One husband was working away from home at the time of the stillbirth and therefore did not have knowledge of the event. The respondent with the psychiatric history could not recall the father and consequently he did not know about the pregnancy or stillbirth. One husband had an alcoholic problem and did not show any distress overtly. According to the subject, this particular husband blamed her for the stillbirth when he was under the influence of alcohol. In one case the father did not acknowledge an interest in the child because he was a married man.

Question 4:

What was the reaction of the other children in the family and the reaction of the grandparents to the stillbirth?

Those respondents (nineteen out of thirty) who had other children reported that children over the age of five years asked many questions about the baby and were upset about the death of an expected sibling. Younger children, namely those under the age of five, did not seem to understand the situation. When questioned about the reactions of the subjects' parents or parents-in-law to the stillbirth, the majority were reported to be disappointed about the loss of the expected infants and their prospective grandchildren and were distressed by the death of the infants. Several grandparents were looking forward to the birth of another grandchild.

Question 5:

Were there noticeable changes in the behaviour of the other children following the stillbirth event?

A third of the respondents did not have other children. Seven respondents reported that their children were extremely distressed and one reported that her child had displayed problematic behaviour.

Question 6:

Who looked after the children whilst the respondents were in hospital?

Where respondents had other children (19 cases), the husband looked after the children in ten cases. The maternal mother, sister and friend assisted in the other cases.

Question 7:

What was the general effect of the stillbirth on the family? Respondents were asked what the reactions of family members were and what the overall effect the stillbirth had had.

Twenty nine of the thirty respondents reported that the stillbirth had been a disappointment for their family. The family of the remaining respondent who had a psychiatric history were not overtly disappointed. The degree of disappointment was greater in cases where respondents had had previous pregnancy losses (7). In recalling their experiences, these respondents were more tearful and distressed than the others. Having already experienced the loss of a previous infant, this experience was felt as another blow and trauma and evoked strong emotions of sadness and regret.

Question 8:

Had respondents been visited by nursing sister from the local authority clinic or hospital yet, and, if so, did the nursing sister know that the respondents had had stillborn infants?

Twenty five of the thirty had been visited by a clinic nursing sister by the time the researcher conducted the interview. Of those who had been visited, sixteen reported that the nursing sister who called on them at home did not know that the baby had been stillborn and had thus assumed that the respondents had live babies. In the remaining nine cases, the nursing sister had the knowledge of the stillbirth when she visited the respondents.

Question 9:

Were respondents using some form of birth control?

Twenty-six of the thirty respondenst were using a birth control method. Of the remaining four, two were considering sterilization due to their age and therefore were not contemplating contraception. These pregnancies were planned as their last. One respondent stated that she would not have any more children (39 years) and she did not think that birth control was necessary, and one respondent's husband was away from home for a few months and she did not think that birth control was needed yet.

Question 10:

Who organized the burial of the stillborn infants?

In twenty four cases, the burial was organized by the hospital and in six cases by the husband. Of the six who arranged the burial themselves, five were of the Muslim faith and one husband arranged burial of the baby near the grandparents. A few respondents commented that they would have preferred to arrange the burial themselves but could not afford to do so.

Question 11:

Were respondents given medication to inhibit breast lactation, and, if so, was the medication of help in suppressing lactation?

All respondents had been given medication to suppress the production of breast milk. However, half of the respondents reported that their breasts were still leaking breast milk. Some mothers complained of physical distress caused by this.

Others found it an emotionally painful reminder of their loss, since they were producing milk for a baby that did not exist.

Question 12:

Were respondents who had been employed, eligible for Maternity Benefits?

Half of the respondents were unemployed prior to their admission to hospital. Two were employed part-time. Of the thirteen who were working full-time, only five intended to apply for Maternity Benefits. The remaining eight were not certain whether they were eligible for Maternity Benefits or were convicned that they did not qualify for them.

Question 13:

What was the respondents' state of health during pregnancy?

Seventeen respondents reported feeling well during their pregnancy. The following problems and complaints were mentioned by the other thirteen who were not well:-

a. operation to remove cyst (2) ie one during pregnancy and one prior to pregnancy
b. Crohn's Disease (1)
c. diabetes mellitus developed during pregnancy (1)
d. high blood pressure (2)
e. pain and general malaise (2)
f. experience of severe emotional shock (1)
g. experience of a "blackout" prior to admission to hospital (1)
h. oedema (1)
i. pains and low back pain (1)
j. headaches and lame feeling in legs (1)

Question 14:

What were the events that resulted in the respondents' admission to hospital?

Six respondents were first admitted to the nearest MOU (Midwife Obstetric Unit) before being transferred to Groote Schuur Hospital. All were in active labour when admitted to the MOU's.
Most respondents were emotional and tearful in recalling the events surrounding the delivery of their stillborn infants.
Seven respondents had labour induced after the diagnosis of still-birth was made. The diagnosis was made by foetal heart monitoring and/or ultrasound. A few respondents had stopped feeling foetal movement and had suspected that there may have been something wrong with the baby.
Many recalled painful labour and deliveries of their babies.

SECTION 2

The findings analysed and recorded from the interview schedules are presented as follows:-

Obstetric Characteristics Observed

MOTHER	BABY
Gravidity	Birthweight
Parity	Gestational age
Previous miscarriage	Sex
Previous stillbirth	Whether autopsy performed
Booking status for delivery	Probable cause of death
Place of attendance for antenatal care	
Mode of delivery	

Table 4 : General Medical/Psychiatric History

Relevant past medical history	10
Relevant past psychiatric history	1
Non-relevant medical history	19
Total	30

Table 5 : Gravidity (number of pregnancies)

1st	11
2nd	8
3rd	3
4th	3
5th	4
6th	0
7th	0
8th	1
Total	30

Table 6 : Parity (number of deliveries)

None	12
1st	7
2nd	5
3rd	4
4th	2
Total	30

Three subjects had experienced previous stillbirths, and four had had miscarriages in the past. Approximately one third of the respondents had experienced the stillbirth during their first pregnancy. None of the respondents had had previous neonatal deaths and no one had lost any children thus far.

Antenatal Care:

The place of attendance for antenatal care was as follows: 11 attended at the local authority clinic; and 14 attended at a hospital. Five respondents were unbooked for their delivery and had not attended any place for antenatal care.

Characteristics of Infants and Deliveries

				Total
Sex of infant	Male: 16	Female: 14	-	30
Booked/Risk	Low risk: 14	High risk: 11	Unbooked: 5	30
Mode of delivery	Normal vertex: 20	Breech: 8	Caesarian section : 2	30
Birthweight in grams	Maximum:3770	Mean: 1851	Minimum :1000	30
Gestational age in weeks	Maximum: 40	Mean: 34,4	Minimum : 28	30
Known or probable causes of death *	Abruptio placenta: 12	Placental insufficiency: 1	Pre-eclampsia: 4	17

* In 13 cases no diagnosis of the cause of death was made

Demographic Data Observed

MOTHER	FATHER
Age	Marital status
Religion	Occupation
Marital status	Income
Occupation	Educational level
Education Level	
Social class	
Type of housing	
Marital relationship	
Duration of hospitalization	

Table 7 : Distribution of Subject's Age at Hospital Admission

Subjects	15 - 20 years	21 - 29 years	30 years and over	Total
Number	8	16	6	30
Percentage	26,7%	53,3%	20%	100%

Select Demographic Data of Respondents

				Total
Duration of hospitalization (in days)	Maximum: 14	Mean: 4,5	Minimum: 1	30
Age of subjects	15-20 years: 8	21-29 years: 16	30 years and over: 6	30
Marital status	Unmarried/ divorced/ widowed: 8	Married: 21	Unmarried and living together: 1	30
Desirability of pregnancy	Wanted and planned: 12	Wanted but unplanned: 17	Unwanted and unplanned: 1	30
Closeness of the family	Very close: 22	Close: 6	Not close: 2	30
Occupational status prior to delivery	Full-time: 13	Part-time: . 2	Unemployed: 15	30

Religion

Roman Catholic = 3
Protestant = 7
Muslim = 5
Other = 15

Type of Housing

Self-owned house/flat	= 8
Rented house/flat	= 5
Council house	= 6
Council flat	= 5
Rented room	= 6

Level of Crowding: This was assessed according to the Batson Scoring System for occupational density. See Appendix IV for Batson Scoring System.

Uncrowded	= 7
Crowded	= 5
Overcrowding	= 11
Gross overcrowding	= 7

The majority of subjects lived in crowded and overcrowded conditions.

Table 8 : Occupation of Subjects

Occupation	House-wife	Professional	Clerical	Factory	Domestic	Student	Total
Number	8	2	5	13	1	1	30
Percentage	26,7%	6,7%	16,7%	43,3%	3,3%	3,3%	100%

Table 9 : Occupation of Chief Breadwinner in the Household

Occupation	Professional/ technical related workers	Clerical	Service workers	Production and transport	Total
Number	2	3	8	17	30
Percentage	6,7%	10%	26,7%	56,6%	100%

These occupations were coded according to the 1970 Population Census List of Major Divisions, Divisions and Groups.

Income of Breadwinner (per month)

0	-	R 100	=	1
101	-	R 200	=	7
201	-	R 300	=	9
301	-	R 500	=	8
501	-	R1 000	=	4
> R1 000			=	1

Total Income in the Family (per month)

151	-	R 300	=	6
R 301	-	R 500	=	10
R 501	-	R1 000	=	7
> R1 000			=	7

Table 10 : Distribution of Subjects by Social Class as Determined by Occupation and Education of Head of Household of Subject's Family

Subjects	Social Class			
	1	11	111	Total
Number	10	16	4	30
Percentage	33,3%	53,3%	13,4%	100%

According to the writer's classification of social class, Class 1 combines social classes 1, 11 & 111 and is referred to as professional, upper-middle and skilled; social class 11 refers to semi-skilled; and social class 111 refers to unskilled.

Table 11 : Distribution of Subjects by Educational Attainment

Subjects	Number of years or standard passed at school						
Standard	0 - 2	3 - 5	6 - 7	8 - 9	10	10+	Total
Number	2	8	14	6	0	0	30
Percentage	6,7%	26,7%	46,6%	20%	-	-	100%

Minimum number of years at school	= 0
Maximum standard attained	= 9
Mean	= 5,8
Variance	σ^2 4,23
Standard deviation	σ 2,057

Education of Father/Partner:

Minimum number of years at school	= 0
Maximum standard attained	= 10
Mean	= 6,06
Variance	σ^2 7,37
Standard deviation	σ 2,71

One husband had post-matric education and one had standard 10.

Select Data on Respondents' Interpretation of Management in Hospital

				Total
When diagnosis of stillbirth was made	Before outset of labour: 15	During labour: 7	At/after delivery: 8	30
Time period between diagnosis and delivery (in weeks)	Less than 1 week: 27	(Mean: 2)	More than 1 week: 3	30
Person who informed subjects of stillbirth	Doctor: 22	Midwife: 8	-	30
Recall of explanation about possible cause of death	Remembers: 13	Not sure:0	No explanation: 17	30
Contact with infants	Yes: 22	No: 8	-	30
Assessment of hospital stay	Long enough: 24	Too long: 1	Too short: 5	30

More than half the subjects (seventeen) reported that they were not given an explanation. This is subjective information and only the mothers' comments were recorded in this matter. Of the 13 who could recall this information, the doctor had explained the cause in 9 cases and a midwife or nursing sister in 4 cases. Twelve stated that they had understood the explanation given. When asked if any subjects had asked for more details relating to the delivery of stillbirth, only one subject had done so.

What Subjects Thought the Cause of Death Was

Maternal action	=	3
Maternal physical condition	=	2
Foetal defect	=	2
Did not know	=	23

Where Subjects were Nursed after Delivery/Postnatally

General postnatal ward	=	21
Single ward	=	5
With other mothers who had had a stillbirth	=	1
With other mothers postnatal but whose babies were not with them	=	3

Where Subjects Would Have Liked to be Admitted after Stillbirth

General postnatal ward	=	5
Single ward	=	15
With other mothers who had had stillbirths as well	=	4
With other mothers whose babies were not with them	=	5
With antenatal mothers	=	1

Half of the subjects expressed the desire to be nursed in a single or private ward after the stillbirth experience.

Did subjects have any contact with their babies

Twenty two wanted to have contact with their baby. The remaining eight did not want to see their babies.

Were subjects offered the opportunity to see/touch/hold their babies

Twenty four subjects were given the opportunity for contact with their infants.
Six subjects reported that they were not offered this opportunity.
In five cases, the doctor showed subjects their babies, and in the remaining nineteen, the nursing sister or midwife did so.

No subjects received genetic counselling, although two babies had genetic defects. The counselling would probably have been offered or discussed during their six week postnatal check-up appointment.

Only one subject was visited by a social worker whilst in hospital. This subject had been recommended for psychological testing and was already in receipt of a Disability Grant.

Who had organized the burial of the babies

In twenty two cases, the burial was organized by the hospital. In eight cases, the husband or family arranged the burial.

How many subjects had named their babies

The five subjects of Muslim faith had had their infants christened. Nineteen had thought of a name and the remaining six had not yet done so.

How many had been visited by the clinic/district nursing sister since discharge

This question is repetitive of the one discussed during the tape-recorded interview.

Twenty five had been visited and five had not yet been visited.

Of the twenty five who had been visited, sixteen reported that the clinic sister had not known that their babies were stillborn.

Table 12 : Physical Reactions of Subjects to Stillbirth

Reaction	Present	Not Present	Total
Loss of appetite	22	8	30
Sleep problems	20	10	30
Tightness in throat/ chest	25	5	30
Episodes of crying	28	2	30
Choking sensation	16	14	30
Shortness of breath	15	15	30
Sighing	24	6	30
Fatigue	24	6	30
Aching arms	7	23	30

Table 13 : Reactions of Subjects to the Stillbirth (emotional)

Reaction	Present	Not Present	Total
Guilt	12	18	30
Depression	29	1	30
Empty, lonely feeling	23	7	30
Irritability, hostility, anger toward those close to you	12	18	30
Increased emotional distance from others	21	9	30
Inability to return to usual patterns of conduct	23	7	30
Loss of femininity	18	12	30
Sense of futility	9	21	30
Preoccupation thinking about baby	29	1	30
Praying for the baby	29	1	30
Disbelief, feeling of unreality	30	0	30

Who had provided the most emotional support and help since the loss of the baby

The husband or partner had done so in twenty three cases. The extended family provided emotional support for five subjects and for the remaining two, friends of the subjects had provided the emotional support after their losses.

Are subjects on any form of medication other than for suppressing lactation

Ten of the thirty reported that they were on some form of medication.

Medication was for high blood pressure, iron supplements and analgesics. No tranquilizers or sleeping tablets had been prescribed by the hospital.

FINDINGS OF INTERVIEW TWO CONDUCTED AT THE SIX WEEK VISIT

How many subjects had prepared for their expected babies

Twenty eight of the thirty had made preparations for the babies.

Disposal of preparations

Ten had given away the items. The remaining eighteen had kept or packed away the items.

Did the husband/partner take time off work when subject returned from hospital

Sixteen husbands had taken off work; four had wanted to but were not in a position to do so; and ten did not take time off.

Did subjects have domestic help when they returned home; and who helped

Of these, an adult relative helped in twenty two cases, a friend in three cases and a domestic servant in one case.

Did subjects feel that they needed help

With the exception of two subjects, all the others felt that they needed help when they returned home from hospital.

Table 14 : Stated Needs of the Family after Stillbirth

Areas Causing Problems and Needs	Yes	No	Total
Readjustment	10	20	30
Handling children at home	2	28	30
Domestic situation	3	27	30
Marital relationship	7	23	30
Dealing with friends and socializing again	7	23	30
Feelings of inadequacy and failure	16	14	30

Did subjects wish to consult with somebody in connection with (a) genetic counselling; (b) planning another baby; and (c) their feelings about losing the baby

(a) Five wished to consult with a medical person about genetic counselling.
(b) Eighteen wished to talk to somebody about planning another baby.
(c) Eight wished to discuss their feelings about losing the baby with somebody.

Were subjects interested in meeting other mothers who had been through a similar experience

Twenty two were interested in meeting other mothers; three were uncertain; and five stated that they were not interested at the time that the interview was conducted.

Were subjects back at work at the time of the 6 week interview

Seven subjects had returned to work by this stage.

Would subjects have liked a photograph of their babies

Twenty three replied in the affirmative; one subject was uncertain; and six stated that they did not want photographs of their infants. Therefore, the majority would have wanted photographs if these had been available.

Subjects' opinions of the questionnaire

Twenty seven of the thirty found the interviews and questionnaires to be helpful and interesting. The remaining three experienced the questions as painful but felt relieved after the interviews. There were no reports of the interviews or questions being offensive or embarrassing.

CHAPTER V : DISCUSSION

Section One:
Medical and Social Data

Section Two:
Discussion of Findings from Transcribed Interviews

DISCUSSION

"For Patricia"

Ask me what her name was.
Ask me what she weighed.
Ask me what color her eyes were.
Talk to me about labors and deliveries,
Talk to me about stitches, nursing, and baby schedules.

Tell me how sorry you are.
Tell me you're at a loss for words.
If you cried privately, let us know.
Hold my hand if words don't come.
Tell me you don't know what to say.

But please don't turn your back.
Don't not say anything.

Linda McCann, 1984

In the writer's experience, the loss of a baby through stillbirth is a distressing and often devastating experience for parents. The loss results in a grief response similar to that in which an older family member has died. The parents' emotional response is not always understood by family members, friends and medical personnel. Consequently, this lack of understanding can lead to inadequate care of the parents, both from the professionals and family support systems. It is hoped that as a result of this study and through discussion of the issues questioned, increased insight into the overall problems associated with stillbirths will evolve. The delivery of a stillborn infant has been described as a crisis, which challenges personal and family integrity. In order to achieve a positive outcome for the family, immediate intervention is needed, as well as follow-up management. Effective crisis counselling can make a major difference in helping the family through the experience.

A crisis is generally considered to be a transitional, uneven period between stable phases, in which there is both cognitive and affective upset.[101] Personal integrity is threatened by some stressful event, such as a stillbirth, and the individual's habitual problem-solving activities may not be adequate to resolve the crisis situation. Some individuals may be able to cope by developing new coping mechanisms and are thus able to deal adequately with the crisis. Others are not able to respond appropriately and therefore the event and its sequelae may continue to be a source of stress. In the latter circumstances, the need for intervention is indicated. The social worker working with these families in crisis has the dual purpose of "reducing stress and using the present crisis to strengthen adaptive and coping mechanisms, both for the present and the future".[102] Therefore, the social worker should be available to the parents and provide the emotional support they require. The parents also need to have an understanding of the grief process and the special problems that they will be confronted with as a result of the stillbirth experience. The role of the social worker will be elaborated on in this chapter.

The discussion of the writer's findings will be presented in two major parts. The first part will discuss the social and medical data as recorded from the interview schedules, and the second part will discuss the data from the transcribed interviews.

MEDICAL AND SOCIAL DATA

Medical Characteristics of Respondents

The majority of respondents had no past medical problems that may have complicated their pregnancies or contributed to the stillbirth. For a large proportion of respondents, the pregnancy was their first. The writer speculates that the loss of an infant in a first pregnancy would be greater and more traumatic than in subsequent pregnancies. For women who have had one or more children and then experience a stillbirth, the event itself would be traumatic, but these women have proved their ability to have children and therefore do not feel as inadequate as those who lose their first babies. Kirk (1984) observed that part of the spectrum of response to perinatal loss includes an "expression of an ashamed failure, a general sense of failure and responsibility for failed reproductive performance".[103]

A small percentage of subjects (16,6 percent) were not booked for the delivery at the time they experienced their stillbirth. This could indicate a lack of interest or concern in the pregnancy and expected infant or an alienation from the medical system. The writer speculates that for those who had not booked for delivery, the guilt of losing the baby could have been an added stress factor in the overall experience. However, this was not investigated and further research is indicated in this area. The remaining subjects were booked for delivery and attended the local clinic or hospital regularly.

The mean gestational age of the stillborn infants was found to be 34,4 weeks. Having reached this stage of pregnancy, one could

assume that most women would feel confident about the outcome of their pregnancies. The longer the pregnancy, the greater the bonding relationship between mother and unborn infant is expected to be. It was also found that the majority (28 of the 30) of respondents had prepared for their infants and were therefore anticipating the delivery of live, healthy babies. The cause of death was unknown in almost half the sample (13 cases or 43 percent). Although it is not always possible to ascertain the cause of death, in view of the fact that no autopsies were performed, the parents are often left dissatisfied. They may continue to search for and wonder about what caused their babies' deaths. This continual searching for an answer causes distress for some parents that may continue for years. Knowing the cause helps in the resolution of feelings. The unknown can encourage guilt feelings to be magnified.

Social Characteristics of Respondents

The average age of the mothers was 25,5 years. The youngest subject was sixteen and the oldest forty one years. Twenty-six percent of the subjects were between ages fifteen and twenty and, thus, are young to have to cope with a significant loss. A few of the respondents in their mid-thirties to early forties were considering sterilization after this particular pregnancy. Losing this baby made a few of them re-consider sterilization and the finality of not having more children. For some respondents, this pregnancy and expected baby was planned to be their last.

The majority of subjects were married and reported their marital relationships as good and stable. This is an important factor in terms of the emotional support available at a time of loss and stress for the families. Many relationships and marriages begin to

break down during these periods of stress. Marital conflicts after a perinatal death have been well documented in the literature and were discussed in Chapter II.

There were no significant findings related to housing, level of crowding, occupation of subjects, occupation of chief breadwinner, total family income or social class of the family. The findings are typical of the greater population from which the subjects were selected. The mean educational level achieved by the respondents was standard five, and for the fathers, standard six. Three fathers had post matric education but none of the subjects had achieved this level.

Hospital Management

The diagnosis of the stillbirth was made before the onset of labour in 50 percent of the cases. For the remainder, seven subjects knew that their babies were dead during labour, and eight were told at or just after the delivery. For those who knew beforehand, the news that they were carrying a dead foetus was a shock which evoked feelings of disbelief. These subjects were, however, prepared for the delivery of a dead baby and could begin the anticipatory grieving process beforehand. For those subjects whose babies had died some time before delivery, waiting for labour to begin was a difficult and unpleasant situation. According to Lewis, who studied areas which caused distress to parents following a stillbirth, the waiting period was very traumatic. Her study subjects described their feelings of carrying a dead baby inside them as "felt very cold, awful" "unclean", "walking coffin" and so on. The subjects she studied found the prospect of labour daunting, although not one would have preferred to learn of their baby's death after delivery.[104]

Mourning that begins before the loss actually occurs is known as anticipatory grief. This type of grief may range from quiet periods of sadness and tears to those symptoms usually associated with grief over actual loss.[105]

Therefore, when a woman has prior knowledge that her infant is dead, she can begin the grieving process and thus start to sever her relationship with the unborn baby.

When a death has been confirmed, parents need a period of privacy to express their feelings of shock and disappointment. The staff should be available to answer questions and to offer emotional support. As the parents are usually in a state of crisis, they may have difficulty in absorbing the information and may have to have explanations repeated several times. The parents should be informed of all the options available to them and the implications that will follow. The parents may request immediate induction of delivery to allay further distress, or may opt to postpone delivery and carry the foetus to term. Whatever decision is made, the staff should make plans for follow-up, both medical and psychosocial. "Continued support is essential to a healthy resolution of the crisis".[106]

The shock and disappointment occurs whether the diagnosis of the stillbirth is made sometime before or during the actual delivery. Three subjects in the study had to wait longer than one week from the time the stillbirth was confirmed until the actual delivery of the stillborn infant.

All the subjects could recall who first had informed them about their infant's death. In most cases it was a doctor. When asked if they could recall who first offered an explanation about the

possible cause of death, 56,6 percent stated that no explanation had been given. This is subjective information supplied by the respondents and may not be a true reflection of what occurred. As many subjects could have been in a shocked state after the delivery, recall of an explanation about the cause of death may have been vague and inaccurate. However, it has been previously stated that in thirteen cases, or 43,3 percent, no known cause of death had been recorded. Those subjects who were offered an explanation expressed satisfaction with the reason given. Only one respondent asked for additional details concerning her infant's death. A possible explanation for this apparent complacency on the part of the respondents may have been their reluctance to query medical opinion due to the high regard that many patients have for medical personnel.

A small percentage (16,6 percent) of subjects considered their state of health or some action taken during their pregnancy, to have been the cause for the stillbirth (for example, strenuous housework, experiencing an emotional shock, and so on). For these parents, guilt can be overwhelming and a constant source of stress for them. Such parents need to work through their guilt feelings therapeutically. They need emotional support and guidance in learning to cope with and resolve these feelings.

The question of postnatal care after delivery evoked a range of responses. Seventy percent (70 percent) of the respondents were nursed in a general postnatal ward after delivery and were thus among other patients who had their babies with them. This can be an additional source of pain for mothers who have just lost their own babies. However, there are special practical problems to consider in postnatal placement. What patients request is not always available. In this study, 50 percent of the respondents stated that they would have preferred to be in a single or private ward after their delivery. Only five subjects stated that they did not mind

being in a general ward with other patients and their babies. The remainder wanted the company of other patients but were not ready to be exposed to live, healthy infants.

The trend in some hospitals is to keep the mother on the labour ward floor and not to send her to a general or private ward. She thereby avoids contact with other mothers and babies and can have privacy. The needs of mothers during these periods vary; some may request the company of others in preference to being isolated, while others want the solitude of a private room or single ward. It is therefore desirable that hospitals implement a flexible policy of ward placement, when this is possible. Permission for fathers to spend as much time as possible with their spouses is also suggested. Sleeping arrangements for fathers at hospitals are made in various hospitals, locally and overseas.

Furlong and Hobbins comment that after delivery, the mother should be given the option of returning to the obstetric floor or going to another one. "Whatever floor she chooses, her chart and room name tag should be flagged, so staff will be aware of her loss".[107] Using this procedure of marking the mother's room and folder, the staff can be better informed beforehand about the stillbirth.

The writer analyzed the subjects contact with their infants and their desirability for such contact. Seeing the dead baby gives parents "someone tangible to mourn".[108] The majority of respondents, by choice, saw their infants (73 percent). Most of the respondents were also offered the opportunity to touch and hold their babies. The importance of encouraging parents to see and have contact with their stillborn infants has been widely recommended in the literature and previously discussed in this paper.

To the writer's knowledge, no published data to date has indicated a detrimental effect of parental contact with their stillborn baby.

Those parents who choose not to see or have contact with their infants, often make this decision hastily, while still in a state of shock. In the future, these parents are likely to regret their decisions and may experience an intense desire to know what their infants looked like. The importance of having a photograph of the baby is evident. The question of photographs was discussed with each respondent during the six-week interview. Seventy-six percent (76,6 percent) stated that they would have appreciated photographs of their babies. At the time that the interviews were conducted, the policy of taking photographs had not yet been implemented at the hospital from which these subjects were selected.

The Social Worker's Role

Only one mother in the study population was seen by a social worker. This particular subject had been referred for psychological assessment and therefore a social work report had been indicated. Other subjects were thus seen by medical and nursing staff only. The reason for the lack of social work services are practical ones. Due to the large turnover of patients in the hospital, the social worker is not able to visit everyone in need.

Craig writes that "bereavement is not a problem for social workers to solve but an experience in which we are invited to be companions, listening with warmth and sympathy, accepting expressions of grief, and giving the death of the loved one significance".[109] This succinctly sums up the social worker's basic role in dealing with the parents

of stillborn infants. There are, however, other important functions to fulfil. It is important to realize that stillbirth touches many aspects of womens' lives and that these need to be focussed on as well. The following are a few such aspects: the husband's grieving, the marital relationship, future pregnancies, and the effects that the stillbirth has on other children. Where the social worker is not able to deal with these aspects, the families should be referred to an appropriate social work agency that serves these types of clients.

The social worker plays a valuable role as part of the health care team. An assessment of the parents' understanding of why their babies have died will be helpful information for all professionals involved in the care of the parents. Areas of confusion and misunderstanding can be pinpointed by the social worker who can then facilitate further communication between medical staff and the patients where this is indicated. This will avert later instances in which parents become angry about not receiving sufficient information and explanations about their babies' deaths.

The social worker plays an important role in counselling parents about grief reactions, in facilitating parents' mourning responses, and in encouraging the release of feelings. Parents need to be told about the grief that will ensue in the time following the death of the baby. They should also be informed about the probable duration and intensity of their feelings. Although parents' reactions and duration of grief vary, it can be helpful if they have an estimated time period in which to expect their reactions to be evident.

Rappaport comments that she usually tells parents "that they may experience intense feelings of grief and mourning for the first six weeks or more and that gradually the pain will become more bearable,

until over the course of the next year or so they will find that they feel this sadness less often, mostly when something happens to remind them of the baby".[110]

The importance of fostering good communication between parents is essential. The death of an expected baby may result in serious marital discord, especially when the parents do not share their feel ings. Parents may assume that by avoiding discussion of the still-birth, the pain will be lessened. However, to ignore the stillborn infant in conversation can increase both the intensity and duration of the pain of that loss. It is important to explain to the parents that the wife is likely to take longer than the husband to come to terms with the loss. The concept of "incongruent grieving" and marital conflict has been previously noted in the literature review.

Resolution of grief work can be impeded if parents are not encouraged to express and release their feelings. Grief can be immobilizing if feelings of anger, confusion and pent-up hostility are not dealt with and expressed. "In order for catharsis to occur, the grieving parents need someone willing to listen to them without judgement, without platitudes, and without false reassurances".[111]

When family members are not able to provide the necessary outlet for release of parents' feelings, the social worker can offer parents opportunities for doing so.

For families with other children "the death of a baby brings with it the task of informing the surviving children of the baby's death and assisting them in the understanding of this loss".[112] Mahan and Schreiner acknowledge that while a young child may not understand exactly what is wrong, most children over the age of two realize in

their own way that something is amiss".[113] Parents may need help with encouragement about the importance of informing their children about the stillbirth. The social worker can be of value in assisting parents with this task.

The social worker performs an important function in follow-up counselling. If he/she is not in a position to provide this service, referral to an appropriate source is indicated. In follow-up counselling, the social worker can evaluate how well the parents' griefwork is progressing and how they are adapting to the loss of their baby. Unanswered questions and problems can be discussed and plans for the future considered.

Planning the Next Pregnancy

Parents may wish to plan another baby as soon as possible. This may be their own desire or due to pressure from family members and friends. The danger in replacing the baby too soon has been previously explained and is well documented in the literature (Cain and Cain 1964; Newcombe and Rhynes, 1962; and Poznanski, 1972). Therefore, parents should be encouraged to wait before making decisions about another pregnancy. The length of time that parents wait before starting again is a personal matter and they should not be dictated to about how long to wait. Rather, the dangers of replacing the dead baby should be pointed out and they should be encouraged to plan subsequent pregnancies with these considerations in mind.

In-Service Training and Education of Professionals

Mahan and Schreiner highlight another important role that the social worker performs as a member of the health team; ie contributing to programmes of education, support, and sensitization for new staff nurses and rotating house officers, as well as students in medicine, nursing, and social work.[114] These programmes are intended to provide emotional support for staff, improve interstaff communication and awareness, and increase the staff's ability to help parents effectively with their own grief work. Discussion groups, case conferences and in-service training programmes are common means to these goals.

Burial Arrangements

Discussion about burial of the baby showed that in twenty-two (73,3 percent) cases the burial was organised by the hospital. The reasons for requesting that the hospital arrange the burial could be the following:- (i) financial: private burial of a baby is expensive and many families are unable to afford the expense; (ii) after the delivery and the consequent feelings of shock and distress, many parents are not in a position to make rational decisions and thus the easiest solution to the question of burial is to request that the hospital organise it, and (iii) some parents feel that they are not emotionally strong enough to go through a burial and/or memorial service for their dead baby. When questioned about these burial arrangements, some respondents stated that they regretted not arranging the burial themselves and were disappointed that they had no grave to visit. It has been documented in the literature that people under stress or in a state of crisis experience cognitive upset and are not capable of making rational decisions.

One could conclude that parents are often indecisive when it comes to burial and need guidance from members of the health care team.

Naming the Baby

Respondents were asked whether they had thought of a name for their babies. The five subjects of Muslim faith had christened their infants and a proper burial had been organised according to their beliefs and religious customs. Six (20 percent) respondents out of thirty had not yet thought of a name for their infants. Nineteen (63,3 percent) had selected a name for their expected babies. Having a name in mind for an expected child shows that parents have established a relationship with and bonded with the unborn baby. They have already thought about its future. In addition, a name makes the infant more real and facilitates healthy mourning.

Evaluation of Hospital Stay

In analyzing respondents' satisfaction in terms of their hospital stay, the majority considered their period of hospitalization as sufficient. For many parents, the hospital is a constant reminder of their recent loss and they look forward to discharge as soon as possible. However, some parents dread leaving the hospital "with empty arms" and feel insecure about facing people and the future.

Post-Natal Nursing Services

The respondents were questioned about being visited by a local authority nursing or district sister. Twenty-five of the thirty subjects had been visited by the time the writer conducted the first interview. A startling fact emerged when subjects were asked if the nursing sister knew that their babies had been stillborn. Sixteen (65 percent) of the twenty-five stated that the nursing sister, when calling on them at home, did not know that their babies had been stillborn and actually asked how the babies were progressing. In an attempt to explain this finding, the writer considers the following as possible reasons: (a) a breakdown in communication between the hospital and the community nursing service, and (b) that the nursing sisters concerned had not read their folders which had details about the stillbirths, prior to visiting the respondents. The respondents were asked in the tape-recorded interview about the nurses' responses to finding out that the infants had been stillborn. They stated that the nurses had shown considerable surprise and discomfort. This matter was subsequently discussed with the relevant authorities and the writer was assured that it would be investigated. The writer therefore assumes that this oversight no longer exists and that channels of communication have improved.

Physical and Emotional Reactions

Analysis of the physical and emotional reactions of the respondents showed the following reactions as being evident after the stillbirth The most common physical reactions found were loss of appetite (22 out of 30); sleep disturbances (20); episodes of crying (28); feelings of tightness of the throat/chest (25); sighing (24); and fatigue (24).

Half the respondents complained of shortness of breath and a choking sensation. The emotional reactions most commonly experienced were the following: feelings of emptiness and loneliness (23); increased emotional distance from other people (21); depression (29); inability to return to their usual patterns of conduct (23); feelings of loss of femininity (18); preoccupation with thinking about the baby (29); praying for the baby (29); and a feeling of disbelief or unreality (30). Twelve of the thirty reported feelings of guilt about the stillbirth and of these twelve, nine also reported feelings of personal inadequacy. Nine felt a sense of futility and hopelessness and twelve expressed feelings of irritability and anger towards those close to them.

The emotional and physical reactions found in this study concur with those described by various authors and represent typical symptoms of the grief process (Schreiner, Greshan and Green (1979); Kennel, Slyter and Klaus (1970); Lindemann (1944); Parkes (1972); and Benfield, Leib and Vollman (1978)). The reactions of the subjects that were recorded by the writer are similar to those found by Benfield et al in their study on the grief response of parents to neonatal death. It is difficult to ascertain what factors influence the maternal grief response and few studies have attempted this task to date. Benfield et al have stated that a parent's grief response is highly individualized and may depend more on the compassionate concern of care-givers than on any other single factor.[115]

Factors that can aid in ameliorating emotional problems in the parents include follow-up counselling, referral to self-help groups or support organisations, and assisting parents in the sharing of mutual support and communication. The latter is an especially important source of strength during their bereavement.

The Needs of Parents after Stillbirth

The writer attempted to highlight specific needs of the subject as a result of their stillbirth experiences. In analyzing situations that respondents found to be causing problems or that indicated specific needs, the following was noted: a third (10 of the 30) admitted experiencing readjustment problems; seven were experiencing marital difficulties; seven were having problems socializing with friends again; and sixteen admitted having feelings of inadequacy and failure due to the loss of their babies. The needs and problems expressed by the subjects indicate the necessity for follow-up of these families and the provision of counselling and other special services in their total care. Many women experience problems in returning to their prepregnancy state and in adjusting to their daily life patterns without the expected baby. This problem is exacerbated when the baby has been planned, and particulary when the baby is anticipated as the completion of the family.

The conflicts that may arise in the marital relationship after a stillbirth have been described in the literature review. The husband or partner should not be ignored in the management of families experiencing a stillbirth.

Feelings of inadequacy or failure as a woman is a common reaction, as many women feel they have not fulfilled their womanly role in producing a live, healthy infant.

Most of the subjects who experienced this feeling of inadequacy had also expressed feelings of a loss of femininity as part of their grief responses. Other needs highlighted were the desire to meet other women who had been through a similar experience (22 out of 30)

and wanting a photograph of their babies. It was reported earlier that 23 of the 30 subjects had experienced feelings of emptiness and loneliness after the stillbirth. One could assume that the desire to meet others who have been through a similar loss and to have the opportunity to share one's experiences would be of great importance to these women. The sharing of a common experience leads to comfort and mutual reassurance. The establishment of self-help groups and other voluntary organisations that offer group support has been beneficial in helping bereaved families. In many countries, family bereavement groups have been organised to provide recognition of the crisis of stillbirth, to identify and discuss problems affecting family stability, and to address emotional trauma particular to parents who have suffered the loss of an infant.

A positive outcome of this investigation has been the establishment of a support organisation for bereaved parents. The writer, using knowledge gained from the study, assisted with the planning and implementation of a new support organisation, called SHARE (Source of Help in Airing and Resolving Experiences). SHARE runs monthly support group meetings, trains bereaved parents to become lay "counsellors", aims to educate professionals working in the field of perinatal death, and aims to educate the public at large about the nature of and problems associated with perinatal death.

DISCUSSION OF FINDINGS FROM TRANSCRIBED INTERVIEWS

Several significant issues emerged from the transcribed interviews which will be discussed. Parts of this discussion may be repetitive.

General Response to Stillbirth

The writer found that all the respondents except one reacted to their stillbirths with disappointment and typical grief responses. During the taped interviews, respondents were asked to describe the circumstances surrounding their admission to hospital, their deliveries, and their reactions to the stillbirths. The maternal grief response to involuntary loss of a foetus or infant has been described in the literature by various authors (Benfield, Leib and Vollman, 1978; Kirkley-Best, 1982; Furlong and Hobbins, 1983; Seitz and Warrick, 1974; Yates, 1972; Zahourek and Jensen, 1973; Kowalski, 1980; and Peppers and Knapp, 1980). Factors such as the educational level, social class, cultural background and the age of the respondents were not related to the degree or severity of the grief response. This agrees with Benfield et al (1978) who found that parent grief was not significantly related to factors such as previous perinatal loss, parent age or extent of parent-infant contact.[116]

The writer found that the subjects did not respond any less emotionally to their loss than subjects described in other studies and from different cultures. The duration of the grief response and mourning period for this sample was not investigated and research to analyze this would be of importance in terms of follow-up services.

Birth Control

The question of birth control was raised with each subject and, in addition, the writer attempted to analyze the subjects' feelings about subsequent pregnancies. Twenty-six of the thirty were using a form of birth control, which is the usual practice after a delivery. It has been previously reported that two subjects were in their late thirties and had been considering sterilization after this pregnancy. However, the failure of this pregnancy evoked feelings of doubt about going through with sterilization. The finality of having sterilization was less acceptable following the recent loss.

These feelings reflect the difficult decisions that women have to face after a stillbirth but the advanced age of these particular subjects made their decision especially difficult. The writer found that most subjects were not planning another pregnancy soon. Most commented that they were contemplating waiting about a year before having another baby. Their decision to wait was important in terms of the grieving process and the time needed to work through the loss. However, what actually occurred or how long the subjects did wait before the next pregnancy is unknown and was not investigated in this study. Follow-up of these subjects for at least a year would have to be undertaken in order to report on this matter.

Reactions of Siblings

Subjects who had other children were asked whether their children's behaviour had changed following the stillbirth. They reported that their children showed distress about the loss of the expected sibling. As previously noted in the findings, children under the age of five did not seem to grasp what had taken place. However, children above this age asked many questions, some of which were difficult for parents' to handle. For parents who have recently had to cope with the tragic outcome of their pregnancies, the task of coping with older children's questions and behavioural problems is an added source of stress. Some children do cope adequately with the situation whereas others are unable to do so. Parents and teachers, in other studies, report significant alterations in the behaviour of surviving siblings following a loss in pregnancy. (Cain, Fast and Erikson, 1964; Gilson, 1976; Hardgrove and Warrick, 1974; and Hollingsworth and Pasnau, 1977). In view of this finding, parents may require guidance and support with the task of interpreting the event to their children. In discussing the stillbirth with children, the following suggestions for parents have been shown to be helpful: (a) listen to your child; give him/her your acceptance; (b) be honest; do not avoid explanations; (c) accept your child's feelings; let your child talk about anger, hurt, sadness and so on; (d) give your child brief explanations at his/her level of comprehension; (e) show love and warmth; (f) share your own feelings and encourage your child to do the same; (g) be patient with yourself and your child; (h) use examples in nature to explain death; and (i) try to maintain some household routine. [117]

Although the above suggestions appear to be straightforward, in times of stress many parents will not be able to behave rationally and deal adequately with their childrens' needs.

Choice of Burial

The question of the organisation of the burial showed that for twenty-four of the thirty subjects, the burial had been arranged by the hospital. For the remaining six, a private burial had been arranged. At the time that the interviews were conducted, hospital burial was offered to parents. However, this service is no longer available. As previously mentioned, those who had had the burial privately done, were of the Muslim faith (5), and one husband had buried the baby next to his parents. Private burial of an infant is expensive and many parents were financially not able to pay for a private cremation or burial. Another explanation for choosing hospital burial over private, is that subjects, after the trauma of losing their infants, did not want the added stress of having to organise a burial. Thus, the easiest and most convenient solution was to accept a hospital burial or cremation. It was noted that some subjects regretted their decision and, in retrospect, wished that they had had a private ceremony so that they could say "goodbye" to their infants. This finding supports several other studies in the field of perinatal death (Peppers and Knapp, 1985; Borg and Lasker, 1981; and Kennel and Trause, 1978).

Besides having the opportunity to say goodbye to the baby, the funeral has other benefits. It facilitates the grieving process in that it formalizes the death of the infant as an event worthy of time and attention, and the baby's grave provides a specific place that the parents can visit when they wish to "be with" their baby. "It is a place where one has permission to experience and express one's sadness".[118] Parents need guidance and direction with the decision about burial. The state of confusion that often results after a stillbirth may cloud important issues, such as burial, and may cause parents to make hasty decisions that are regretted at a later stage.

Recommendations for caregivers based upon these implications have been proposed by Kirkley-Best:

(i) education of the community at large;
(ii) offer all options for parents; discuss possibility of future regrets;
(iii) encourage participation of both parents in the decision;
(iv) offer aid in dealing with funeral personnel;
(v) find out about the procedure with which the baby's body is disposed, and be able to honestly and fully answer questions posed by parents; and
(vi) listen carefully.[119]

Suppression of Breastmilk

The issue of the suppression of breastmilk by medication was discussed with subjects. It is routine procedure after the delivery of a stillborn infant to give the mother medication to suppress lactation (the production of breastmilk). For many mothers, it is a sad reality that the body produces milk for a baby that is not present. All the respondents had been given the required medication in hospital. However, once the medication had been used up, respondents did not know that they could obtain additional medication and that it had to be medically prescribed. Thus, half the respondents reported that they were still lactating, which was a source of distress.

The problem of lactation has not received as much attention in the literature as other problems associated with stillbirths have. Some comments made by the subjects in the study about this issue are

as follows: "I feel bad when my breasts leak, and I cry"; " ... feel sad, I had planned to breastfeed my baby; and " ... it is painful ... ". Friedman and Gradstein state that since one's body has no way of knowing that the foetus has died, it reflexively prepares for breastfeeding. "Engorgement may cause some physical discomfort, but normally the actual physical pain is less troublesome than the emotional pain that may accompany it".[120] The medication prescribed for suppression of lactation is effective, but it can have side effects that the writer believes should be explained to women using it.

Assessment of Interview by Respondents

Subjects were asked for their opinions of the interview schedules and to answer whether they found the interviews helpful, embarrassing, offensive or hurtful. Twenty-seven of the thirty found it helpful and three commented that it had been hurtful as it evoked painful memories. The following is quoted from one subject's response to the writer's interview:

> "You're now an answer to my prayers.
> because I have just been left alone ...
> I must talk, get if off my chest, ... I
> was so glad when you phoned ... "

In general, the writer was willingly accepted into the homes of the respondents and was the only person, outside the family, to discuss the pregnancy loss with many subjects. The subjects studied did not receive emotional support from any community or social service. The writer suggests that many of the subjects would have benefited from a support group where they could meet other women who have been

through a similar experience. In addition, subjects should have been followed up, counselled and assessed for any problems at about two to three months after the stillbirth.

Intervention and Management

Recovery from the stillbirth loss and grief is achieved when the mother no longer displays acute grief symptoms, nor any pathologic grieving, and when she can cope adequately with her feelings and environment again (Peretz, 1970).

This process "requires time, environmental support, and the natural resources of the bereaved".[121] It is not possible to formulate the exact time period required for resolution of grief, but some authors have proposed that six to twelve months is approximately the time needed to come to terms with a loss (Kowalsky, 1980; Kirk, 1984). Anniversary dates of the loss and subsequent pregnancies are times that women need extra support and counselling.

In managing families who experience a stillbirth, a team approach is important and the understanding of each member's role is vital. If certain team members do not feel comfortable with the task of helping families work through their grief, then the task should be delegated to a member who is comfortable and skilled in the area. The grief process should be facilitated so that it will follow a healthy course, leading to complete recovery. The role of various team members will be expanded upon in the following chapter.

In the past few years, a number of intervention programmes have arisen overseas with the intent of offering support and information to families experiencing a stillbirth. There are bereavement teams, services run by parents themselves, and programmes involving in-hospital contacts and follow-up of parents at regular intervals. These programmes have been found to be beneficial in terms of aiding parents work through their grief and in supporting them in problem areas that they encounter after a stillbirth. The major goals of a grief support team are "to provide basic human comfort and support; to encourage the expression of grief; and to promote the mourning process as appropriate to each individual".[122]

The following quotation stresses the importance of a structured approach to grief support: "The danger lies not in the distress that follows stillbirth, but rather in bypassing it".[123]

"When your parent dies
you have lost your past.
When your child dies
you have lost your future".

Dr Elliot Luby

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CHAPTER VI : CONCLUSIONS AND RECOMMENDATIONS

Conclusions

Recommendations : In the Hospital
Follow-up Care
Recommendations for Additional Research

CONCLUSIONS AND RECOMMENDATIONS

"Strange that feet so precious charged
Should reach so small a goal"

Emily Dickson

The fact that stillbirth occurs when the fulfilment of pregnancy is so near, makes it a tragedy for parents. It may be quite unexpected or occur with some forewarning. It results in a crisis for the parents, family and staff dealing with the delivery and after-care.

The stillbirth rate for the population served for by the Peninsular Maternity and Neonatal Services was 13,1 per 1000 deliveries (for infants with a birthweight of over 1000 grams) in 1985. The stillbirth rate for Groote Schuur Hospital during the same year was 34,6 per 1000 deliveries. This figure was for persons of mixed race and blacks.[124]

The literature dealing with the topic of stillbirths indicates that the death of a baby precipitates a grief and mourning response as severe as that seen in families in which adult members have died. (Hilderbrand and Schreiner, 1980; Speck and Kennell, 1980; and Peppers & Knapp, 1980).

The writer found that the subjects investigated displayed typical grief reactions similar to those described in the literature. As the subjects were not seen after the second interview at six weeks, it was not possible to record the time period that the subjects took to work through and resolve their grief. In analyzing the data of this study, the writer found the following:

(1) The emotional and physical reactions to mothers following a stillbirth:-

The reactions of the subjects studied were similar to and concurred with those described in other studies. All the subjects experienced some or a combination of reactions. The most common emotional reactions experienced were emptiness and loneliness; depression; feelings of disbelief; preoccupation with thinking about the baby; praying for the baby and the inability to return to their usual patterns of conduct. The most frequently reported physical reactions recorded were crying episodes; fatigue; sighing; tightness in the throat/chest; and loss of appetite.

(2) The positive and negative impact that the stillbirth may have on the mother and her family:-

With one exception, every respondent had been distressed and disappointed about the stillbirth, and as mentioned above, this led to a typical grief response. In some instances, the event had made the family closer and most subjects received the emotional support of their spouses or partners. The impact was experienced as negative by those subjects whose pregnancies were their last and who felt they were "too old to try again" in the future; by those whose self-esteem and sense of femininity had been shaken; and by those who felt guilty about the death of their infants. A crisis such as a stillbirth can bring a family closer together and result in mutual reassurance and growth, or, on the other hand, it can split a family in which members do not communicate openly nor share their feelings and problems.

(3) The assistance that families require in order to adjust constructively:-

...es require the assistance from caregivers who provide them with basic human comfort and emotional support; who encourage the expression of feelings and grief reactions; who help confirm the reality of the infant's death; who alert parents to possible problems that they may encounter, both in their own relationship and in relationships with others; who prepare parents for encounters in the community and assist with handling of older children; and who are basically available should parents need help and/or advice. One could conclude that parents' basic needs are compassion, understanding and care.

(4) The hospital and community services (i) rendered and (ii) needed with the intent of assisting constructive adjustment to the event:-

A few issues need to be clarified before drawing conclusions about the hospital services rendered to the respondents. Firstly, the hospital from which the respondents were selected has a high turnover of patients (ie 4859 deliveries during 1985)[125] and most patients are discharged as early as possible; secondly, at the time this study was conducted, there was only one social worker available to deal with all the patients who required social work assistance and counselling. Only one of the subjects interviewed had been seen by a social worker. None of the subjects had received any form of counselling during their hospitalization and none of them were referred to a community agency or service for follow-up. However, the subjects were offered an opportunity to see and hold their infants and encouraged to do so. No community service was rendered to the subjects although routine visits by the local

authority nursing sisters were done. It is appropriate at this point to comment on some of the nursing sisters' lack of knowledge about the death of the infants (16 of the 25 subjects visited by the clinic sister reported that the sister had not known that their infants were stillborn). The conclusion drawn from this finding is that a lack of or breakdown in communications caused this oversight and improvements in this area are needed.

In looking at the hospital and community services that are needed with the intent of assisting constructive adjustment to the stillbirth event, the writer recommends the following: It is important for the mother to have quality nursing care, preferably if this can be provided by one individual. The mother needs to have her physical needs attended to in addition to her emotional needs. The mother should be given a choice regarding postpartum placement. Her spouse or partner should be permitted to be with her as much as she desires. She should be offered the services of a social worker and a hospital chaplain. Mothers should receive an explanation about the baby's death, where this is possible. Time should be allowed for questions. The availability of photographs of the babies is important. Parents may not want photographs initially, but at a later stage may desire photographs and momentos of their babies. Parents should receive an explanation about the grieving process so that they can recognise their reactions and realize that they are normal and to be expected.

Community services that are needed are basically follow-up of the mothers and their families. This could be provided by a social work agency or local authority health clinic. It is important that one person provide counselling on a continuous basis for as long as their services are needed.

Referral to a lay support group or other support organisation should be undertaken, if these are available. Parents face many difficulties and stress situations after discharge from hospital and, therefore, follow-up is essential.

(5) The mothers' interpretation of their management in hospital:-

The subjects did not express negative criticism about their management. They seemed to accept whatever was told to them without asking for more information or details. All the subjects remembered who informed them of their infant's death, and for seventeen of the thirty no explanation about the cause of death had been offered. The majority (24 of the 30) were offered the opportunity for contact with their infant. The only dissatisfaction expressed was placement in a general postnatal ward with other mothers and their babies. Many of these subjects would have preferred placement in a single ward or alternative arrangements.

In conducting the interview with the subjects, the writer performed the task not only of interviewer or researcher, but also that of counsellor. Most of the subjects were grateful to have an opportunity to relate their experiences and share their feelings with someone who showed understanding, acceptance and insight into their emotions. The majority expressed a desire to meet other women who had been through a similar loss experience which is indicative of the loneliness and isolation that they experienced after their stillbirths. Few people, beyond the immediate family, understand the intensity of the grief associated with the loss of an infant.

With the death of a baby comes the end of a dream. Stillbirth is a lonely sorrow. Parents do not always receive the emotional and social support that is needed to cope with the loss. Crisis counselling and a comprehensive plan of management can be effective in helping parents and families deal with their pain and loss.

RECOMMENDATIONS

A number of authors have proposed various intervention programmes and made suggestions for health professionals involved in perinatal management. Before summarizing recommendations, the writer will introduce a few guidelines for managing stillbirths that could be implemented in local hospitals.

The first suggestion is the taking of photographs of stillborn infants. Parents may, or may not, want to see them. In the latter case, photographs should be kept in patients' folders in the event that parents request them at a later stage. The second is the introduction of a special code and marker on the patients' folders and on the entrance doors to the wards where these patients are being nursed. This would indicate that a specific patient has had a stillbirth and staff members can thereby be forewarned about the situation. Thirdly, the grieving process should be explained to parents and they should be assessed at regular intervals to ascertain their progress or regression in coming to terms with their losses. This follow-up assessment should be organised through a community service or agency. The fourth guideline is the introduction of a special perinatal loss team which consists of members from the following professions: obstetrics, paediatrics, pathology, social work, theology, nursing and mental health. Each team member would have a specific role to perform and regular discussions between team members are essential. Liaison with the local authority clinics and support services in the community is important for referral and feedback. Finally, the writer recommends that when women are prescribed the medication to suppress production of breastmilk, they be told (i) that they can obtain additional tablets if they need to for which a prescription is required, and (ii) about possible side-effects of the medication.

The writer also recommends that the many comments and clichés frequently used by relatives, friends and medical staff in talking to parents after their loss be dropped. They do little to assuage grief. The following are examples: "It's all for the best", "The baby would have been abnormal ... ", "You're young and have plenty time for more", "You'll be pregnant again soon and will have no problems", "You're lucky ... " or "be grateful, you have other children ... ", and "forget it and put it all behind you". These comments are false reassurances and do nothing to make parents feel better. Things one can say that are helpful are: "I am sorry", "I know this is a bad time for you", "Is there anything I can do for you?", and "Is there anyone who would be helpful to you now that I can call?".

A team management approach would be the most effective in assisting families, as each member relates to the family differently and meets different needs. The following guidelines for managing stillbirths are proposed:-

(A) <u>In the Hospital</u>

(1) Keep the mother informed; be honest and forthright.
(2) Recognise and facilitate anticipatory grieving.
(3) Encourage the mother's major support person to remain with her throughout labour and delivery.
(4) Support the couple in seeing or touching the infant.
(5) Describe the infant in detail, particularly for couples who choose not to see.
(6) Encourage the mother to make as many choices about her care as possible.
(7) Teach the couple about the grieving process.
(8) Offer to show infants again during post-partum hospitalization on request.
(9) Allow photographs of the infant.

(10) Prepare couples for hospital paper work such as autopsy requests, death certificates and burial.
(11) Discuss funerals or memorial services.
(12) Help the couple think about informing siblings.
(13) Assist the couple in deciding how to tell friends of the death and in packing away the baby's things.
(14) Discuss subsequent pregnancy.
(15) Use public health nurse referrals.
(16) Schedule additional office visits.[126]
(17) Express feelings about the baby's death with consoling words to parents.
(18) Refer parents to self-help groups or support organizations.

(B) Follow-up Care

(19) Some parents may need to be referred for professional psychotherapy or psychiatric consultation which should be arranged.
(20) A subsequent pregnancy can evoke anxiety. This anxiety needs to be recognised, accepted and discussed.
(21) Parents should be forewarned about anniversary dates and the possible resurgence of grief that may occur.
(22) Parents should be actively monitored and their bereavement reaction should be routinely reviewed.

Follow-up visits should be made as often as necessary as parents need to talk about their fears, regrets, disappointments and hopes. Hospital social work staff can be very supportive to families during the adjustment period.[127] The social worker should offer the following services:

(1) crisis intervention immediately after the event to initiate constructive resolution of the crisis and grief counselling to facilitate the grieving process;
(2) ongoing emotional support to parents while in hospital;
(3) assessment and identification of problem areas which must be communicated to other team members;
(4) evaluation of the extended families' understanding and reaction to the event; and
(5) utilization of available community resources for referral.

The social worker can also assist by advocating for change in hospital policies and procedures that would make carrying out above mentioned recommendations possible.

The primary physician's effectiveness will be enhanced if the following points are taken into consideration:-

(1) The news should be given to the family in the best possible physical surroundings, and in private.
(2) At the time the news is given, both parents should be present.
(3) The wording used to announce the stillbirth should be gentle, rather than abrupt, and compassionate but factual.
(4) The physician should remember that some people hear only what they want to hear. Therefore, other family members or close friends may need to be briefed to help interpret the facts.
(5) A kindly gesture, such as physical contact with the parents, is a response that is frequently remembered and appreciated by parents.[128]

Suggestions for quality nursing care are presented as follows:-

(1) The nurse must firstly be comfortable with her own reaction to foetal/infant death before she can begin to help a couple cope with their loss.

(2) Some of the nurse's major contributions are empathy, sympathy and an understanding of her patient's feelings.[129]

(3) It is important not to leave patients alone when they are in active labour. The mother suffers fear and pain, as in most deliveries, and should be closely watched and supported.

(4) It is important that patients are physically comfortable and measures should be undertaken to ensure their comfort.

(5) The nurse should be alerted to signals of patient anxiety which may indicate requests for help.

(6) If a patient is unsure about whether she should see her infant, the nurse needs to explain the positive aspects of viewing the infant and to discuss and assess the patient's concerns about it.

(7) If a patient chooses to see her infant, she should be prepared for the infant's appearance.

(8) The nurse can also be instrumental in facilitating the grieving process "by conveying to the patient that the nurse has the time and concern to listen; by talking with the patient and encouraging her to express her feelings; by sharing with the patient the nurse's own feelings of distress over the stillbirth; and by crying with the patient if the nurse is moved to do so". [130]

Although each team member has specific roles to fulfil, overlap may occur and therefore open communication between members is essential. Team members also require an opportunity to talk about their own feelings after a stillbirth. It is suggested that group discussion sessions be held regularly for assisting all members to identify

their feelings and consequent behaviour patterns and the effects that these have on each member and the team as a whole. These group sessions can increase team identification and strengthen the team spirit. This should improve the quality of care that is given to patients. The social worker is in an ideal position to facilitate such groups.

> " ... dying involves real people, even unborn fetuses; significant relationships are disrupted and familiar bonds are severed. Death is always a human tragedy, leaving survivors to seek advice and comfort".[131]

(C) Recommendations for Additional Research

(1) This study investigated fathers' responses to stillbirth only indirectly. It is important to assess the reactions and responses of fathers and analysis of these in indicated.

(2) The psychological effects of stillbirths on professional personnel has not been investigated. It would be of importance to look at these areas and to record the reactions of doctors and nurses to stillbirths. This information would highlight whether there is a need for formal discussion groups for medical and nursing personnel to air their feelings and problems. In addition, a study of this nature would evaluate the need for a formal programme of training and in-service training of professional personnel involved in perinatal death.

(3) This research study did not aim to record the duration of the subjects' grief responses. It would be of interest to record these over a longer term and to ascertain how successfully or unsuccessfully the subjects handled their grief.

(4) The danger of the "replacement child" is well documented and it would be of importance to follow-up the families to record the time period before the subsequent pregnancy. Additionally, long-term follow-up would be necessary where there is a subsequent infant to assess whether this infant is a "replacement", and, whether any problems arise within the family or with the child concerned.

(5) Some of the respondents were unmarried at the time of their stillbirths but had intentions of marrying their partner. It would be of interest to investigate whether these respondents did so and what effect the stillbirth had upon their marital relationships.

(6) Follow-up of families to assess the long-term effects of the stillbirths on the marital relationships would be important.

(7) The research findings indicated that no autopsies were performed on the stillborn infants. It would be of importance to the hospital to ascertain parents' views on autopsy and whether they would give permission for this procedure.

STILLBORN

I carried you in hope,
the long nine months of my term,
remembered that close hour when we made you,
often felt you kick and move
as slowly you grew within me,
wondered what you would look like
when your wet head emerged,
girl or boy, and at what glad moment
I should hear your birth cry,
and I welcoming you
with all you needed of warmth and food;
we had a home waiting for you.

After my strong labourings,
sweat cold on my limbs,
my small cries merging with the summer air,
you came. You did not cry.
You did not breathe.
We had not expected this;
it seems your birth had no meaning,
or had you rejected us?

They will say that you did not live,
register you as stillborn.
But you lived for me all that time
in the dark chamber of my womb,
and when I think of you now,
perfect in your little death,
I know that for me you are born still;
I shall carry you with me forever,
my child, you were always mine,
you are mine now.

Death and life are the same mysteries.

Leonard Clark

NOTES

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APPENDIX I

UNIVERSITY OF CAPE TOWN

SCHOOL OF SOCIAL WORK

RESEARCH STUDY FOR M Soc Sc

CONSENT FORM FOR STILLBIRTH STUDY

I, ..., hereby give consent to be interviewed by Mrs A Friedlander in connection with the above study.

Signed: .....

Date: .....

UNIVERSITY OF CAPE TOWN

SCHOOL OF SOCIAL WORK

RESEARCH STUDY FOR M Soc Sc

CONSENT FORM FOR STILLBIRTH STUDY

I, ..., hereby give consent to be interviewed by Mrs A Friedlander in connection with the above study.

Signed: .....

Date: .....

APPENDIX II

UNIVERSITY OF CAPE TOWN

Memorandum

TO .....

.....

.....

CONFIDENTIALITY FORM

FOR DICTAPHONE TYPING/TRANSCRIBING

MASTER'S THESIS : STUDENT : Anne Friedlander

TITLE OF THESIS : Stillbirth : A Psychosocial Crisis

TYPIST : Mrs Barbara Ross

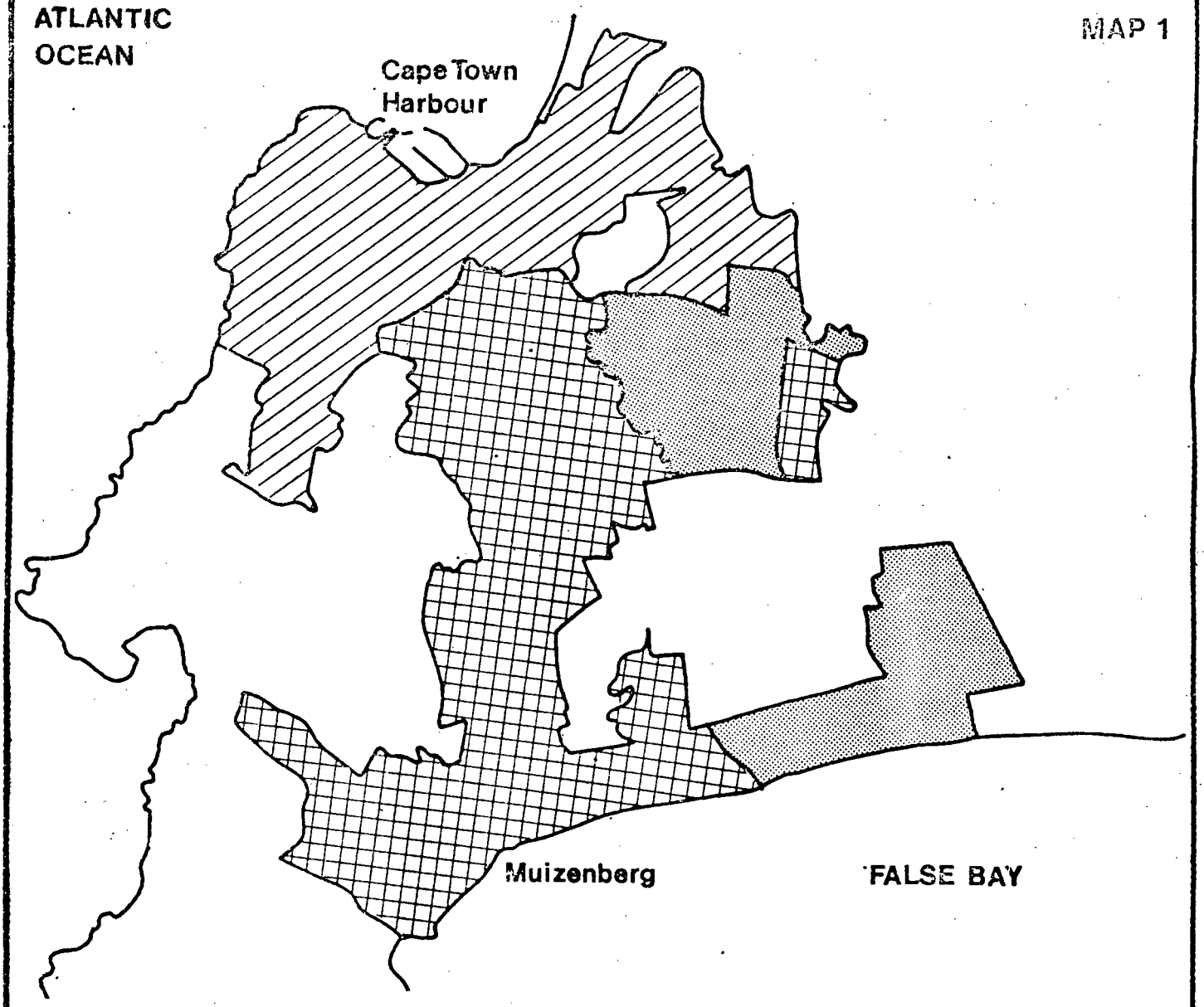
I, Mrs Barbara Ross, residing at 17 Jupiter Road, Kirstenhof, do hereby undertake to transcribe tape-recorded interviews for Anne Friedlander for the above thesis. I also undertake to treat all contents of this thesis, i.e. names of clients and details of interviews as confidential.

Signed: *signature removed*

Date: 13-9-84

Student: *signature removed*

APPENDIX III



	NORTHERN ZONE	SOUTHERN ZONE	EASTERN ZONE
Population (Estimated)	217 348	357 866	435 709
Principal Medical Officer	1	1	1
Medical Officers	3	3	4

CITY OF CAPE TOWN HEALTH ZONES

APPENDIX IV

BATON SCORING SYSTEM

Counting any person of ten years and over as one adult equivalent, and any person under ten years as half an adult equivalent, the number of rooms needed is as follows:

Up to 2,5 equivalent persons	1 room
3,5	2 rooms
5,0	3 rooms
7,5	4 rooms
10,0	5 rooms
12,5	6 rooms
15,0	7 rooms
17,5	8 rooms
20,0	9 rooms

Formula:

$$\frac{\text{Number of equivalent persons in house}}{\text{Number of persons allowed per rooms used for sleeping}} \times \frac{100}{1}$$

Percentage of Overcrowding

< 100% = uncrowded

100% = crowded

100% - 149% = overcrowded

> 150% = gross overcrowding

APPENDIX V

INTERVIEW SCHEDULE

FOR

RESEARCH STUDY FOR M.Soc. Sc. (S.W.)

Title of Study: STILLBIRTH - A PSYCHOSOCIAL CRISIS

(A study of Coloured patients at Groote Schuur Hospital)

University of Cape Town

1983/1984

CONTENTS

INSTRUCTIONS FOR ADMINISTRATION OF INTERVIEW SCHEDULE

(i) All questions which are not applicable to a respondent, are to be left blank and scored as missing values.

(ii) In Interview Schedule I, information for Sections B, C and D is to be obtained from respondents' medical folders.

(iii) Interview Schedule II, Section C: Housing/Accomodation data.
In order to calculate the level of crowding, the Batson Scale for household density is used.
i.e. $\frac{\text{No of persons in house/flat}}{\text{No of rooms used for sleeping}} \times \frac{100}{1}$

(iv) Interview Schedule II, Section D: Occupational status/income/social class.
Occupation of chief breadwinner in the family is assessed according to the occupational rankings of the S A National Census 1980.

(v) Interview Schedule II is used in combination with a tape-recorded interview.

INTERVIEW : SCHEDULE I

DATA FROM FOLDER:

SECTION A : IDENTIFYING DATA

NAME: .....

HOSPITAL FOLDER NO: .....

DATE OF ADMISSION: .....

DATE OF DISCHARGE: .....

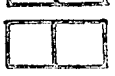
ADDRESS: .....
.....
.....
.....

TELEPHONE NO: HOME:..... WORK: .....

REFERRED BY: .....
.....
.....

. INDEX (SURVEY) NO: 

. Duration of hospitalization (days) 

. Age (years) 

. Time lapse (days) : From delivery - first interview (9 ⩾ 9) 

. Religion:

Roman Catholic	= 1
Protestant	= 2 (specify)
Muslim	= 3
Hindu	= 4
None	= 5
Other	= 6 (specify)

Specify: .....
.....
.....

. SECTION B : GENERAL MEDICAL/PSYCHIATRIC HISTORY

Specify: .....
.....
..... 
.....

1 = Relevant
2 = Not relevant

SECTION C : OBSTETRICAL HISTORY

7. Gravida (state actual number) (9 ≫ 9) ☐

8. Para (actual number) (9 ≫ 9) ☐

9. Miscarriages (actual number) (9 ≫ 9) ☐

10. Stillbirths (actual number) (9 ≫ 9) ☐

11. Neonatal deaths (actual number) (9 ≫ 9) ☐

12. Mortality other children (actual number) (9 ≫ 9) ☐

13. Booked/Risk: ☐
1 = Booked/low risk
2 = Booked/High risk
3 = Unbooked

If booked, ask questions 14 and 15

14. Place of attendance for antenatal care: ☐
1 = Clinic
2 = Hospital
3 = Private practitioner
4 = Combination

15. Frequency of attendance: ☐
1 = Regularly
2 = Irregularly

16. Mode of delivery - spontaneous: ☐
1 = Vertex
2 = Breech

17. Mode of delivery - assisted: ☐
1 = Forceps
2 = Vacuum

18. Mode of delivery - surgical: ☐
1 = Caesarian
2 = Destructive

SECTION D : DETAILS OF SB INFANT

19. Birthweight (Kgm) ☐☐☐☐

20. Gestational age (weeks) ☐☐

21. Sex: 1 = Male; 2 = Female ☐

22. Autopsy done: 1 = Yes; 2 = No ☐

23. Photo taken: 1 = Yes: 2 = No ☐

24. Deformation of baby: 1 = Yes; 2 = No ☐

25. Probable cause of death: ☐☐

1 = Abruptio placenta
2 = Placenta praevia
3 = Placental insufficiency
4 = Pre-eclampsia
5 = Maternal diabetes
6 = Eclampsia
7 = Amniotic infection
8 = Congenital syphilis
9 = Congenital abnormality
10 = Prolapsed/knotted cord
11 = Mechanical causes
12 = Unknown
13 = Combination of above

Specify: .....

.....

.....

.....

26. Drug therapy in hospital after delivery: ☐

1 = Antidepressant
2 = Tranquilizer
3 = Analgesic
4 = Sleeping tablets
5 = Combination
6 = Other
7 = No therapy

.....

.....

.....

INTERVIEW : SCHEDULE II

SECTION A : IDENTIFYING DATA

1. Index number: ☐☐

2. Marital status: 1 = Unmarried/divorced/widowed
   2 = Married
   3 = Living together ☐

3. Marriage/cohabitation: 1 = Good
   2 = Average
   3 = Poor + conflict ☐

4. Desirability of pregnancy: 1 = Wanted/planned
   2 = Wanted/unplanned
   3 = Unwanted/unplanned
   4 = Unwanted/planned ☐

SECTION B : FAMILY/HOUSEHOLD COMPOSITION

5. Parents (actual number) ☐

6. Children (actual numbers) (9 ≫ 9)
   U column = dependent in home
   T column = independent in home
   H column = not living at home

   H T U
   ☐☐☐

7. Other home/family members (9 ≫ 9)
   U = Grandparents
   T = Other relatives
   H = Other residents

   H T U
   ☐☐☐

8. Age and number of children in family unit/house: (actual numbers) (9 ≫ 9)
   U = 0 – 2 yrs
   T = 3 – 5 yrs
   H = 6 – 10 yrs

   H T U
   ☐☐☐

9. Age and number of children in family unit/house: (actual numbers) (9 ≫ 9)
   U = 11 – 17 yrs
   T = 18+ yrs

   T U
   ☐☐

10. Closeness of family: 1 = Very close
    2 = Close
    3 = Average
    4 = Not close
    5 = Other ☐

Specify: .....

.....

SECTION C : HOUSING/ACCOMMODATION DATA

11. Type of housing:
1 = Self-owned house/flat
2 = Rented house/flat
3 = Council house
4 = Council flat
5 = Rented room
6 = Domestic servant's room

12. Level of crowding/household density:

No of persons over 10 years .....

No of persons under 10 years .....

No of rooms used for sleeping .....

1 = Uncrowded
2 = Crowded
3 = Overcrowded
4 = Gross overcrowding

SECTION D : OCCUPATIONAL STATUS/INCOME/SOCIAL CLASS

13. Occupational status of mother prior to pregnancy

1 = Unemployed
2 = Full time
3 = Part time

14. Occupation of mother:
1 = Housewife
2 = Professional
3 = Clerical
4 = Factory
5 = Domestic
6 = Combination
7 = Other

15. In receipt of state grant:
1 = Yes
2 = No

Specify: .....

.....

.....

.....

16. Mother's monthly income:
1 = 0 - R50
2 = R51 - R100
3 = R101 - R150
4 = > R150

17. Occupation of chief breadwinner in family:
1 = Professional/technical related workers
2 = Administrative and managerial
3 = Clerical
4 = Sales workers
5 = Service workers
6 = Agriculture, fisheries, hunters
7 = Production and transport workers
8 = Not economically active
9 = Not classified by above

Specify: .....

.....

If pensioner, previous occupation .....

.....

18. Income breadwinner:
1 = 0 - R100
2 = R101 - R200
3 = R201 - R300
4 = R301 - R500
5 = R501 - R1000
6 = > R1000

19. Total income in family/household unit per month
1 = 0 - R150
2 = R151 - R300
3 = R301 - R500
4 = R501 - R1000
5 = > R1000

20. Social class of the family:
1 = Professional, upper middle, skilled
2 = Semi-skilled
3 = Unskilled

SECTION E : EDUCATIONAL DATA

21. Educational level - mother:
0 = 0 - Sub B
1 - 10 = actual standard obtained

22. Post matriculation qualification:
1 = University
2 = Technical

23. Educational level - partner/husband:
0 = 0 - Sub B
1 - 10 = actual standard obtained

24. Post matriculation qualification - husband/partner:
1 = University
2 = Technical

SECTION F : DATA OF MOTHER'S INTERPRETATION OF MANAGEMENT IN HOSPITAL

(First interview in Unit column : Second interview in Ten column)

25. Did you have any illnesses during pregnancy? T U
1 = Relevant/important
2 = Irrelevant or no

26. When was diagnosis of stillbirth made? T U
1 = Before onset of labour
2 = During labour
3 = At or after delivery

27. Time lapse between knowledge of SB and delivery (weeks) T U
(less than 1 week = 0)

28. Can you remember who (first) told you that baby was stillborn? T U
1 = Remembers
2 = Not sure
3 = Cannot remember at all
4 = Was not told at all

29. Who was/were this/these person/persons? T U
1 = Docotor
2 = Midwife
3 = Combination of 1 and 2
4 = Combination of 1, 2, 5
5 = Other (specify)

Specify: .....

30. Can you remember who (first) explained the possible cause of SB? T U
1 = Remembers
2 = Not sure
3 = Cannot remember at all
4 = Was given no explanation at all

31. Who was/were this/these person/persons? T U
1 = Doctor
2 = Midwife
3 = Combination 1, 2
4 = Combination of 1, 2, 5
5 = Other (specify)

Specify: .....

32. Did you understand and agree with this explanation? T U
1 = Understood
2 = Understood/disagreed
3 = Not understood/agreed
4 = Not understood/disagreed

34. Did you ask for more details? 1 = Yes; 2 = No T U

35. Whom did you ask for more details? T U
1 = Doctor
2 = Midwife
3 = Combination of 1, 2
4 = Combination of 1, 2, 5
5 = Other

36. What did you think was the cause of death? T U

1 = Maternal action
2 = Maternal physical wellbeing
3 = Foetal defect
4 = Management by medical staff
5 = Other (specify)
6 = Does not know

Specify: .....

37. Who do you think should have told you about baby's death? T U

1 = Doctor
2 = Nursing staff
3 = Social Worker
4 = Does not know
5 = Other (specify)

Specify: .....

38. Where were you nursed during the first week postnatally? T U

1 = General postnatal ward
2 = Single ward
3 = With other mothers (P/N) with SB
4 = Mothers postnatal but babies not with them
5 = Antenatal mothers
6 = Combination
7 = At home

39. Where would you have preferred to be? T U

1 - 7 = Options from Ques. 38
8 = Indifferent

40. Did you have any contact with baby? (See/touch/hold) T U

1 = Yes; 2 = No

41. Did you want to have contact with baby? T U

1 = Yes; 2 = No

42. Did you ask to see baby? 1 = Yes; 2 = No T U

43. Were you offered a chance to see/touch/hold baby? T U

1 = Yes; 2 = No

44. Who showed you the baby? T U

1 = Doctor
2 = Nurse
3 = Other
4 = Did you see the baby inadvertantly?

45. Was this the same person who told you that the baby would be/was stillborn? T U

1 = Yes; 2 = No

46. Did you receive genetic counselling? 1 = Yes; 2 = No T U

47. Was an autopsy done? 1 = Yes; 2 = No T U

48. If yes, do you know what was found at autopsy? 1 = Yes; 2 = No T U

49. Are/were you interested in knowing the results? T U

1 = Yes; 2 = No; 3 = Indifferent

50. Did/have you made enquiries about the results? T U

1 = Yes; 2 = No; 3 = Was told

51. Were you visited by social worker? 1 = Yes; 2 = No

T U

52. Who organised the burial of baby? 1 = Self
2 = Hospital
3 = Other

T U

53. Did you name the baby? 1 = Registered name
2 = Christened
3 = In her mind only
4 = No name

T U

54. Did you feel your stay in hospital was: 1 = Long enough
2 = Too long
3 = Too short

T U

55. Have you been visited by clinic sister since discharge?
1 = Yes; 2 = No

T U

56. If yes, did the sister know that your baby was stillborn?
1 = Yes; 2 = No

T U

SECTION G : DATA IN CONNECTION WITH THE REACTIONS OF THE MOTHER AND THE IMPACT OF THE STILLBIRTH EVENT ON THE FAMILY

Which of the following reactions/feelings did you have/do you still have?

Physical:

57. Loss of appetite: 1 = Yes; 2 = No ☐

58. Sleep problems (insomnia, vivid dreams, nightmares) 1 = Yes 2 = No ☐

59. Tightness in throat or chest (heartache) 1 = Yes; 2 = No ☐

60. Episodes of crying: 1 = Yes; 2 = No ☐

61. Choking sensation: 1 = Yes; 2 = No ☐

62. Shortness of breath: 1 = Yes; 2 = No ☐

63. Sighing: 1 = Yes; 2 = No ☐

64. Fatigue (lack of strength, exhaustion) 1 = Yes; 2 = No ☐

65. Aching arms (arms hurt from not being able to hold baby) 1 = Yes; 2 = No ☐

Emotional:

66. Guilt: 1 = Yes; 2 = No ☐

67. Depression: 1 = Yes; 2 = No ☐

68. Empty, lonely feeling: 1 = Yes; 2 = No ☐

69. Irritability, hostility or anger towards those close to you: 1 = Yes; 2 = No ☐

70. Increased emotional distance from others: 1 = Yes; 2 = No ☐

71. Inability to return to usual patterns of conduct: 1 = Yes; 2 = No ☐

72. Loss of femininity: 1 = Yes; 2 = No ☐

73. Sense of futility: 1 = Yes; 2 = No ☐

74. Preoccupation – thinking about baby: 1 = Yes; 2 = No ☐

75. Praying for baby: 1 = Yes; 2 = No ☐

76. Disbelief/feelings of unreality: 1 = Yes; 2 = No ☐

2/...

77. Who has given you the most emotional support and help since loss of baby?
1 = Husband/partner
2 = Children
3 = Extended family
4 = Friends
5 = Religious leader
6 = Combination (specify)
7 = Cannot say
8 = Nobody
9 = Other (specify)

Specify: .....

.....

78. Are you on any form of medication? 1 = Yes; 2 = No

79. What kind? (Check with hospital records)
1 = Antidepressant
2 = Tranquilizer
3 = Analgesic
4 = Sleeping tablet
5 = Combination
6 = Does not know
7 = Other (specify)

Specify: .....

80. Is it of any help to you? 1 = Yes; 2 = No; 3 = Uncertain

81. Are you taking any home remedies? 1 = Yes; 2 = No (specify)

Specify: .....

82. Opinion of questionnaires: 1 = Interesting/helpful
2 = Embarrassing
3 = Painful/hurtful
4 = Offensive
5 = Waste of time
6 = Noncommital
7 = Combination

SECOND INTERVIEW : SCHEDULE III

SECTION A:

Index No. ☐☐

1. Time lapse date of SB – interview II (days) ☐☐

2. Preparation for baby (e.g. pram, room, cot etc.) ☐
1 = Yes; 2 = No

3. Disposal of preparations: Th H T U ☐☐☐☐
Column U – packed away (1 = Yes; 2 = No)
T – given away (1 = Yes; 2 = No)
H – kept (1 = yes; 2 = No)
Th – other (1 = Yes; 2 = No)

4. Did your husband/partner take time off from work when you came home? ☐
1 = Yes
2 = No
3 = Wanted to but was unable

5. If so, how long? 1 = Less than one week ☐
2 = More than one week
3 = Other (specify)

Specify: .....

6. Did you have domestic help when you got home? 1 = Yes; 2 = No ☐

7. If yes, who helped you? Th H T U ☐☐☐☐
Column U – adult relative (1= Yes; 2 = No)
T – children (1 = Yes; 2 = No)
H – friend (1 = Yes; 2 = No)
Th – other (1 = Yes; 2 = No)

8. Did you feel you needed help? ☐
1 = Yes
2 = No
3 = Uncertain

SECTION B : STATED NEEDS OF FAMILY

Which of the following situations are causing problems?

9. Readjustment (1 = Yes; 2 = No) ☐

10. Handling children (1 = Yes; 2 = No) ☐

11. Domestic situation (1 = Yes; 2 = No) ☐

12. Marital relationship (1 = Yes; 2 = No) ☐

13. Dealing with friends and socializing again (1 = Yes; 2 = No) ☐

14. Feelings of inadequacy/failure (1 = Yes; 2 = No) ☐

2/...

15. Do you wish to consult with somebody in connection with the following:-

15.1 Genetic counselling: 1 = Yes; 2 = No; 3 = Not sure ☐

(a) If yes, to whom do you wish to speak? ☐
1 = Doctor at hospital
2 = Midwife/nursing sister at hospital
3 = Social worker
4 = Somebody unconnected with hospital
5 = Interviewer
6 = Combination (specify)
7 = Not sure

Specify: .....

(b) Are you going to make an arrangment to see this person? ☐
1 = Yes; 2 = No; 3 = Not sure

15.2 Planning another baby? 1 = Yes; 2 = No; 3 = Not sure ☐

(a) If yes, to whom do you wish to speak? ☐
1 = Doctor at hospital
2 = Midwife/nursing sister at hospital
3 = Social worker
4 = Somebody unconnected with hospital
5 = Interviewer
6 = Combination (specify)
7 = Not sure

Specify: .....

(b) Are you going to make an arrangement to see this person? ☐
1 = Yes; 2 = No; 3 = Not sure

15.3 Your feelings about losing your baby: ☐
1 = Yes; 2 = No; 3 = Not sure

(a) If yes, to whom do you wish to speak: ☐
1 = Doctor at hospital
2 = Midwife/nursing sister at hospital
3 = Social worker
4 = Somebody unconnected with the hospital
5 = Interviewer
6 = Combination (specify)
7 = Not sure

Specify: .....

16. Would you like to meet other mothers who have experienced similar loss? ☐
1 = Yes; 2 = No; 3 = Not sure

17. Is mother back at work? 1 = Yes; 2 = No ☐

18. Would you have liked a photo of your baby? ☐
1 = Yes; 2 = No; 3 = Not sure

☐