THE EXPERIENCE OF MOTHERS WHO GAVE BIRTH TO STILLBORN BABIES

by

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Tutor: Prof AGW Nolte

Co-tutor: Dr CS Dörfling

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CONTENTS

SUMMARY

The purpose of this study is to determine the experiences of mothers after delivery of a stillborn baby. Parents who experience this event have mixed emotions, that is feelings of helplessness, disbelief, powerlessness, fear and anxiety.

Unstructured in-depth interviews were held with ten (10) mothers three months after the death of their babies, the experiences of the ten mothers were compared afterwards. A literature study was undertaken in order to determine what the conclusions of other researchers in the field were. The result of the literature study was compared with that of the present study.

Recommendations are made at the end of this study on the practical education and further research that can be undertaken on this subject.

OPSOMMING

Die doel van hierdie studie is om te bepaal wat moeders ervaar nadat hulle babas doodgebore is. Ouers wat dit ervaar het gemengde gevoelens van hulpeloosheid, ongeloof, magteloosheid, vrees en angs.

Ongestruktureerde in-diepte onderhoude is met tien (10) moeders gevoer drie maande na die dood van hulle babas en die ervarings van die tien moeders is later vergelyk. 'n Literatuurstudie is onderneem ten einde vas te stel watter gevolgtrekkings ander navorsers op dié gebied gemaak het. Die resultaat van die literatuurstudie is vergelyk met dié van hierdie studie.

Aanbevelings word aan die einde van hierdie studie gemaak met betrekking tot die praktiese opleiding en verdere navorsing wat oor hierdie onderwerp gedoen kan word.

CHAPTER 1

THE EXPERIENCE OF MOTHERS WHO GAVE BIRTH TO STILLBORN BABIES

1. INTRODUCTION

Parental bereavement may be different from bereavement for other causes. Some people believe that it is not as difficult as the loss of another family member because the fetus or the newborn never "lived". This is not true. The woman bonds with her fetus early in pregnancy, and the father and other family members often do so also once they perceive movements and hear heartbeat (Dickason, Silverman & Schultz, 1994:820).

Parents who experienced this say it is something one cannot describe. As one mother said, *"When a child is born dead, there is nothing. The world remembers nothing, and the gap in the womb is replaced by an emptiness in your arms."* She continued, *"You are not recording a birth or a death, but both at once. It is the ultimate contradiction - I felt I had created death."* (Kennell & Klaus, 1982:264)

When a newborn dies in hospital, all evidence of his existence is sometimes removed with amazing rapidity, and nothing is left to confirm the reality of his death. One mother said: *"Everything just happened so fast... My mind kept going around in circles. I didn't really understand. Just last Sunday I was thinking about her, thinking that my husband and I were the only ones who saw her - it's like there is no proof there was a baby. We were the only ones who ever saw her, and it was just a couple of days. When a baby dies so small, there is no funeral, no masses. It seems like sort of a shame that there isn't something more... I felt I was on an island by myself... lost..."* (Kennell & Klaus, 1982:265).

Often no special arrangements are made for parents. They may not have any privacy or a comforting individual who allow them to express their grief freely. There are

sometimes no planned follow-up contact with the family to see how the mourning process is proceeding, and information about the results of the postmortem examination is sometimes delivered in a latter (Kennell & Klaus, 1982:265).

One interesting study showed that parents who were given the opportunity to view and hold their infant after he had died, helped them initiate the grieving process. Viewing and holding their deceased infant as well as having photographs and other mementos to keep allow concrete attachment by the parents and provide prominent memories (*Neonatal Network,* Volume II, No. 6, September 1992).

But for a young woman her miscarriage seemed like the end of the world. She had loved that tiny child in her womb, she had developed a relationship with it. She had read books about its development. She knew its size and shape. to her it was a real miniature person, not a lump of tissue. It was another human being growing inside her. She was discharged from the hospital and received sympathy from the family and friends. Soon she felt physically strong and looked good (Storkey, 1989:8), but deep inside she was in a state of frozen grief and mourning. She had lost her baby. Yet no ceremony had marked its death and no friends had cried with her.

Similarly, those who had stillborn children receive no public recognition in their bereavement for their loss, too, is seen even by those in the delivery room not as a living child who has died, but as a fetus that didn't quite make it (Storkey, 1989:9). No-one talks about it. *"Just where are all these women who have lost babies?"* one anguished mother demanded. *"I don't think anyone I know has been through miscarriage besides me."* (Rank, 1985:18). Her complaint points out one of the key factors that gives pregnancy losses their peculiar kind of hurt. It is a life experience women often don't talk about. Why not? There are several reasons. A woman may feel ashamed. She has failed somehow, she tells herself - failed herself, her husband and most of all, her child (Rank, 1985:18).

Comments are made over and over again by couples who experienced a miscarriage. *"A*

miscarriage is nature's way of sparing you from having an imperfect baby." "It's all for the best." "You can have another baby." (Borg & Lasker, 1981:27).

But when pregnancy ends in tragedy, friends and relatives are even more uncertain about what to do. Too often, therefore, they say inconsiderate things or nothing at all. The whole situation is confusing. Is it or is it not bereavement? Should the parents be treated as though they had "lost a loved one"? What others often do not realise is that a major tragedy has occurred - probably the worst so far in the life of the young adult (Borg & Lasker, 1981:113).

For the majority of women whose fetuses died in utero, carrying the dead baby and waiting for spontaneous labour or induction is sad and difficult for her entire family as well. Feelings such as helplessness, disbelief and powerlessness characterise this period. There is often an uncontrollable urge to flee and escape from the unpleasant situation (Merenstein & Gardner, 1993:532).

2. PROBLEM STATEMENT

There are many complaints from mothers who delivered stillborn babies with regard tot he lack of psychological support given to them during the grieving process. All doctors and nurses seem to care about is that the baby has been delivered and then they apparently do not care about the emotional trauma the mother is undergoing, and probably the strongest reactions occur when there are comments suggesting that the family should forget about the loss and get on with their lives, or get on with another pregnancy, or the baby was small and therefore their loss should not be as great as when the baby had lived longer (Kennell & Klaus, 1982:267).

The research questions that arise from the above are:

1. What are the experiences of mothers who gave birth to stillborn babies?
2. what can be done to encourage psychological support from care-givers and the

family?

3. AIMS OF THE STUDY

The aims of this study are:

- to explore and describe experiences of mothers who gave birth to stillborn babies;
- to draw guidelines of the psychological support needed by the mothers during the grieving process.

4. PARADIGM

this research is based on the Jude-Christian philosophy, that is stressing Biblical principles and values. It is also based on Nursing for the Whole Person Theory (Oral Roberts University, Anna Vaughn School of Nursing, 1990:136-142). This theory reflects the focus on the human being as a whole, that is body, mind and spirit, as well as the parameters of nursing service and beliefs about person, health, illness and nursing.

4.1 Meta-theoretical assumptions

- **Person**

A person is a spiritual being who functions in an integrated biopsychosocial manner to achieve his quest for wholeness. A person interacts with his internal and external environment holistically (Oral Roberts University, Anna Vaughn School of Nursing, 1990:136-142). A person in this study means a mother who delivered a stillborn baby.

- **Family**

It is a group which is a basic unit of society, composed of individuals mutually valued and interacting. In this study the family refers to the husband or lover, siblings and

grandparents.

- **Health**

Health is a state of spiritual, mental and physical wholeness. The person's pattern of interaction with his internal and external environment determines his health status. Health can be qualitatively described on a continuum from maximum to minimum health. Illness potential exists in those who are healthy.

- **Nursing**

This is a goal-directed service to assist the individual, family or community to promote, maintain and restore health. Central to this service is the concept of Nursing for the Whole Person. Maintenance, promotion and restoration of health have been defined as follows:

Maintenance of health refers to those nursing activities directed towards continuing and preserving the health status of the individual, family and community.

Promotion of health refers to nursing activities contributing to a greater degree of wholeness for the individual, family and community.

Restoration of health refers to those nursing activities which facilitate the return of health to previously experienced levels of individuals, families and communities.

4.2 Theoretical assumptions

These are derived from within the theoretical framework of Nursing for the Whole Person Theory (Oral Roberts University, Anna Vaughn School of Nursing, 1990:136-142).

4.3 Methodological assumptions

A functional approach to nursing is followed in this research. The approach means that the aim of research and theory development in nursing is to improve nursing practice. The concept needs to be theoretically defined and, secondly, theoretical definition needs to be operationally defined.

- Definitions

Grief: Intense emotional suffering caused by loss or the emotional reaction to the loss of a significant person.

5 RESEARCH DESIGN AND METHOD

5.1 Research design

An exploratory, descriptive and qualitative design was followed within the context of a public hospital in Gauteng Province.

5.2 Research method

A phenomenological approach was used, which is an approach to human inquiry that emphasizes the complexity of human experience, and the need to study that experience holistically as it is lived (Polit & Hugler, 1991:651). The aim of the phenomenological approach is to describe an experience as it is lived by the person, such as an experience of pain (Burns & Grove, 1993:30). In this study, the mothers who gave birth to stillborn babies describing their experience of grief.

An unstructured interview was used, the mothers were told about the purpose of the study and they were asked one question, to describe their whole experience around their babies' death.

During the interview the following communication skills were used: slow verbal communication, silence, listening and encouragement.

An interview guide was also drawn, that is a list of topics within an area of inquiry about which the researcher wished to gather information. It provided a framework for the interviewer to develop questions, sequence and to make decisions about the information to be pursued in great depth.

5.3 Population and sampling

A selected group of ten mothers who gave birth either to fresh stillborn and macerated stillborn babies was approached three months after the birth of the babies. These mothers were selected from a public hospital which is situated in Pretoria in Gauteng Province.

The criteria used for selection was as follows:

- Mothers could be married or unmarried.
- Mothers' ages were unrestricted.
- Economic status could range from low, middle and high class.
- They had to be able to communicate in one of the following languages: English, Northern Sotho, Southern Sotho, Tswana or Zulu.
- Respondents were selected from the Provincial Hospital in Pretoria in Gauteng Province.
- The mothers had to be 28 weeks or further pregnant.
- The babies had to be either fresh or macerated stillborn.

The above criteria were used to select these mothers as the researcher works in this Provincial Hospital and from the above prerequisites it is evident that a purposive sample selection of respondents was to be done when mothers came in after three months post-delivery.

5.4 Data gathering

A selected group of mothers who gave birth to either fresh stillborn babies or macerated stillborn babies were approached and the purpose of the study was explained to the respondents. They had to state whether or not they were willing to participate. Personal interviews were conducted and recorded on tape for purposes of transcription and analysis. Permission was asked from the client to use the tape. Open-ended research questions were asked and ethical aspects related to research were respected.

6. VALIDITY AND RELIABILITY

6.1 Validity

Validity in research is concerned with the accuracy and truthfulness of scientific findings (Le Compte & Goetz, 1982:32). According to Burns and Grove (1993:265), validity is a measure of the truth or accuracy of a claim and is an important concern throughout the research process. A valid study should demonstrate what actually exists and a valid instrument or measure should actually measure what it is supposed to measure (Brink in *Curationis*, Volume 16, No. 2, June 1993). There are many types of validity, and in this study two types will be concentrated on, namely internal and external validity according to Guba and Lincoln, which are referred to as credibility and transferability.

7. DATA ANALYSIS

"The intent of the analysis is to organize the data into a meaningful, individualized interpretation or framework that describes the phenomenon studied." (Burns & Grove, 1993:29)

Tape recordings of the interviews will be transcribed. Transcription will be verbatim in the language in which the interviews were held. Transcriptions will be analysed by the researcher and a qualified independent nursing researcher (coder), who is able to

understand the language used in the transcriptions.

Photocopies of the transcribed interviews will be made, and handed over in a sealed envelope to the coder. This is to ensure that confidentiality is maintained, which Lincoln and Guba describe as trustworthiness.

8. CHAPTER DIVISION OF THE STUDY

CHAPTER 1 : Overview of the research.

CHAPTER 2 : Method of the research.

CHAPTER 3 : Research results and literature control.

CHAPTER 4 : Conclusions and recommendations.

CHAPTER 2

RESEARCH METHOD

1. INTRODUCTION

In the first chapter the rationale and purpose of the study were concentrated on. In this chapter the research method and research design will be discussed.

2. RATIONALE

The mother who gave birth to a stillborn baby is the central focus of the study. The death/loss of her baby affects her health and the immediate external environment, especially the husband, siblings and grandparents, while there is a lack of psychological support for her. Since our society has lost the extended family, one finds that them other is just staying with the husband and children, so there is limited support and lack of psychological support from doctors and nurses. All they apparently care about is the delivery of the baby and they do not seem concerned about the emotional trauma the mother is undergoing.

3. PURPOSE OF THE STUDY

The purpose of the study is to:

- explore and describe the experiences of mothers who gave birth to stillborn babies;
- draw guidelines for the psychological support needed by the mother during the grieving process.

4. RESEARCH DESIGN

An exploratory, descriptive and qualitative study which is contextual in nature, will be used in a hospital in Gauteng province.

It is a qualitative study hence the research problem needs to be explored as little South African information exists on the topic (Creswell, 1994:10) and the variables are unknown. The researcher also wanted to focus on the context that may shape the understanding of the phenomenon being studied.

It is a descriptive study in that the researcher wants to describe the experiences of mothers who gave birth to stillborn babies in a natural setting (Creswell, 1994:57) and to describe the psychological support needed by the mothers during the grieving process.

It is a contextual study because it is bound to a unique context/situation since the study was done in the ante-natal clinic, ante-natal ward, labour ward and post-natal wards of a specific provincial hospital in Gauteng Province and the aim here was to subject a single group to a searching investigation. Therefore, the findings of this study cannot be generalised or used in other hospitals, that is they are limited by time, place, space or uniqueness of a particular group which has been studied, namely mothers who delivered stillborn babies (Mouton & Marais, 1993:50).

5. RESEARCH METHOD

Phenomenological research was undertaken with the aim to describe an experience as it is lived by the person. In this study the experiences of mothers of stillborn babies are described. This research method involves thorough in-depth analysis of an individual (Polit & Huglar, 1991:640) and it is an intensive exploration of a single unit of study, such as a person, family, group, community or institution. In this case it is the person (Burns & Grove, 1993:763).

5.1 The role of the researcher

Qualitative research is interpretative research. As such, the biases, values and judgement of the researcher are stated explicitly in the research report. Such openness is considered to be useful and positive. Gaining entry to a research site and the ethical issues that might arise, are two elements of this role.

Statement about past experiences of the researcher are included that facilitates familiarity with the topic, the setting or the informants. These experiences will likely shape the interpretation of the report (Creswell, 1994:147).

Steps are taken to gain entry to the setting and to secure permission to study the environment or archival sites by seeking the approval of gate-keepers (Creswell, 1994:148).

Comments are made about sensitive ethical issues such as maintaining confidentiality of data, preserving anonymity of informants and using research-intended purposes (Creswell, 1994:148).

The interviewer must make the interviewing experience and task sufficiently meaningful, sufficiently rewarding and sufficiently enjoyable to attain and maintain the necessary respondent motivation (Mouton & Marais, 1993:88).

5.2 Ethical measures

1. The purpose of the study was explained to the respondents, and they stated whether or not they were willing to participate. Personal interviews were conducted and recorded on a tape recorder for transcription and analysis. Permission was obtained from the clients to use the tape recorder and open-ended research questions were asked.

2. Consent was obtained from the institution to use patients' records and the service was approached for consent to do research in the hospital.

3. Consent was obtained in writing to take photographs of the stillborn babies.

4. Informed consent was obtained, therefore the patient was informed of the research in a way that was clear and understandable to her, that is:
   - objectives of the research;
   - research method;
   - the type of participation expected of the patient;
   - how confidentiality and privacy would be safeguarded.

5.3 Population and sampling

For the purpose of this study, the population group included mothers who delivered stillborn babies in a public hospital which is situated in Pretoria in Gauteng province. A small sample of 10 was chosen as the researcher planned an intense, in-depth study of the respondents' experiences. The selected group of mothers who gave birth either to fresh stillborn and macerated stillborn babies was approached three months after the birth of the babies.

This sample was purposively selected and had to meet the following criteria:

(a) Respondents were selected from the Provincial Hospital in Pretoria in Gauteng Province.
(b) Mothers had to be either married or married.
(c) Mothers ages were unrestricted.
(d) Economic status could range from low, middle and high class.
(e) Respondents had to be able to communicate in one of the following languages: English, Northern Sotho, Tswana or Zulu.
(f) The mothers had to be 28 weeks or more pregnant.

(g) The babies could be fresh stillborn or macerated stillborn.

These mothers were interviewed in the hospital since most of them were staying far and it was not easy to reach them at home.

At the beginning of the interview the interviewer had to establish rapport with the respondents to create a warm and accepting atmosphere. The purpose of the interview as well as any risks were pointed out and permission was asked to use a tape recorder. anonymity at all times was promised.

5.4 Data gathering

Unstructured interviews were used a data-gathering method.

The purpose of the study was explained to the respondents so that they could state whether or not they were prepared to participate. The respondents were approached in the labour ward or post-natal ward after delivery and verbal consent as obtained from the respondents to record their experiences on tape for transcription and analysis. Anonymity at all times was assured.

Appointments were arranged for interviewing the respondents three months after delivery. The interviews were conducted after three months because, immediately after the delivery, the mothers were still shocked and most of them were just crying. These interviews were conducted within the maternity section of the public hospital concerned. The mothers were asked one question, namely: "Describe in as much detail as possible your whole experience around your baby's death". An interview guide was drawn up to provide a framework for the interview. After the mother gave her description in as much detail as possible, the following questions were asked if not covered by the mother.

- How did you feel when you were told for the first time that your baby died in the uterus?

- What was your reaction when you were told to carry back home the dead fetus in your uterus?
- How did you feel when you were told after delivery that your baby was dead?
- Did you get any support at home?
- After delivery, did you get any support from nurses and doctors?
- After delivery, did you get to see and hold the baby?
- Did you want your baby photographed or her/his picture taken?
- Did you wish to name your baby?
- How can nurses and doctors help you through this process?

Follow-up interviews were conducted with all respondents to ascertain if the results obtained by the researcher were indeed what the respondents described.

The following communication skills were used by the researcher: Probing, open-ended phrases, reflection, *et cetera*. Thus the interview progressed without much interruption.

5.5 Data analysis

Transcription was verbatim in the language in which the interviews were conducted. The interviews were transcribed. Both the researcher and an external controller (coder) analysed the transcriptions independently. The researcher and controller then discussed and correlated the content of their individual analyses to reach an objective conclusion. The coder was also able to understand the language used in the transcription.
For analysis of the information in this study, Kerlinger's (1986:479) content analysis

method was used and the following steps were followed:

Data (all the transcribed interviews, field notes, documents and literature) were coded by the researcher. Bracketing (placing preconceived ideas in brackets) and intuiting (focusing on challenges in the nursing profession and ways to address them) were used, while the researcher read through the data for the first time (Burns & Grove, 1989:80-81). Personal experiences were then underlined in the transcribed interviews.

5.6 Trustworthiness

Trustworthiness of the study was established by means of credibility, transferability and dependability.

Credibility was established by prolonged engagement, that is investment of sufficient time to achieve certain purposes in the study, such as being able to deal with personal distortions so that one should be accepted as a member of the group (Lincoln & Guba, 1985:302). The period of prolonged engagement is intended to help the investigator to build trust. In this study the clients were seen several times, that is during ante-natal care, during delivery, after delivery, after six weeks and then after three months. The clients were interviewed and observed as different data collection modes by means of triangulation (Lincoln & Guba, 1985:306).

Transferability. In this study transferability was established by proper dense descriptions, that is providing a possible range of information which will provide a data base that makes transferability judgements possible on the part of potential appliers (Lincoln & Guba, 1985:316).

Dependability. As stated in Lincoln and Guba (1985:317), there is no credibility without dependability.

5.7 Literature control

One of the main reasons for conducting a qualitative study is that the study is exploratory. Not much has been written about the topic or population being studied and the researcher seeked to listen to informants and to build a picture based on their ideas (Creswell, 1994:21). The literature was used to "frame" the problem in the introduction to the study (Creswell, 1994:23). The literature control was carried out after the data had been analysed. It will be presented in the next chapter, together with the results, to show the similarities or differences between the results obtained and the findings in the literature.

6. CONCLUSION

According to hospital records, there is a high percentage of these mothers. Most of them were found to be single, uneducated and unemployed, and therefore they did not have any means of support even at home. Those who were married, expressed a lot of guilt or blamed themselves for what had happened, while some had fears of losing their partners as they thought they had disappointed them. Again, patients were not satisfied with the psychological support given to them during their stay in the hospital. They felt that doctors and nurses were only worried about the delivery of the baby, but showed little concern after delivery of the baby about the emotional trauma experienced by the mothers.

7. SUMMARY

In this chapter the research methodology was described in detail - the results will be described in the next chapter.

CHAPTER 3

ANALYSIS OF DATA AND LITERATURE CONTROL

1. INTRODUCTION

The research results and the results of the literature control will be described simultaneously in this chapter to show the similarities and differences between the two.

2. THE MATERNAL EXPERIENCES

The number in brackets after the experience indicates the number of mothers who responded in the same way.

2.1 Sadness (7)

One mother said: *"I felt sad and angry with myself"*, while another one said: *"I felt... what can I say; empty and sad."*

Pilkington (1993, volume 6) states that one participant wanting to remember and talk about the baby, cried sadly, although she did not want to become emotional as she was trying to unwind and relax.

The majority of women whose fetuses had died in utero spontaneously started labour within two (2) weeks of fetal demise. Carrying the fetus and waiting for spontaneous labour or induction, is sad and difficult for the woman and her entire family. Feelings such as helplessness, disbelief and powerlessness characterise this period. There is often an uncontrollable urge to flee and escape from the unpleasant situation (Merenstein & Gardner, 1993:532).

There is also an overwhelming sadness as is usual after any tragedy. some parents feel

sad for the baby. They say that it seems particularly unfair for a baby to die. It is expected that an elderly person, who has experienced life, will die, but an infant is thought to deserve a chance at life. As one mother expressed her feelings: *"She seemed so innocent. what did she ever do to deserve this? It just doesn't seem fair and it makes me feel sorry for her."* They are sad for themselves as well, sad because of the emptiness and disappointment. Their wish to become parents - to have someone to nurture, to love, to teach, to care for, to play with, someone who would care for them in their old age and inherit the benefits of their work - has not been granted (Borg & Lasker, 1981:20).

2.2 **Confusion** (6)

One mother said: *"I really feel terrible. I feel confused and I feel as if I am going to lose my head."*

Parents who have experienced infant death are in crisis. They are in a state of shock, they become confused and their personalities may change (Pauls, 1991:291).

When a newborn dies in hospital, all evidence of its existence is sometimes removed with amazing rapidness and nothing is left to confirm the reality of its death. *"Everything just happens so fast... My mind kept going around in circles, I didn't really understand."* (Kennell & Klaus, 1982:22).

The sense of anxiety commonly experienced by the bereaved can be acute for parents when their child dies. They know that life is no longer predictable. They feel vulnerable, especially in the early months. They may lose all confidence in themselves as parents, and feel confused in their attitude to their surviving children (Pecia & Metze, 1981:171).

2.3 **Pain** (7)

One mother said: *"The pain and sadness was severe that I should have had her."* another one said: *"You know carrying a child for nine months is difficult and it is so painful just*

to lose him!"

For the parents of the one-in-a-hundred babies who died each year in the latter part of pregnancy or shortly after birth, mourning is made eve more traumatic by the fact that their grief is for a person who never was a social being. they may experience the same sadness, anger, guilt and disruption in their lives as they would at the death of an older child or an adult relative (Rajan, 1992:354).

According to Katz and Sidell (1993:131), early miscarriages can be just as traumatic as late miscarriages. Most parents regard pregnancy in terms of the baby. They may make plans, decide on names, speculate about whether it will be a boy or a girl, and wonder about its development.

If a baby is stillborn then the hopes built up during the months of pregnancy are suddenly gone. It is not only the mother who is affected, fathers also develop an attachment to the baby before it is born and may be present at the birth. some stillbirths occur with foreknowledge of the event and it is known that the baby is already dead. This is very painful for parents, especially if they have to wait for the natural onset of labour to produce a dead baby (Wright, 1992:).

2.4 A feeling of being lost (2)

One mother said:*"It was as if I was lost. I just sat there, said nothing. Maybe everything happened so fast. I was just staring, confused."*

According to Kennell and Klaus, during the mourning process, parents seek consolation, meaning and faith from any source that is available. However, many parents mourn the loss of their child in isolation and solitude. One mother said that when a baby died, she and her husband were the only ones who saw her. *"It's like there is no proof there was a baby. When a baby dies so small, there is no funeral, no masses. It seems like sort of shame that there isn't something more... It felt I was on an island by myself... lost..."*

(Kennell & Klaus, 1982:).

Some couples speak freely while others sit quietly and cry silently. some speak about what occurred during delivery. They talk about the mourning process, the trial of continuing to live the feelings of isolation and depression, an attempt at restitution and the search to find the meaning of life and death (Garfield, 1993:276).

In a study of eighty mothers who had abortions, it was found that most of the mothers complained that they had no-one to whom they could talk about what had happened (Colin, 1994:), and when doctors and nurses are unwilling and frightened to approach someone who is distraught, a parent may interpret their response as a sign that he or she is an outcast, someone terrible to be ignored and isolated (Borg & Lasker, 1981:125). According to Raian (Volume 65) parents of the one-in-a-hundred babies who died each year in the latter part of pregnancy or shortly after birth, stated that mourning is made even more traumatic by the fact that their grief is for a person who never was a social being. they may experience the same sadness, anger, guilt and disruption in their lives as they would at the death of an older child or adult relative.

According to some literature, patterns of reaction to loss of a loved one is that of profound shock, often accompanied by difficulty comprehending the impact of loss. It is a common immediate reaction to bereavement, but shock and disbelief are likely to be more acute when the death is sudden and unexpected (Katz & Sidell, 1993:).

Parents who have experienced infant death are also in crisis. They are in a state of shock and become confused, while their personalities may also change (Pauls, 1991:Volume 16).

The suddenness of fetal demise in labour and birth affects both parents and professionals with feelings of shock, denial and anxiety (Merenstein *et al.*, 1993:).

The grieving process is a natural response. It is beneficial in that it gives the individual time to absorb the gravity of the tragedy by delaying impact (Borg *et al*, 1981:).

2.5 **Emptiness** (4)

One mother said: *"You know, I just felt confused. I could not cry, I really felt empty."*

Another mother said: *"When a child is born dead, there is nothing. The world remembers nothing and the gap in the womb is replaced by an emptiness in your arms. You are not recording a birth or a death."* (Colin, 1990:).

One participant felt completely empty with shattered dreams and lost hopes. The participant reached to God for strength and found acceptance and a desire to pull through one step at a time (Pilkington, 1993:131).

The "empty tragedy" of stillbirth forces the mother to deal with both inner loss of the fetus and outer loss of the expected newborn (Merenstein *et al.*, 1993:).

It is said that the parental emotional responses to the loss of a baby are numerous and may occur in varying order on many different levels of intensity. Intense feelings of loss and emptiness are the primary emotions initially. The loneliness is magnified by the constant reminder of a recent birth, as evidenced by the mother's breasts (Dickason, Silverman & Schulz, 1994:819).

2.6 **Anger** (3)

One participant said: *"I felt sad and angry with myself."*

According to Rajan, Volume 65) parents of the one-in-a-hundred babies who died each year in the latter part of pregnancy or shortly after birth, stated that mourning is made even more traumatic by the fact that their grief is for a person who never was a social being. They may experience the same sadness, anger, guilt and disruption in their lives as they would at the death of an older child or adult relative.

One participant said: *"I needed people to acknowledge what had happened, not to trivialize it. Gestures like giving us the scan picture conveyed that. I was grateful for the people who listened, and stayed, knowing that they could not take away the hurt. I was angered by those who tried to make it better, with false comfort and too quickly offered explanations."* The participants mourned the loss almost instantly and felt angry with the lack of options while blaming no-one (Shuttleworth, 1995:254).

Feelings of anger are strongly related to more severe loss reactions, as well as a higher level of health problems. A finding of some importance is that, although anger is strongly related to dysfunction, it does not follow the pattern of the loss reactions. Systematic differences between the kinship groups and the modes of death are minimal. This indicates that anger after a loss must be seen as an individually defined way of coping with the loss, rather than a 'typical' part of the loss reaction. At this point in time it is one of the most consistent predictors for a high level of loss reactions and to a smaller extent, for health and problems with social functioning (Cleirel, 1991:256).

Feelings of anger are often regarded as protest against the loss. It has been found that it may be directed towards different persons, objects or circumstances which may also be held responsible for the death. Anger may also be experienced as a more general feeling without a concrete aim or switching from one object to another (Cleirel, 1991:256).

Other emotions which are part of grief and which need to be expressed, are anger and anxiety. Much anger may be felt and bitterness voiced against anyone who is seen to be involved with the child's death (Pegg & Metze, 1981:170).

Parents do not limit their blame to themselves; their feelings of guilt and frustration also turn into anger towards others. They blame God, doctor and even the baby for causing them so much heartache (Borg & Lasker, 1981:22).

2.7 **Guilt** (4)

One mother said: "I still feel guilty".

Rajan (1992:1356) states that some parents may find that miscarriage or other pregnancy loss is not regarded by others as a significant emotional experience, but as a non-event where there is guilt and shame with no tangible person to mourn.

In the process of coming to terms with the death of one's child an intense emotion which must be acknowledged is that of guilt. Guilt is a vital component of mourning and where the loved one mourned for is a child, guilt seems to be acute. The parent feels that he is guilty of failing his child. His function as a parent is to nurture and care for his child, and that child is dead (Pegg & Metze, 1981:170).

Guilt is one of the strongest emotions bereaved parents feel. Many parents blame themselves for the tragedy and wonder what they have done to cause it. What some parents feel most guilty about is the ambivalence they had experienced in response to the idea of becoming parents and the memory is one of the sources of the strong feelings of guilt and depression that assail parents whose infants die (Borg & Lanker, 1981:136).

Parents generally felt more guilty about the death than other relationship groups (Cleirel, 1991:253). Anger, guilt and blaming are unavoidable responses tot he tragic loss - the parents seek in every possible way to make sense of what has happened to find reality to hold on to (Borg & Lanker, 1981:137).

2.8 **Fear** (6)

One participant said: *"I still feel sad and I have fear of falling pregnant again."*

For the family who experiences an intrapartum demise, the joyous expectations of labour and birth suddenly change to fear, anxiety and dread that the 'worst' could have possibly

happened to them (Merenstein & Gardner, 1993:532).

The sense of anxiety commonly experienced by the bereaved can be acute for parents. When their child dies, they know that life is no longer predictable. They feel, especially in the early months, very vulnerable. They may lose all confidence in themselves as parents, confused in their attitude to their surviving children. A subsequent pregnancy is a source of great anxiety and the birth of another child is accompanied by strong conflicting emotions - fear for the future of a new child, doubts about her adequacy as a mother, the reawakening of grief for the dead child, especially if the newborn resembles him (Pegg & Metze,,1981:171).

2.9 **Cannot describe** (2)

One participant said: *"I feel eh... you know, it is something I cannot describe. I feel like a failure."*

Parents who experienced this, say that it is something one cannot describe. As one mother said: *"When a child is born dead, there is nothing. The world remembers nothing, and the gap in the womb is replaced by an emptiness in your arms."* (Kennell & Klaus, 1982:136)

2.10 **Feeling low** (2)

One participant said: *"You feel guilty that the loss was caused by you, and eh... this makes one to feel low."*

For both men and women there can be a loss of confidence and self-esteem. After all, they had embarked on one of the most important endeavours of their lives and it ended in tragedy (Borg & Lanker, 1981:11).

Detachment is similar in kind and intensity as anger, guilt, fury and horror. The pain is

different from that of being unable to walk or see. There are feelings of emptiness, loss of self-esteem and feeling low (Colin, 1996:).

2.11 **Denial** (1)

The participant said: *"The belief I had, and which my in-laws had, I had too many problems, the belief my in-laws had. Eish! That the baby is still alive."*

Although it is essential that bereaved parents express their emotions over time and talk about their loss, some degree of denial is a normal part of grieving. It is a form of protection, a way of not having to face up to the pain. *"This didn't happen to me"* is a common feeling (Borg & Lasker, 1981:19).

2.12 **Lost hope** (2)

The participant said: *"felt empty because I knew I was going to give birth to a dead baby, and I lost hope."*

The death of a newborn infant is a tragedy. The parents feel robbed of the future. All the hopes and dreams they had for their child are lost (Thompson in *Neonatal Network*, volume II, No. 6).

One participant said she was feeling empty with shattered dreams and lost hope. The participant reached to God for strength and found an acceptance and desire to pull through one step at a time, while weighing her blessings and finding ways to fill hollow feelings (Pilkington, 1988:134).

Early miscarriage means the loss of all that baby meant to them. It may have deeper significance. It may be the third miscarriage and thus represents the loss of hope of becoming a parent at all (Katz & Sidell, 1993:).

"My emotions, I feel like crying. You know carrying a child for nine months, it's difficult."

Some couples speak freely while others sit quietly and cry silently (Garfield, 1993:178).

Pilkington (1988:135) states that wanting to remember and talk about the baby, the participant cries sadly.

2.13 **Failure** (2)

The participant said: *"I feel eh... you know, it is something I cannot describe, but I feel like a failure."*

According to Pegg and Lasker (1981:148) it is common for parents, especially the mother, to feel that they are a failure as persons and to be afraid of facing people as failures.

If it is a life experience women often do not talk about it. Why not? There are general reasons. A woman may feel ashamed that she has failed somehow. She tells herself she has failed herself, her husband and, most of all, her child (Rank, 1985:18).

CHAPTER FOUR

RESULTS, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

1. INTRODUCTION

It is clear from this study that parents who delivered stillborn babies, experienced a lot of emotional turmoil, that is feelings of helplessness, disbelief, powerlessness, fear and anxiety. It is thus important that the midwife expands her knowledge concerning the parents' experience so that the parents may receive effective guidance and support during this crisis.

2. RESULTS

Due to the small sample size, the findings cannot be generalised. However, the findings may have implications for professionals in clinical practice settings.

3. CONCLUSION

The following are common experiences of mothers, but they differ according to the individual. With all these experiences it is necessary for the care providers to be knowledgeable about the grief process and to be comfortable in sharing another's grief, if equipped to assist the family and its members towards a long-term healthy adjustment rather than a dysfunctional and pathological one.

3.1 Some of the mothers' experiences

The mother felt terrible and confused, and it was very painful because she was looking forward to have the baby. Wright (1992:135) wrote about the pain (see chapter 4:3.4). The mother said that she felt lost. She sat there, said nothing. *"Everything happened so fast. I was just staring... confused."* Kennell & Klaus, 1982:231) wrote about the loss

(Chapter 4:4.1). The mother felt sad and angry with herself. Merenstein and Gardner (1993:532) wrote about the feeling of sadness (Chapter 4:1.12).

4. LIMITATIONS

- Failure of nurses to realise the importance of this study. They failed to call the researcher when the parent came for a check-up.

- Clients did not realise the importance of coming back for a check-up.

- Some clients had some reservations when talking to the researcher as they feared that they would be harassed by the staff.

- An obvious limitation of this study was the small population sample which precluded any generalisation of data, thus necessitating further research.

- Difficulty in getting clients to express emotions openly, which is perhaps due to culture.

5. RECOMMENDATIONS

5.1 Staff

This study showed an obvious need for equipping care providers with knowledge about the grief process and how to assist mothers and their families during this period. It is also necessary for care providers to receive support in dealing with their own reactions and therefore they will be able to support families who experience loss.

6. GUIDELINES FOR MANAGING THESE PATIENTS

6.1 Environment

To facilitate support to parents in their grief, it is important to create an environment that is supportive, promotive and conducive to the expression of feelings. This type of environment is non-judgemental and should be characterised by an attitude of openness and freedom. People feel safe enough to ventilate a full range of feelings such as sadness, anger, despair, without fear of condemnation or rejection.

6.2 Seeing and touching

It showed in this study that as a care provider one must not make decisions for the parents such as they cannot see the baby because he is badly deformed or badly macerated and the baby is hidden and whisked away immediately. As these women are often left with fears and fantasies because seeing and touching and holding the baby promote completion of the attachment cycle, and this confirms the reality of the stillbirth because it is easier to grieve the reality of a situation than a mystical and dreamlike fantasy. Contact with the stillborn enables parents to grieve the baby's reality rather than their most frightening fantasies about the infant, and if parents are not ready at that moment perhaps hospitals should provide more time before moving the baby.

6.3 Information

It should be a major role of the care providers to provide and clarify facts and information relevant to the perinatal loss situation. Sketchy or no information only serves to contribute to parental denial of the reality or to their fantasies of the cause.

6.4 Acknowledgement of the loss

Not talking about the loss is a powerful way of denying that it ever existed. The inability

of professionals to acknowledge that the loss has occurred and that the family is in pain maintains denial and repression. Not discussing the loss prevents parents from learning the facts and facing reality. Professional avoidance and unwillingness to talk with parents after a loss, communicates other powerful messages that impede grief work. Distraction is another way of denying the loss or its significance. Professionals or family members try to distract parents from the feelings and emotions of acute grief by engaging in light, social conversation or by keeping them busy with work or recreation. In this study there were different opinions. Some mothers wanted to be mixed with mothers who had babies and some wanted to be in private rooms. Seeing other mothers looking after their babies caused them to feel more pain.

6.5 Supportive, trusting relationships

For the mourning mother, the relationships established with helpful professionals are more important than the physical care given. Support can be as simple as remaining with the mother. Being there indicates not merely physical presence, but an emotional availability and willingness to share their experience of loss. If one does not know what to say, usually words are initially unnecessary, so silent "thereness" may convey the message better.

Involvement of clergy and religious organisations is often comforting and supportive to the family.

Formation of parent support groups afford mothers an opportunity to discuss their feelings with others who have been through similar traumas. Knowing how others who have experienced perinatal loss have felt and dealt with similar situations is emotionally comforting and stabilising to parents experiencing their own loss.

6.6 Encourage expression of emotions

Because grief is an emotional reaction to loss, expression of these emotions is necessary

for grief work to begin and proceed. Valid parental reactions as appropriate reassures them that they are not crazy, that is crying or talking about the loss. Professionals should also share grief with clients, for example crying with them, but it is not a sign of unprofessionalism and they feel a special bond of love and care.

6.7 Open visits and plans for the dead body

In this study there was a need for open visitation to the mother by her husband, grandparents and friends to decrease the loneliness and isolation of death as the client needs support from them. As one client said: *"I wish our hospitals could change their practice and allow open visitation to mothers who lost their babies because you are only allowed during visiting hours and thereafter you are told that time has run out."* Parents need to be given the opportunity to make final plans for the deceased infant, as this will help them to face death and facilitate the grieving process. If a funeral has been chosen this burial leaves a specific memory that this baby as a part of them.

6.8 Autopsy

This is necessary in the search for a cause, but the doctor or nurses should approach the family for permission for an autopsy and this must be done with the utmost tact and respect for the family's feelings. Parents also need to deal with the reality of death before they are ready to think about the autopsy. The professional who receives permission for an autopsy is then obliged to discuss all the feelings with the parents.

6.9 Momento's

These are necessary in order to remember the child and in this study the momento which was favoured was a photograph which mothers valued a lot. It is important, however, to dress the babies properly so as to obtain a beautiful picture and if some mothers would like to dress them in clothes that they have bought, that should be respected.

6.10 Long-term follow-up care

Grieving parents need follow-up care and contact with professionals. These function as catharsis for parents as well as an opportunity for assessment, counselling and possibly referral.

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ADDENDUM 1: TRANSCRIPTION OF A INTERVIEW

IDENTIFICATION DATA

Age: 27

Career: Nurse

Language: English

Nationality: Tswana

Researcher: How are you feeling today?

Respondent: Okay, I guess.

Researcher: Why do you say "I guess"?

Respondent: Because sometimes it is difficult to cope.

Researcher: Oh! But may we start to talk about before delivery of your baby, if it is okay with you.

Respondent: It is fine.

Researcher: When did you know that your baby had died?

Researcher: And then what happened after that?

Respondent: It is because on the 6th I experienced little contractions. The movements were funny, then I went to the doctor for a sonar.

Researcher: Oh!

Respondent: when I arrived there, he was the one who told me that he cannot see the fetal heart.

Researcher: And then?

Respondent: I could not take it and I was alone. and I told my husband to go to work because I did not know that I am going to experience such a thing.

Researcher: Hm!

Respondent: You know usually when I go to see the doctor I go with him, but because on that day it was not a planned thing, I usually wait for him to come back from work and go together to the doctor.

Researcher: Oh!

Respondent: On that day he asked if I was not going with him.

Researcher: Hm!

Respondent: And I said I would take a taxi.

Researcher: Hm. (Nodding her head.)

Respondent: Then when I reached there I found that I am alone, and I don't have anybody to support me.

Researcher: Hm! It must have been hard for you!

Respondent: Otherwise the doctor tried to reassure me the way he could.

Researcher: Hm!

Respondent: Otherwise I could not take it but after a few hours, about two hours, hei! There was nothing I could do, and I saw the sonar myself. I had to accept it. Then the doctor asked somebody to escort me to the hospital for further treatment.

Researcher: Hm!!

Respondent: And when I reached the hospital sonar was done again, and it was confirmed to be intra-uterine death, and because I already knew, I just took it.

Researcher: Anything more?

Respondent: then the doctor told me that I should wait for pains to start. They took the bloods. Then they gave me an appointment of the 12th June 1996.

Researcher: Hm!

Respondent: I came back on the 12th and I was still alright and they gave me another appointment the 18th June.

Researcher: Please go on.

Respondent: So I felt alright. At about 11 a.m. I started to experience a slight pain next to the bladder and when I went to the doctor, he did vaginal examination and he told me labour had started.

Researcher: Oh!

Respondent: When I reached home I had a tough time because my in-laws did not understand and accept it.

Researcher: Hm! Why?

Respondent: Even my parents did not accept it. they wondered why and even myself, I did not know what happened, because even during ante-natal clinic everything was just alright. I don't really understand what happened.

Researcher: Hm! I want to ask you a question if it is alright with you?

Respondent: Yes, it is okay.

Researcher: How did you feel when you were told that the baby had died, but you were expected to carry that baby home and wait for pains?

Respondent: Eish! The problem was just that time when they told me. But I have knowledge as well. And that is the support I give to other mothers.

Researcher: Hm! Hm! You just...

Respondent: That is I just accepted it as it was. And the belief I had, and which my in-laws had. I had too many problems. The belief my in-laws had, eish! That the baby is still alive. Is the belief I had.

Researcher: That belief is the one which gave you strength.

Respondent: Yes!

Researcher: so before delivery, how did you feel?

Respondent: I* had fear that I did not want to sleep in the hospital, and I was crying.

Researcher: Why did you have the fear?

Respondent: I don't know.

Researcher: And how did the nurses treat you in the labour ward?

Respondent: One of them, when I was crying, she just said why is she crying? Then the other one said it is an IUFD and she said can she really cry about it?

Researcher: Hm! Hm! But it went on alright?

Respondent: Yes. I delivered alright and by then I did not have any fear.

Researcher: Hm!

Respondent: It was just after delivery in the ward when I started to think and feel very sad.

Researcher: Why?

Respondent: I think when I started to see others preparing their kids for baths and for immunization, I started to feel this pain.

Researcher: Hm! anything more?

Respondent: Another thing is maybe there should be space for us (Those who have lost their children).

Researcher: Hm! Hm!

Respondent: Because it is really not nice to stay with mothers who have kids in the same room. Maybe a side ward can be chosen because we are not many at the same time.

Researcher: Hm! And how do you feel now?

Respondent: I am okay although I feel empty and wanting to forget. It is not easy.

Researcher: Hm!!

Respondent: And what makes it worse is my husband, he does not accept this even now, and you remember he is the one who said he does not want the picture of the baby.

Researcher: Yes!

Respondent: But now he is saying if only he had her picture, it would maybe be better, but it is too late.

Researcher: Maybe you can bring him along to our next appointment.

Respondent: Yes! Maybe it must help, I will talk to him about it.

Researcher: Do you have anything else?

Respondent: No.

Researcher: I will see you in our next appointment, but if there is anything else please don't hesitate to call or come.

Respondent: Thank you.