

CONRY, JENNIFER ROBYN

**MOTHERS' EXPERIENCES OF ACCESSING
SERVICES FOLLOWING THE DEATH
OF A BABY THROUGH STILLBIRTH OR
NEONATAL DEATH**

MSD UP 2005

**MOTHERS' EXPERIENCES OF ACCESSING
SERVICES FOLLOWING THE DEATH
OF A BABY THROUGH STILLBIRTH OR
NEONATAL DEATH**

by

JENNIFER ROBYN CONRY

Completed as a requirement for the degree

MSD

In

SOCIAL WORK (PLAY THERAPY)

In the

**DEPARTMENT OF SOCIAL WORK AND CRIMINOLOGY
UNIVERSITY OF PRETORIA**

SUPERVISED BY DR. C.E. PRINSLOO

PRETORIA

NOVEMBER 2005



This work is dedicated to Gemma-Leigh Conry, Matthew De Wet and all of the babies who were taken too soon. We will never forget.

TO GEMMA-LEIGH

When the early glow of dawn brushes across the fields
And lights the waiting dew, I will see your smile.

When the misty rain trickles softly down my face
And mingles with my tears, I will feel your touch.

In the evening silence when the birds have sung their vespers
And the feathered chorus fades, I will hear your voice.

When the night wind softly dancing, swirls through the leaves
And whispers through my window, I will feel your breath.

In the loneliness of midnight, in the comfort of my dreams
I will wrap my love around you, and feel you there beside me.

Your memory will live forever in the oceans of my soul,
Sometimes hidden deeply in the currents of my mind,
Sometimes drifting brightly in the gently swelling waves,
But always there, my Gemma-Leigh, my precious babe.

Grandpa Ruddock

ACKNOWLEDGEMENTS

My sincere gratitude and appreciation are extended to the following people: -

- Dr C.E. Prinsloo whose constant guidance, kindness, understanding and support made the writing of this study possible.
- My family - Sean and Ashleigh, my deepest thanks, for their love, concern, understanding and support.
- Heather whose support, guidance and superior editing ability were all invaluable to the completion of this study.
- My mother, father and Peter. Their support motivation and consistent belief in me – even when I doubted myself, made finishing this study possible.
- Leial De Wet, my very dear friend, without whom I would most certainly not have managed this study. Her invaluable guidance and constant support will not be forgotten.
- All of the mothers who participated in this study. Their bravery, courage and willingness to open up their hearts to me, despite the sensitivity of the material under examination, have made this study possible.
- The Compassionate Friends, particularly Sharon and Shannon, and Baby Angels, for their referrals.

ABSTRACT

**MOTHERS' EXPERIENCES OF ACCESSING SERVICES FOLLOWING THE DEATH
OF A BABY THROUGH STILLBIRTH OR NEONATAL DEATH**

by

JENNIFER ROBYN CONRY

**SUPERVISOR
DR C.E. PRINSLOO**

**DEPARTMENT OF SOCIAL WORK AND CRIMINOLOGY
MSD Play Therapy**

This research study examined mothers' experiences of gaining access to services following the death of a baby through stillbirth or a neonatal death. An exploratory research design was used to conduct applied research into the said topic through the use of a semi-structured interview schedule. The research sample consisted of fifteen mothers, all having lost a baby within the last five years to stillbirth or neonatal death. These mothers were met in propinquity and the interview schedule was conducted with them. The findings were analysed and presented both quantitatively, by means of percentages and graphs, and qualitatively, by means of themes and sub themes.

The research was particularly relevant in that it is estimated that between three and five percent of all pregnant mothers in South Africa will lose their babies to a stillbirth or neonatal death every year. For this reason it is essential that adequate and quality services be offered to these mothers to prevent complications in their grief. The study conducted by the researcher focused on the accessibility of quality hospital, religious, formal and social support services to bereaved mothers following the death of a baby through stillbirth and neonatal death.

The researcher then discussed, in detail, the literature informing the study. The discussion of the literature, as outlined by the researcher, was set in a logical progression – beginning with a discussion on grief, the grief process, dysfunctional grief and models of grief, then moving onto a discussion of the grief following the loss of a baby and maternal grief predictors. The theory ended with a discussion on the services, particularly hospital services, religious services and formal services, available to bereaved mothers.

The researcher then presented the findings of the study, drawing comparisons between the literature and the empirical findings where relevant. Conclusions and recommendations were then formulated and presented. The researcher firmly believes that the research conducted holds the potential of providing significant practical suggestions to the functioning of the services that are available to bereaved mothers.

LIST OF KEY TERMS

- 1. GRIEF**
- 2. STILLBIRTH**
- 3. NEONATAL DEATH**
- 4. SERVICES**
- 5. ACCESSING SERVICES**
- 6. SUPPORT**
- 7. HOSPITAL SERVICES**
- 8. RELIGIOUS SERVICES**
- 9. FORMAL SERVICES**
- 10. SUPPORT GROUPS**

OPSOMMING

**MOEDERS SE ERVARING VAN TOEGANG TOT STEUNDIENSTE NA DIE DOOD
VAN 'N STILGEBORE OF PASGEBORE BABA**

deur

JENNIFER ROBYN CONRY

**STUDIELEIER
DR C. E. PRINSLOO**

**DEPARTEMENT MAATSKAPLIKE WERK EN KRIMINOLOGIE
MSD Speltherapie**

Hierdie studie ondersoek die ervarings van moeders wanneer hulle poog om toegang te verkry tot steundienste na die dood van 'n stilgebore of pasgebore baba. 'n Verkennende navorsingsontwerp is gebruik om toegepaste navorsing uit te voer ten opsigte van die genoemde onderwerp deur middel van semigestruktureerde onderhoudskedules. Die steekproef het bestaan uit vyftien moeders wat in die afgelope vyf jaar geboorte gegee het aan 'n stilgebore baba of wie se pasgebore baba gesterf het. Hierdie moeders is tuis ontmoet en die onderhoudskedule is met hulle gedoen. Die resultate is ontleed en beide kwantitatief deur middel van persentasies en grafieke en kwalitatief deur middel van temas en subtemas voorgestel.

Die navorsing is toepaslik omdat tussen drie en vyf persent van verwagte moeders in Suid Afrika volgens skatting elke jaar hulle babas sal verloor, óf deur geboorte te gee aan 'n stilgebore baba, óf deur die sterfte van hulle pasgebore babas. Dit is noodsaaklik dat voldoende dienste van hoë gehalte aan hierdie moeders aangebied word om komplikasies tydens die rouproses te voorkom. Die ondersoek is spesifiek toegespits op die toeganklikheid van steundienste van hoë gehalte aangebied deur die hospitaal, godsdienstige organisasies, ander formele steundienste en maatskaplike steundienste vir bedroefde moeders na die dood van 'n stilgebore of pasgebore baba.

Die navorser het die literatuur wat op die onderwerp betrekking het, breedvoerig bespreek. Die bespreking van die literatuur vertoon 'n logiese progressie. Eerstens is aandag gegee aan die verskynsel van rou, die rouproses, disfunksionele rou en roumodelle. Dit is gevolg deur 'n bespreking van rou na die sterfte van 'n baba en voorspellers vir moederlike rou. Die teorie is afgesluit met 'n bespreking van die dienste,

veral hospitaal-, godsdienstige- en ander formele dienste wat aan die bedroefde moeders beskikbaar is.

Daarna het die navorser die resultate van die empiriese navorsing aangebied, waarin toepaslike vergelykings tussen die literatuur en die empiriese resultate getref is. Gevolgtrekkings en aanbevelings is toe geformuleer. Die navorser is oortuig dat die navorsing wat uitgevoer is, die potensiaal het om betekenisvolle en praktiese voorstelle te verskaf met betrekking tot die funksionering van die hulpdienste wat aan bedroefde moeders beskikbaar is.

LYS VAN SLEUTELWOORDE

- 1) **ROU.**
- 2) **GEBOORTE VAN `N STILGEBORE BABA.**
- 3) **STERFTE VAN `N PASGEBORE BABA.**
- 4) **DIENSTE.**
- 5) **TOEGANG TOT STEUNDIENSTE.**
- 6) **HULP.**
- 7) **HOSPITAALDIENSTE.**
- 8) **GODSDIENSTIGE DIENSTE.**
- 9) **FORMELE DIENSTE.**
- 10) **STEUNGROEPE.**

TABLE OF CONTENTS

| | |
|-------------------------------------------------------------------------------------------------------------|-----------|
| CHAPTER 1 | 1 |
| INTRODUCTION TO THE RESEARCH | 1 |
| 1. INTRODUCTION | 1 |
| 2. MOTIVATION FOR THE CHOICE OF THE SUBJECT | 2 |
| 3. PROBLEM FORMULATION | 4 |
| 4. AIMS AND OBJECTIVES OF THE STUDY | 7 |
| 5. RESEARCH QUESTION FOR THE STUDY | 7 |
| 6. RESEARCH APPROACH | 8 |
| 7. TYPE OF RESEARCH | 10 |
| 8. RESEARCH DESIGN | 11 |
| 9. RESEARCH PROCEDURE AND STRATEGY | 11 |
| 10. PILOT STUDY | 13 |
| 10.1 Literature Study | 13 |
| 10.2 Consultation with Experts | 14 |
| 10.3 Feasibility of the Study | 15 |
| 10.4 Pilot Test of Measuring Instrument | 16 |
| 11. DESCRIPTION OF THE RESEARCH POPULATION, DELIMITATION OF THE SAMPLE AND SAMPLING METHOD | 16 |
| 12. ETHICAL ISSUES | 17 |
| 13. DEFINITIONS OF KEY CONCEPTS | 19 |
| 14. LIMITATIONS OF THE STUDY | 20 |
| 15. CONCLUSION | 21 |
| | |
| CHAPTER 2 | 22 |
| THE LOSS OF A BABY AND THE SERVICES AVAILABLE TO A MOTHER FOLLOWING THE LOSS OF A BABY | 22 |
| 2.1 INTRODUCTION | 22 |
| 2.2 GRIEF, MOURNING AND BEREAVEMENT | 22 |
| 2.3 THE GRIEF PROCESS | 24 |
| 2.3.1 Shock, denial and isolation | 26 |
| 2.3.2 Anger | 27 |
| 2.3.3 Bargaining | 28 |

| | | |
|------------------------------|--------------------------------------------------------------------|-----------|
| 2.3.4 | Depression..... | 29 |
| 2.3.5 | Acceptance | 29 |
| 2.4 | DYSFUNCTIONAL GRIEF RESPONSES..... | 30 |
| 2.4.1 | Fixated grief..... | 31 |
| 2.4.2 | Denial..... | 31 |
| 2.4.3 | Reversibility of the loss..... | 32 |
| 2.4.4 | Mementos..... | 32 |
| 2.4.5 | Identification / assuming the characteristics of the deceased..... | 33 |
| 2.4.6 | Mistaking others..... | 33 |
| 2.4.7 | Emotions in disguise..... | 34 |
| 2.4.8 | Anniversary reactions..... | 34 |
| 2.4.9 | Replicated loss..... | 34 |
| 2.4.10 | Disenfranchised grief..... | 34 |
| 2.5 | MODELS OF GRIEF | 35 |
| 2.6 | GRIEVING A BABY | 41 |
| 2.7 | MATERNAL GRIEF PREDICTORS | 42 |
| 2.7.1 | Support..... | 43 |
| 2.7.1.1 | Familial support | 43 |
| 2.7.1.2 | Social support..... | 44 |
| 2.7.2 | Relationship satisfaction | 45 |
| 2.7.3 | Ways of coping..... | 47 |
| 2.8. | SERVICES AVAILABLE FOLLOWING THE DEATH OF A BABY | 48 |
| 2.8.1 | Hospital services..... | 48 |
| 2.8.2 | Religious services..... | 50 |
| 2.8.3 | Formal services..... | 52 |
| 2.9. | CONCLUSION | 54 |
| CHAPTER 3 | | 55 |
| EMPIRICAL STUDY | | 55 |
| 3.1 | INTRODUCTION | 55 |
| 3.2 | FINDINGS OF THE STUDY | 56 |
| 3.2.1 | Section A: The demographic data of the study..... | 56 |
| 3.2.2 | Section B: Support..... | 58 |
| 3.2.3 | Section C: Hospital services..... | 62 |

| | | |
|--------------------------------------------------|-----------------------------------------------|-----|
| 3.2.4 | Section D: Religious services..... | 72 |
| 3.2.5 | Section E: Formal services..... | 79 |
| 3.2.5.1 | Hospital counselling | 79 |
| 3.2.5.2 | External individual counselling..... | 80 |
| 3.2.5.3 | Support Groups..... | 84 |
| 3.2.6 | Section F: General..... | 88 |
| 3.3 | SUMMARY | 91 |
| | | |
| CHAPTER 4 | | 93 |
| SUMMARIES, CONCLUSIONS AND RECOMMENDATIONS | | 93 |
| 4.1 | INTRODUCTION | 93 |
| 4.2 | SUMMARY, CONCLUSIONS AND RECOMMENDATIONS..... | 93 |
| 4.2.1 | Chapter 1..... | 93 |
| 4.2.1.1 | Summary | 93 |
| 4.2.1.2 | Conclusions | 95 |
| 4.2.1.3 | Recommendations | 97 |
| 4.2.2 | CHAPTER 2 | 98 |
| 4.2.2.1 | Summary | 98 |
| 4.2.2.2 | Conclusions | 100 |
| 4.2.2.3 | Recommendations | 100 |
| 4.2.3 | Chapter 3..... | 101 |
| 4.2.3.1 | Summary | 101 |
| 4.2.3.2 | Conclusions | 106 |
| 4.2.3.3 | Recommendations | 109 |
| 4.4 | SUMMARY | 111 |
| REFERENCE LIST | | 112 |
| APPENDICES | | 122 |

LIST OF TABLES

| | |
|----------------------------------------------------------------------------------------------------------------|-----------|
| Table 1: Support offered by religious institutions that mothers found helpful (n=15)..... | 76 |
| Table 2: Ways in which mothers felt religious institutions could be more supportive of them (n=15)..... | 78 |

LIST OF FIGURES

| | | |
|------------------|-----------------------------------------------------------------------------------------------------------------------------------------|-----------|
| Figure 1: | Dianne Arcangel’s model of grief, transcendence and fixation..... | 36 |
| Figure 2: | Raymond Moody’s model of grief and transcendence | 38 |
| Figure 3: | Dual-process model of coping | 40 |
| Figure 4: | Ages of the mothers interviewed | 56 |
| Figure 5: | Ways in which mothers feel hospitals could improve their services to bereaved parents | 70 |
| Figure 6: | The length of time that the mothers received counselling | 81 |
| Figure 7: | Mothers’ suggestions on how support groups could better their services | 87 |
| Figure 8: | Mothers’ ratings (out of ten) of the support that they received following the death of their babies..... | 88 |
| Figure 9: | Mothers’ ratings (out of ten) of the ease with which they were able to access services following the death of their babies | 89 |

CHAPTER 1

INTRODUCTION TO THE RESEARCH

1. INTRODUCTION

'Death, no matter how it comes, whether expected or completely out of the blue, is an outrage. It can shake us to our very core and make us question the purpose of life itself.

Why were we born, if only to die?

Why love if it only results in pain?'

(Alexander, 1993: 9).

This chapter is designed to provide the reader with information surrounding the topic of social work research, *'Mothers' experiences of accessing services following the death of a baby through stillbirth or neonatal death'*, and the manner in which the researcher conducted the study. It will explain to the reader the researcher's motivation for the choice of the topic of research and provide the reader with information concerning her research methodology. According to Hornby (2000: 1075 – 1076) a service may be defined as "a system that provides services that the public needs, organised by the government or a private company" or the ability of one to "...be useful or helpful". Services, in the context of this study will refer specifically to those that should be useful and helpful to the mother's emotional needs following the death of the baby and will not include her experiences of gaining access to physical and medical services for her child. Specifically, the focus is on her experience of the services and support offered by the hospital, her community, her religious institution and the formal sector.

The loss of a child who has been deeply loved and cared for is especially painful and difficult and this is particularly relevant with the loss of a baby. According to Kohner and Thomas (1995: 1) "...grieving is never easy, but grieving for a baby can be especially hard". The death of a baby is particularly shocking and unexpected for parents. It appears to be out of the 'natural order' and parents are, generally, completely unprepared for such an eventuality. For many, this is their first encounter with grief and they are left feeling totally overwhelmed by the depth of the emotions that they are experiencing. Parents describe feelings of numbness, emptiness, fear, desperation, frustration and bewilderment. Some are stunned while others cry continuously. Although

parents will all experience grief differently, all will have to do the incredibly difficult grief work (Leon, 1990: 32 – 35, Thomas & Williams, 1995 and Chumbley, 1997: 107 – 109).

Despite this devastation, however, the significance of such a grief is often not accounted for and many mothers (and fathers) feel incredibly isolated following the death of a baby. According to Kohner and Henley (1997: 9) "...the death of a baby, whether at birth or in the weeks or months immediately afterwards, is no less a death than any other. It is no less significant, no less important, no less heartbreaking than the death of an older child or an adult. It is certainly different, but it is not a lesser event. The loss of a baby is the loss of a person". The lack of understanding given by the community for the significance of the death has often resulted in the services and support systems for such mothers being of a poor standard. Consequently, bereaved parents have often struggled alone with a grief, which others have neither understood nor acknowledged. They experience intense feelings of isolation and this, coupled with their normal grief responses, makes such a loss particularly difficult to cope with (Rank, 1985: 17 – 19, Kohner & Thomas, 1995: 1, Thomas & Williams, 1995 and Ryan, 2000: 3).

Parents need the opportunity to be able to talk freely and honestly with others without feeling angry, guilty or ashamed about their feelings (Ryan, 2000: 3). Emotional support of the mother is necessary in order for her to be able to adequately cope with the grief process. The researcher, therefore, chose to study the experiences of mothers who have lost a baby through stillbirth and neonatal death in gaining such support services. This allowed her to gain an insight into those services that are available and the ease with which the mothers were able to access them.

2. MOTIVATION FOR THE CHOICE OF THE SUBJECT

According to Guy, Edgley, Arafat and Allen (1987: 36-39), a researcher's choice of a researchable topic is informed by a number of different factors. Firstly, they believe that the researcher chooses his or her topic of research based on his or her personal interests. Such interest is gained through personal experience and/or reading and intellectual pursuits. Fouché (2002b: 100) prefers to call such an interest in a researchable topic an "informed inquisitiveness". She believes that research ideas do not exist in a vacuum and are most frequently prompted by ideas that have been initiated by others - thus, informed ideas (Fouché & De Vos, 1998b: 55 and Elmes, Kantowitz & Roediger, 1999: 11 - 13). The researcher's motivation for the choice of her topic of

research is informed by a personal interest. Having lost her baby daughter to meningitis at the age of three weeks, she is especially sensitive to the experiences of other mothers who have lost a baby. While her experience of the support services following the death of her daughter has been, for the most part, fairly positive, many of the other mothers with whom she has spoken, find themselves feeling totally isolated and alone in their grief. The researcher was thus interested in exploring their experiences in gaining access to adequate services.

Secondly, social concerns are highlighted as a motivation for the choice of a research topic, as the researcher wishes to address concerns that he or she has about the society within which he or she resides (Guy, Edgley, Arafat & Allen, 1987: 36-39). The researcher's particular social concern was the lack of adequate emotional resources that appear to be available to mothers who are experiencing the loss of a baby. The research itself was set to inform her as to whether or not there are adequate services and how accessible they are to such mothers.

In an interview, Ms Van Niekerk (2003) of Statistics South Africa informed the researcher that their organisation does not record the South African statistics of stillbirth. It has also not recorded the neonatal death statistics of South Africa since 1996, when 495 826 births were recorded, of which 10 789 babies passed away within the first week of life (2.176%). The World Fact Book of the United States Central Intelligence Agency (Author Unknown, 2002: 1), however, recorded the 2002-estimated infant mortality rate (children who passed away within their first year of life) for South Africa as 61.78 babies per 1 000 live births. Thus, in 2002, 6.178% of South African children passed away within their first year of life. The Perinatal Education Programme (Author Unknown, 2003: 2) estimates that the Perinatal death rate (stillbirth and death within the first seven days of life) for developing countries, like South Africa, in 2002 was about 30 deaths per 1 000 deliveries. Although none of these statistics are exactly accurate in describing the phenomenon that the researcher has studied, one may assume from their findings that between 3% and 5% of babies in South Africa are stillborn or die neonatally every year. This statistic means that the same number of mothers will lose a child to such a death.

Thirdly, according to Fouché (2002b: 96 – 99), a researcher should also choose his or her topic of research based on his or her day-to-day activities and the impact that such research would have on his or her interactions within the work environment. Research material should be relevant and should provide basic knowledge concerning a theme

that the researcher deals with in his or her practice. (Compare Fouché & De Vos, 1998b: 51 – 53.) The researcher, along with a colleague who also lost a baby, has started a support network for such mothers who have lost a baby. The results of this study, therefore, will be especially informative in guiding the network's practical inclinations. The study will therefore be directly beneficial to its respondents, and other such mothers.

3. PROBLEM FORMULATION

According to Collins (1990: 253) the problem area in research may be seen as that which the researcher wishes to study. Through observation and a study of theories and literature, the researcher is able to formulate the problem that he or she wishes to investigate. The researcher considers the individuals to be studied, their characteristics, orientations and activities and the social artefacts involved (Van der Merwe, 1996: 285 – 286, Creswell, 1998: 94 –95, Fouché & De Vos, 1998a: 64 – 66 and Fouché 2002a: 104 – 106). The researcher has found that the access to adequate support services available to mothers who have lost a baby is poor. A number of services exist in which improvement may be necessary.

Firstly, it is the researcher's experience, in her discussions with mothers that have lost babies that they received little support from the hospitals in which their babies passed away. Although this is hospital specific, it appears that hospital support programmes are generally not sufficient and in place. As most babies lose their lives within a hospital setting, this is of particular relevance. According to Kohner and Henley (1997: 47) most parents have very vivid memories of their baby's death and all the events surrounding it. The empathy and care that the parents received in the hospital will generally dictate the colour of the memories and so is vitally important (Ryan, 2000: 159 – 165). The researcher experienced extremely supportive care at the hospital in which her baby died and, as a result, her memories of the experience, although still painful, are not highlighted with feelings of unease and regret. Many parents, however, were not as fortunate. Some live in constant regret that they were not afforded the opportunity to see their baby, hold their baby and say good-bye to their baby. Thus, according to Kohner and Henley (1997: 47 – 49) hospitals need to be informed and trained in how to adequately support these mothers.

Secondly, according to Tatelbaum (1980: 80 – 85) it is normal for a person's religious beliefs to be shaken by the death of somebody close. People question the fundamentals of

their religious beliefs and form a perspective that integrates their experience. Many people struggle with this process, however, as it is not accepted by their religious institutions. This further alienates them and makes the grief process all the more difficult. Biebel (1997: 29), an American minister, describes how his faith had been sorely tested following the death of his three-year-old son. In his honest and sincere description of his grief, he is able to give a unique encounter of what it is like to be a minister who is confronted with a life-altering event, and how this informed his future ministry. The parents' experience of the religious support that they receive appears to be dictated by the tolerance that their religious institution has for their changing emotions and for the depth of their mourning, despite the religious beliefs of the nature of the hereafter. As Lewis (1966: 24) put it:

If a mother is mourning not for what she has lost, but for what her dead child has lost, it is a comfort to believe that the child has not lost the end for which it was created. And it is a comfort to believe that she herself, in losing her chief or only natural happiness, has not lost a greater thing that she may still hope to glorify God and enjoy Him forever. A comfort to the God-aimed eternal spirit within her. But not to her motherhood. The specifically maternal happiness must be written off. Never, in any place or time, will she have her son on her knees, or bath him, or tell him a story, or plan for his future, or see her grandchild.

Religious institutions need to be more aware of the needs of mothers following the death of a child and adapt their services so as not to alienate them, but rather support them.

Thirdly, the social support that the mother receives following the death of a baby is far from adequate. This perceived inadequacy of social support ties into the community at large being unable to acknowledge the significance of a death of a baby. Such a death, although an extremely devastating experience for all involved, is seldom understood by those who have not experienced it. Parents are often left feeling extremely isolated and the lack of acknowledgement of their grief often prolongs the grief process, leaving many lingering, unresolved issues. Isolation, according to Kübler-Ross (1997: 51 – 63) is a 'normal' response to grief. 'Nobody understands,' is a feeling that loved ones often express. With the death of a baby, however, this is incredibly acute as, in reality, most people do not understand. Comments like 'you can always have another one' and 'it would have been worse if he or she was older' leave parents feeling even more intensely

isolated. The lack of such acknowledgement and empathy has resulted in few resources being available to many mothers who have had this devastating experience (Rank, 1985: 113 – 122). The community needs to be more informed about the devastation of parents who have lost a baby and more services need to be put in place to help them to cope with the grief process.

Fourthly, and tied with the lack of understanding from the community at large, mothers often find it difficult to access support from their familial resources. According to Kohner and Henley (1997: 74 – 85) the parents' experiences of their familial resources are largely dependant on the nature of her family and are very individual and unique to each situation. Some families tend to be very supportive while others are unable to understand the depth of the parents' grief, encouraging them to simply move on with their lives. The researcher is of the opinion that the nature of this support is also largely dependant on the nature of the relationship that the mother had with her family prior to the death of the baby. A strong relationship tends to result in a more supportive and understanding response while a weaker relationship, results in a more negative response. As with the community at large, families need to be more informed of ways in which they may adequately support bereaved mothers.

Finally, in the formal sector, many mothers have found that they were unaware of the services that were available to them that could offer them support. Such services include support groups and networks, and individual counselling. Most mothers find it incredibly beneficial to speak with other mothers who have also lost a baby and so truly understand their experiences. This kind of support allows mothers to normalise their feelings and work through their grief in a supportive and caring environment (Kohner & Thomas, 1995: 32 – 36 and Thomas & Williams, 1995). The researcher fully agrees as she found that the cathartic experience of speaking with other mothers in a similar situation, allowed her to cope better with the grieving process. Recently, more awareness for the need of mothers to share their experiences in the formal sector has resulted in the formation of support groups to specifically cater for their needs. Mothers, however, need to be made aware of the existence of these services and the benefits that they would gain through using them.

Accessing services that offer support and acceptance is incredibly beneficial in easing mothers who have lost a baby through the grief process. Unfortunately, many such mothers seldom feel these benefits as the services are inadequate and are not easily

accessible. Awareness of the needs of these mothers and the necessity for helpful, accessible services to cater for them needs to be raised as such a phenomenon affects between 3% and 5% of South African mothers.

4. AIMS AND OBJECTIVES OF THE STUDY

According to Collins (1990: 252), it is vital when conducting research to provide planned and measurable aims and objectives for the study in order for its effectiveness in practice to be evaluated. Fouché (2002a: 107) defines a goal or objective as "...the end toward which effort or ambition is directed: aim or purpose" (De Vos, Schurink & Strydom, 1998: 6). The objective is a speedily obtained, concrete and measurable term while the aim encompasses a broader and more abstract conception of objectives. Koontz, *et al.* in De Vos, Schurink and Strydom (1998: 6) further this understanding and describe the aim of a study as the overall purpose of the study, and the objectives as those steps necessary to be completed in order to achieve this purpose.

The aim of this study is: -

- To explore the experiences of mothers in accessing the services that are available to them following the death of a baby through stillbirth or neonatal death.

The objectives of this study are: -

- To do an investigation into the emotions of mothers following the loss of a baby through stillbirth or neonatal death;
- To assess the services that are available to mothers following the death of a baby through stillbirth or neonatal death;
- To assess the accessibility of the services available;
- To provide conclusions and recommendations for practice and for future research on the services offered to mothers who have lost a baby through stillbirth or neonatal death.

5. RESEARCH QUESTION FOR THE STUDY

Collins (1990: 251) defines the hypothesis of a study as "...a prediction of what is expected to be found". This is usually expressed as a statement of a relationship between independent (causative) and dependant (resultant) variables that give direction to the study. It is tested through investigation and may be accepted, should the results of

the study correlate with the assumptions made in the hypothesis, or rejected, should the findings of the study contradict the statements made in the hypothesis. A research question, on the other hand, asks a question which the researcher wishes to investigate. It does not provide a prediction of what the findings of the study will be, but rather identifies a question to be answered through the research. The hypothesis or research question is formulated before the study begins and informs the research method to be used. (Compare Bless & Kathuria 1993: 122; Van der Merwe, 1996: 289; De Vos & Van Zyl, 1998: 267 and Elmes, *et al.*, 1999: 13 - 14.) As the research conducted was exploratory in nature, a research question was used.

The researcher asked the following research question: **What are mothers' experiences of accessing services following the death of a baby through stillbirth or neonatal death?**

6. RESEARCH APPROACH

The choice of a qualitative or quantitative research approach is dictated by the problem that the researcher wishes to explore and the nature in which the data will be collected and analysed (De Vos, Schurink & Strydom, 1998: 15). The research approach that the researcher used for this study was a combination of both the quantitative and the qualitative approaches. The research, thus, was that of the dominant-less-dominant design model as outlined by Creswell (1994: 173 – 190), quantitative being more dominant and qualitative, less dominant (De Vos, 1998: 360 - 361 and De Vos, 2002a: 366). According to Creswell, this approach allows the researcher to present the study with one predominant approach, in the case of this study the quantitative approach, and smaller components of the other, in this case the qualitative approach. Advantageously, this approach allows a researcher to probe for detail in an aspect of the study while providing a consistent paradigm picture. Unfortunately, however, purists believe that this approach combines aspects that are incongruous to the central assumptions of the study (either being quantitative or qualitative in nature). The researcher is of the opinion that this study benefited from the acquisition of both quantitative and qualitative data and does not believe that the combination of approaches was of detriment to the study.

The quantitative approach to research is an attempt by the researcher to 'make generalizations based on precisely measured quantities' (Guy, *et al.*, 1987: 256). The goal of this attempt, as pointed out by McCracken (1990: 16), is to isolate and define

categories as precisely as possible before the study is undertaken, and then to determine the relationship between them. Key characteristics of quantitative research include the production of positivistic and quantifiable data, statistical or experimental control by the researcher, statistical analysis of numerical data and generalisable comparisons (Durrheim, 1999: 42 - 43 and Babbie & Mouton, 2001: 49). Structured observation, structured interviews and questionnaires are some of the methods that are used for data collection.

The qualitative approach to a study, on the other hand, is defined by Schwandt (1997: 129 - 130) as offering "nonnumeric data in the form of words." Qualitative research deals with all data that are principally verbal as opposed to quantitative research, which deals with principally numerical data. Creswell (1998: 15) defines qualitative research as "*...an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting.*" (Compare Van der Merwe, 1996: 283 – 284; Fouché & de Vos, 1998a: 71, Schurink, 1998a: 240 – 241 and Fouché, 2002a: 105.) Key characteristics of qualitative research include the production of anti-positivistic, interpretive data; a holistic understanding of the phenomena of interest; flexibility in collection and analysis of data; and rigorous and time consuming data collection. (Compare Van der Merwe, 1996: 283; Creswell, 1998: 20 – 22; Fouché & de Vos, 1998a: 71 – 72; Schurink, 1998a: 241 and Fouché 2002a: 105 – 106.) Unstructured interviewing and participant observation are methods used to gain in-depth knowledge and further guide the research (Creswell, 1998: 17 - 18).

The nature of the topic that the researcher explored, namely the experiences of mothers in obtaining services following the death of a baby, dictated the need for it to be quantitative in nature. The researcher made use of an administered interview schedule in order to collect data. Although the interview schedule is often used for the collection of qualitative data, for the purposes of this study it was used both qualitatively and quantitatively. Primarily it was quantitative in that many of the questions asked to the mothers in propinquity (thus, administered) were structured and the majority of the information obtained from the schedule was analysed statistically. Although the mothers were given the opportunity to add in their own personal extra information (thus the qualitative aspects and semi-structured), the majority of the schedule was structured and sought a response to a specific question. Based on the data achieved, the researcher

has attempted to make certain assumptions concerning the resources that are available, thus, to a degree, generalising the findings of the study. The study, therefore, is predominantly quantitative.

The study, however, holds qualitative aspects as well. Some of the questions that the researcher put into the interview schedule have a wide berth for the mothers to explore their own personal experiences. The researcher attempted to obtain information concerning the uniqueness of each mother's experience and some of the questions in the schedule were thus open-ended, allowing for further exploration. These open-ended questions have been analysed by looking for themes and sub-themes, an aspect that makes parts of the study qualitative in nature (Poggenpoel, 1998: 343 –344). The qualitative questions in the schedule, however, were fewer than those that are quantitative, thus, making the study predominantly quantitative in nature.

7. TYPE OF RESEARCH

The type of research that the researcher used in this study was applied research. Fouché (2002a: 108) defines applied research as "...the scientific planning of induced change in a troublesome situation". Such research, according to De Vos, Schurink and Strydom (1998: 20), is grounded in scientific theory but geared to the development of knowledge and technology with a view to achieving meaningful intervention. As opposed to basic research, the goals of applied research are practical rather than theoretical and the subject of research, generally, builds on previous research rather than exploring totally new theoretical terrain. It aims at helping the researcher to accomplish practical goals and/or to solve specific policy problems, therefore making qualitative or quantitative research more humanistic and relevant to the lives of people. The findings of such research frequently have implications for knowledge development, in addition to practical aims. (Compare Hendrick, Bickman & Rog, 1993: 2 – 3, De Vos & Fouché, 1998: 80 and Fouché, 2002a: 109.)

The study is an example of applied research in that it builds on an already identifiable field of study, namely the emotional needs of mothers for services following the death of a baby through stillbirth or neonatal death. It aims at increasing the knowledge base in this arena, specifically in the Gauteng area where, in the past, few services have been available to such mothers. Ultimately, however, it aims to develop such a knowledge base to be proactively utilised for practical application.

8. RESEARCH DESIGN

Collins (1990: 256) defines research design as "...the overall plan or strategy by which questions are answered or hypotheses tested." All forms of research design are described as being universally flexible, with a purpose of providing answers for social questions. Unexpected conditions in any social situation may give rise to new questions that require research in order to be answered and understood. The research design is responsible for taking hold of this process.

One is able to classify the design of one's research based on the determination of whether or not research has been previously done on the same topic. If the topic has yet to be researched, the design may be described as exploratory (Van der Merwe, 1996: 285 - 287). The design that the researcher used in this study is an exploratory design.

Durrheim (1999: 39) describes exploratory research as being used to make "...preliminary investigations into relatively unknown areas of research". Such research adopts a flexible, inductive and open approach to research and the understanding of the phenomena under question. Observational studies and clinical case histories often fall into this category of design. (Compare Singleton, Straits, Straits & McAllister, 1988: 90.) The researcher's topic of research is exploratory in nature in that it explored the experiences (as yet unknown) of fifteen Gauteng mothers in accessing services following the death of a baby. Although some research has been conducted in this arena, attention had yet to be given to South African, specifically Gauteng mothers, and their experiences of the services.

9. RESEARCH PROCEDURE AND STRATEGY

The research procedure that the researcher made use of for this study was the interviewing method. According to Greef (2002: 297 – 304), three types of interviews exist, namely unstructured interviews, semi-structured interviews and ethnographic interviews. (Compare De Vos & Fouché, 1998: 90 and Schurink, 1998b: 299 – 304.) The researcher conducted a semi-structured interview, using a semi-structured interview schedule as her strategy for the collection of both quantitative and qualitative data. A semi-structured interview is designed to gain information from respondents concerning their perceptions, beliefs and personal accounts of the subject being researched. This

interview type involves propinquity between the researcher and respondent and allows the researcher to follow up on interesting avenues that the respondent may explore, giving him or her a fuller picture of the topic under investigation. It is used when the topic being explored is fairly personal and relevant to the respondent and is, generally, guided by an interview schedule.

Greef (2002: 302–303) defines a semi-structured interview schedule as “...a questionnaire written to guide interviews”. Grinnell (1993: 267) furthers this definition by describing it as a questionnaire where “...all interviewees are asked exactly the same items in the same order”. The questions, or guidelines for the interview, are asked to the respondents by the researcher who records their answers. These are set in both closed and open-ended form. The semi-structured interview schedule does not dictate the interview that the researcher will conduct but rather guides it gently, allowing the researcher to gain information-rich responses from the respondents. (Compare Fowler & Mangione, 1990: 89 – 93, McCracken, 1990: 37 – 47, Grinnell, 1993: 267, Robson, 1995: 237 – 240 and Strydom, 1998b: 183.)

According to Grinnell (1993: 267), the use of the interview schedule holds a number of advantages. Firstly, it allows the researcher to be present for the interview and, thus, gives him or her the opportunity to clarify any ambiguities for the respondents and to probe for responses and additional information. Secondly, a high response rate is ensured from the respondents who agreed to participate in the study, as the researcher will be present to administer the schedule. Thirdly, as the questions are often of a sensitive nature, a safe and supportive environment is provided in which interviewees will be invited to respond.

Much as the data collection involved both qualitative and quantitative methods, so too did the data analysis. Quantitative data, obtained from interview schedules, was analysed by means of frequency distribution tables and presented statistically and by means of graphs (De Vos & Fouché, 1998: 204 –214). As the study is predominantly quantitative, the majority of the data has been analysed in this manner. Qualitative data, on the other hand, has been analysed according to Tesch’s eight-step approach (Poggenpoel, 1998: 343 – 344). The use of clustering, coding and categorizing of the information obtained will allow for accurate conclusions to be drawn.

10. PILOT STUDY

According to Strydom (2002b: 210 - 221) a pilot study is essential to the production of valuable research. Such a study provides the researcher with background knowledge and allows him or her to adequately orientate him or herself with the research topic prior to the research taking place. A pilot study should cover a number of aspects, including a study of the literature available for the study, a look into the need for possible expert consultation during the study, an assessment of the feasibility of the study and adequate pilot testing to correspond with the topic under investigation. These aspects will be discussed in more detail below.

10.1 Literature Study

According to Collins (1990: 254) a researcher should acquaint him or herself with the literature that is available for his or her study. Guy, *et al.* (1987: 39) echoes this belief and states that a literature study is a vital prerequisite to any research that is going to take place. A literature study may be viewed as the process of discovering the literature that is available for one's research topic. It helps the researcher to build on the findings of others, improve the understanding of the topic at hand and supply information as to why his or her endeavour is important. Books, journal articles and the Internet should be consulted. A decision as to exactly what topic to research should incorporate an understanding of previous research on the topic as an integral step in the decision-making process (Dane: 1990: 61 – 62).The researcher has done a search.

The researcher's topic of investigation namely, '*Mothers experiences of accessing services following the death of a baby through stillbirth or neonatal death*', requires research concerning a number of issues. Firstly, an investigation of available literature on the emotional needs of a mother following the death of a baby is necessary. This includes literature on the grief process itself, as well as those experiences unique to the loss of a baby. Secondly, the researcher also needed to be aware of the current services available to these mothers. Such services include hospital experiences, social support, religious support and formal support.

The researcher has undergone a detailed literature investigation. Some of the literature that the researcher has chosen to include in her study is fairly dated. Despite this, however, the researcher believes that such literature is still very relevant as grief and

grief reactions are not time specific and all such literature, therefore, can prove invaluable. Classical and renowned sources of grief literature from both Elizabeth Kübler-Ross and C. S. Lewis have been used.

10.2 Consultation with Experts

The researcher consulted with a number of experts in order to complete her study comprehensively. Strydom (2002b: 212 – 213) asserts that despite the wealth of literature that may be available on a specific topic, the invaluable contribution given by experts in the field of a specific topic must never be overlooked. The researcher approached a number of experts and obtained their permission to consult with them.

These people include: -

- Ms J. de Kock of the Compassionate Friends. Ms de Kock has started a support group for parents who have lost a baby. The group had its first meeting in March 2003 and is still relatively new, however, she expressed that it was formed out of a need for this specialisation within the general Compassionate Friends. The researcher was of the opinion that, through her contact with parents who have lost babies, Ms de Kock would be able to provide insightful information as to the emotional needs of, and available resources for mothers who have lost a baby.
- Ms L. de Wet of Baby Angels. Baby Angels is a support network that was founded by Ms de Wet and the researcher in October of 2002. Ms de Wet started the network after she found herself feeling very isolated following the death of her baby son. As she has contact with many mothers who have lost babies, the researcher felt she was able to provide much information enriching to the study.
- Sister Wendy, head nurse at the Parklane Clinic Neonatal ICU. Many babies, who pass away, do so in the neonatal ICU. Sister Wendy was able to provide an invaluable insight into the needs and resources available to a mother immediately following the death of a baby. The procedure with which the hospital deals with such mothers provided the researcher with an idea of the quality of care that such mothers receive.
- Ms R. Bates, a resident hospital psychologist at Parklane Clinic. Ms Bates has had a great deal of experience in grief counselling as she works in a hospital. As the hospital is primarily a maternity hospital, she deals with a great many parents who have lost babies. Her experience in this field was invaluable to the study.

- Rev. K. de Beer, a minister of the Lombardy East Methodist Church. As a minister, Rev. de Beer often needs to cater for the emotional needs of the community in which he works. He has had exposure to grief-stricken parents before and so was able to provide information to the researcher concerning their needs and the church's way of dealing with them.

10.3 Feasibility of the Study

According to Collins (1990: 253) it is vital that the researcher considers the feasibility of his or her study prior to conducting the research. The study should be limited to variables which can be investigated in the available time, bear the costs of the investigation, obtain co-operation from all involved and should not clash with the ethics of conducting a study.

Guy, *et al.* (1987: 59 - 61) identifies a number of considerations that should take place in the assessment of the feasibility of a study: -

- The scope of the study needs consideration. This should not encompass too many issues or too many concepts. It should be manageable and the topic of choice should be clearly defined. The researcher chose to narrow the scope of her study to only the mothers' experiences of accessing services following the death of a baby. A study including the experiences of the father, and other family members will, no doubt, also be of great value, however, was too vast a scope to cover;
- The amount of time required for the study should be considered. It should be possible to cover the entire study within the limited time period that is given. The researcher completed the study in the time period that was assigned to her;
- The costs of the study need to be taken into account. These should be within budget. The costs for the researcher will include transport costs, material costs and material for the compilation of the written study costs. These costs were within the researcher's budgeted amount;
- The researcher needs to consider whether or not the subjects of the study will co-operate with the study and express permission needs to be gained prior to the commencement of the study. The researcher was in contact with two support groups, designed especially for bereaved parents. Many mothers in the groups agreed to be involved in the study, however, many also chose not to.

10.4 Pilot Test of Measuring Instrument

According to Grinnell (1993: 267) a pre-test or pilot study holds the advantage of allowing the researcher to identify where ambiguities may lie in the proposed format of the measuring instrument. It is, unfortunately, inevitable that certain aspects of the theoretical and proposed design of a measuring instrument will not translate well into reality. A pilot study allows the researcher to identify such discrepancies and rectify them prior to the commencement of the actual study. According to Robson (1995: 301) all structured measuring instruments "...should be piloted on a small scale in virtually all circumstances". Such a pilot study is beneficial, not only to the researcher and the research, but to the respondents of the research as well. (Compare Strydom, 1998b: 183 and De Vos, 2002b: 410 – 411.) As the researcher's topic of investigation involved the use of an interview schedule as a measuring instrument, it was essential for her to conduct a pilot study of the instrument prior to commencing with the research. The researcher conducted a pilot study with three mothers who were not a part of her final research sample. The study informed the researcher as to areas within the interview schedule that required clarification and this was amended prior to her conducting the actual study.

11. DESCRIPTION OF THE RESEARCH POPULATION, DELIMITATION OF THE SAMPLE AND SAMPLING METHOD

Sampling is a vitally important process in research and holds the objective of allowing the researcher to ultimately estimate the population values based on the information obtained from the research respondents. The sample that one chooses and the size of that sample is dependant on a number of factors including the approach and design of the research and the research population. According to Strydom and Venter (2002: 198 – 199) the research population sets boundaries on study units and describes all individuals in the universe who possess the specific characteristics under investigation. (Compare Strydom & de Vos, 1998: 190.) The research population upon which the researcher focused was mothers, who have been members of either the *Baby Angels* or *Compassionate Friends* support networks, who have lost a baby through stillbirth or neonatal death. The population size, therefore, consisted of more or less twenty-five to thirty mothers.

The research sample that one wishes to investigate describes the respondents of the research and is a portion of the research population. It examines the specific subjects of the study about whom further information is required (Guy, *et al.*, 1987: 173 – 174). The sampling procedure that the researcher used was a **non-probability** sampling method. In such a procedure, probability of inclusion as a subject of the study is unknown and different for each person. Such sampling usually takes place when probability sampling is not viable. Samples are chosen based on their availability and sampling is, therefore, almost “accidental”. The first available people from the given population are chosen to be a part of the sample and, although they meet the criteria for the sample, they are chosen based on convenience. Non-probability sampling holds the advantage of obtaining all of the unique data available, however, has the disadvantage of making generalization extremely difficult (Guy, *et al.*, 1987: 174 –189, Dane, 1990: 302 – 303, Grinnell, 1993: 251, Schurink, 1998a: 254 – 256, Babbie & Mouton, 2001: 166 and Strydom & Delport, 2002: 334 - 336). The researcher used a non-probability sampling procedure in that her respondents were not chosen randomly. She focused on fifteen mothers who have lost a baby through stillbirth and neonatal death as her research sample.

Specifically, the researcher made use of the purposive form of non-probability sampling. Purposive sampling is a type of non-probability sampling that involves the selection of respondents for a study based on already identified criteria for selection. Respondents in the study met the following identified criteria in order to be involved in the study (Strydom & de Vos, 1998: 198 –199, Babbie & Mouton, 2001: 166 and Strydom & Venter 2002: 207). These included:

- The respondents were all mothers, of any age, who had lost a baby;
- The baby was lost through stillbirth or neonatal death;
- The baby passed away within the last five years;
- The mothers were all members of a support group, either the *Compassionate Friends* or *Baby Angels*.

12. ETHICAL ISSUES

Prior to commencing with any research, it is necessary for a researcher to consider whether or not his or her research is ethical. Strydom (2002a: 64 – 73) identifies a number of ethical issues necessary for consideration. (Compare Strydom: 1998a: 25 – 34.) Such ethical issues include:

- The researcher needs to obtain *informed consent* from the respondents of the research study. Informed consent refers to the provision of potential research participants with all of the information necessary to allow them to make a decision concerning their participation (Dane, 1990: 40). This implies that the researcher is transparent with the aims, goals, methods, advantages and disadvantages of the study with all who are involved. The respondents must give permission based on receiving all of this relevant information regarding the study. (Compare Kimmel, 1988: 67 – 68.) The researcher made sure that the mothers were adequately informed about the nature of the study prior to their making a decision to become involved. The respondents knew that they could withdraw from the study at any stage;
- No harm must come to the respondents or experimental subjects. This ethical consideration is intrinsically linked, in many respects, to that mentioned above, as informed consent allows respondents to thoroughly consider, beforehand, the full impact that the study will have on them. Harm includes psychological, emotional and physical harm. It is the researcher's obligation to protect the respondents from any such harm. (Compare Dane, 1990: 44 – 45 and Babbie & Mouton, 2001: 522 – 523.) The researcher underwent a number of steps to prevent the respondents of her study from being exposed to harm. Firstly, the nature of the study focused more on the respondents' experiences of gaining services following the death of their babies, rather than on the deaths themselves. Although it was acknowledged that even the discussion of this experience might be emotional for the mothers, it was more removed from the death itself. Secondly, all of the respondents of the study were from support groups. They were, thus, able to access emotional support should they need it;
- No deception must take place. Loewenberg and Dolgoff (1988: 70) define deception as "...deliberately misrepresenting facts in order to make another person believe what is not true, violating the respect to which every person is entitled". A researcher may become involved in deception through disguising the real goal of the study, hiding the function of the respondents' actions, or hiding the experiences that the subjects will go through. (Compare Dane, 1990: 42 – 43 and Babbie & Mouton, 2001: 525). The researcher strove not to deceive the respondents of her study;
- The researcher needs to take care to protect the privacy of each respondent and the highest levels of confidentiality must be maintained. (Compare Kimmel, 1988: 85 – 99, Dane, 1990: 51 and Babbie & Mouton, 2001: 523 – 524.) The researcher has not exposed the names of the mothers who participated in the study or those of others involved who wished their identities to remain confidential. She strove to ensure that their privacy was protected at all times;

- The findings of the study should be released or published. (Compare Dane, 1990: 53 – 54 and Babbie & Mouton, 2001: 526 – 527.) The results of the study will be published according to the expectations for a mini-dissertation as required by the Department of Social Work and Criminology, University of Pretoria;
- The researcher must be sure to restore the respondents and debrief them if necessary. The researcher spent long periods of time with each respondent of the study being sure that they were adequately debriefed before she left.

Finally, Kimmel (1988: 77) further adds that ethical sampling must take place and that the researcher should always mention the limitations of the sampling method and research in the written study. The reader should be fully informed when assessing the validity of the study to his or her particular frame of reference.

13. DEFINITIONS OF KEY CONCEPTS

For the purposes of this study, central terms are defined as follows:

- **Neonatal death** – The perception of what construes a neonatal death appears to differ between authors. According to Ryan (2000: 200), "...a baby which is born alive at between twenty and forty weeks gestation but which dies within forty-two days of birth", has suffered a neonatal death. Kohner and Henley (1997: 10), however, define a neonatal death as one "...within the first twenty-eight days of life". The Child Bereavement Trust (2000: 33) echoes this belief and defines neonatal death as referring to "...babies who are born alive but die within the first four weeks of life". The discrepancy appears to be in the length of time that the baby lives following his or her birth. For the purposes of this study, therefore, the researcher will refer to neonatal death as the death of a baby (who was born alive) within the first four weeks (twenty-eight days) of life.
- **Stillborn** – As with the definition of neonatal death, there are differing opinions amongst authors as to what construes a stillbirth. Leh, Reiser and Pauli (2002: 1) define stillbirth as "...the death of a baby after the twentieth week of pregnancy but before delivery". (Compare Ryan, 2000: 201 and Keaggy, 2002: 41.) Other authors refer to stillbirth as the death of a baby, before birth, but after the twenty-fourth week of pregnancy (The Child Bereavement Trust, 2000: 33) or after the twenty-sixth week of pregnancy (Author unknown, 1999: 1). According to Peinemann (2003: 1 – 2), the discrepancy exists because different countries have different legislation as to when a baby is considered stillborn as opposed to miscarried. It is, thus, necessary to focus on

South African literature in determining a definition. Lehohla (2002: 17) believes "...a stillbirth is a death prior to the expulsion or extraction from its mother's womb of a product of conception, irrespective of duration of pregnancy. That indicates the death after such separation, the child does not breathe or show other evidence of life". This definition appears to include miscarriage in its definition; however, Peinemann (2003: 2) states that in South Africa, the legal definition of stillbirth includes the death of a baby after the twenty-eighth week of pregnancy and before birth, or the death of a baby, before birth, which weighs 1 000 grams or more. For the purposes of this study, as it is conducted in South Africa, Peinemann's definition will be used.

- **Support groups** – According to Toseland and Rivas (1998: 21) a support group is one that is established to "...help members cope with stressful life events and to revitalize and enhance members' coping abilities so they can effectively adapt to and cope with future stressful life events". Corey and Corey (1997: 432) further describe a bereavement support group as one that aims to "...educate the mourner to the reality that grief is a process that is measured in years, not months..." and to support him or her through this process. For the purposes of this study, the support group will be seen as one that supports the mothers through the grief process by helping them to cope with the stress of having lost their babies.

14. LIMITATIONS OF THE STUDY

The primary limitations of this study are as listed below: -

- As a result of the nature of the sample under examination (small, reasonably alike in characteristics and not random), the findings of the study are probably not generalisable to society at large. This may affect the reliability, validity and statistical significance of the study. A study investigating the perceptions of mothers across religious, racial and financial boundaries would be very valuable.
- Since the study is limited to the mothers' perceptions of the accessibility and quality of the services, it may also have a limitation of being biased.
- As a result of the study being conducted by means of an administered schedule, in the presence of the interviewer, respondent bias may have been present.
- Very limited local literature was available on the subject material. Largely American and British literature was studied as a result. The reliability of the study may, therefore, have been affected by the lack of indigenous literature on the study material.
- Certain aspects of the material gained required that the mothers recall their perceptions of an emotionally clouded event that happened some time ago. Although

the study limited the sample to mothers who had lost babies within the last five years, time may still have influenced their perceptions. Their current recollections of the events might not be accurate as a result, thereby affecting the validity of the study.

- As some of the mothers were on medication at the time of the deaths of their babies, their memories may have been affected and the validity of the study tested, as a result.
- As a result of the researchers own personal experiences and interest in the content of the research, questions may have been drawn up, and data collected in such a way so as to accommodate the specific perceptions of the researcher.

15. CONCLUSION

It is estimated that between three and five percent of all pregnant mothers will lose their babies to a stillbirth or neonatal death every year. For this reason, it is essential that adequate and quality services be offered to these mothers to prevent complications in their grief. The study conducted by the researcher looked to examine the accessibility of quality hospital, religious, formal and social support services to bereaved mothers, following the death of a baby through stillbirth and neonatal death.

The research design was exploratory in nature and applied in type. The researcher used a combination of the quantitative and the qualitative approaches in the form of the dominant-less-dominant model (quantitative research being more dominant). The procedure that she used to collect the data was the semi-structured interview schedule. This allowed her to gain insight, in propinquity, to the mothers' perceptions, beliefs and personal accounts of their experiences in gaining access to support services. Quantitative information obtained was analysed by means of percentages and graphs and qualitative information, according to themes and sub-themes. The sampling method used for the research was a non-probability sample, specifically being purposive in nature. A sample of fifteen mothers was selected. No harm came to the mothers and the researcher undertook to do any debriefing that was necessary. The limitations of the study methodology were mentioned along with the possibility of publishing the research. The researcher believes that the research conducted will be invaluable in informing services that are available to such bereaved mothers.

CHAPTER 2

THE LOSS OF A BABY AND THE SERVICES AVAILABLE TO A MOTHER FOLLOWING THE LOSS OF A BABY

2.1 INTRODUCTION

The understanding of grief, the grief process and complicated grief is essential to the study in that it demonstrates the need for adequate social services to be provided to bereaved mothers following the loss of a baby. According to The Child Bereavement Trust (2000: 1):

Grief, in its many forms, is one of the most painful experiences that anyone can suffer, and every year it happens to thousands of families...Grief that is ignored can harm us in countless ways. To support families at such difficult times and to minimize the effect of long-term psychological problems, it is crucial that professional carers are able to recognize and respond appropriately to families' varied emotional needs.

As many as three to five percent of mothers are affected by the loss of an infant every year (Author Unknown, 2002: 1 and Author Unknown 2003: 2). It is, thus, essential that these mothers be provided with the adequate services that they require in order for their grief not to become complicated.

This chapter is designed to provide the reader with an in depth look at grief and the grief process, defining grief, mourning and bereavement and then providing an in depth look at the grief process. Here, the accepted stages of shock, denial and isolation; anger; bargaining; depression and, finally, acceptance will be discussed. Dysfunctional, or complicated grief, and models of grief will be discussed to aid the reader in his or her understanding of the topic at hand. The discussion on grief will then specifically take a look at the grief of a mother who has lost a baby. Maternal grief predictors, namely, support, relationship satisfaction and ways of coping will be discussed and the need for adequate support services will be demonstrated. Finally, the hospital, religious and formal services available to such mothers will be examined.

2.2 GRIEF, MOURNING AND BEREAVEMENT

Grief, mourning and bereavement are three very closely linked concepts, working together to define one's reaction to the death of a loved one. Although closely linked, however, these terms

have distinctly separate meanings. These differences are essential to take note of in order to better understand the contents of this chapter.

According to Stroebe and Schut (1998: 7), *bereavement* may be defined as "...the situation of a person who has recently experienced the loss of someone significant through that person's death". Alternatively, as put by Moody and Arcangel (2002: 37), bereavement may be seen as the "...state of being deprived after a loved one's death." In other words, bereavement is the state of deprivation that one experiences following the death of a loved one.

Grief, as outlined by Curren (2001: 91), is a slightly more difficult concept to define. It is multi-faceted in nature and, therefore, requires outlining a number of definitions in order to gain a holistic understanding of its various aspects. For this reason, the researcher has included three different definitions of grief. According to Moody and Arcangel (2002: 36), grief is "...a process with a host of feelings." This process is instinctive in the face of loss and consuming of one's mind, body and soul for a period of weeks or months. Howe (1995: 58) defines grief as "...the process through which one passes in order to recover from a loss", and finally, Stroebe and Schut (1998: 7) see grief as the "...primarily emotional reaction to the loss of a loved one through death, which incorporates diverse psychological and physical symptoms and is sometimes associated with detrimental health consequences".

The various aspects of grief become apparent by comparing and contrasting these three definitions. They are listed below (Curren, 2001:91 – 93): -

- Grief is generally accepted to be an emotional process. This process is believed to be comprised of a number of different stages, which appear in a unique intensity and order, depending on the nature of the bereaved.
- Grief is not an easily solved process and can be engulfing and time-consuming for the grieving individual. Although primarily an emotional process, the strong emotional demand of the process may affect one's physical being and health.
- Grief results in recovery. This is a highly debatable point. Although some people are able to recover from their grief and come to terms with their loss, others may become engulfed in their grief and may never reach a point of 'recovery' and acceptance of the loss. (Compare Moody & Arcangel, 2002: 136.)
- Grief involves the reconstruction of one's world and one's relationships with significant others, absent of the deceased person. (Compare Zucker, 1998: 63 and Davis, 2000: 56.)

Finally, mourning is the “...outward expression of grief – any action that helps us to adapt to our loss” (Moody & Arcangel, 2002: 37). It is influenced by one’s cultural upbringing, and one’s adult culture. (Compare Curren, 2001: 92.)

The differences between these three concepts are evident by their definitions. Despite these differences, however, they do not exist in isolation and each one impacts on the other. Oliviere, Hargreaves and Monroe (1998: 121) summarise the differences and connections aptly, stating that “...bereavement is the event, grief is the emotional process, mourning is the cultural process”. In other words, bereavement is the loss of the loved one, grief is the emotional process that occurs in one’s longing for the loved one and mourning is the cultural way in which one expresses the grief.

2.3 THE GRIEF PROCESS

Experts on grief generally agree that grief occurs in a process consisting of a number of stages, comprised of distinct emotions that the grieving individual experiences. No two people experience grief, and therefore, the grief process in the same way (Kohner & Thomas, 1995: 19, Kübler-Ross, 1997: 25 – 47, Moody & Arcangel, 2002: 58 and Parkes, 2003: 37 - 46). As Alexander (1993: 9) describes it: “...each bereavement is unique. The range of feelings from hurt to anger, from jealousy to guilt, and from love to feeling let down and abandoned by the person who died when you still needed them can only be experienced by you”. Rosenblatt (2000: 37 – 39), however, believes that as a result of grief being unique to each person, it does not necessarily progress as a part of a process containing stages. He believes that, while thinking in terms of stages may be beneficial to some people, it may not be beneficial to others at all. A number of emotions can be felt simultaneously and, as a result, one needs to see grief in the way that best suits oneself as an individual. The researcher echoes this belief and further asserts that, as there is an enormous range and complexity to grieving, one has to be flexible when approaching the topic.

Experts argue over the length of time that may be considered as reasonable in grieving the loss of a child. Most, however, agree that the most intense feelings should have subsided after about two years and continue to lessen over time. Reminders, however, frequently evoke intense emotions, often years after the loss of the child. Anniversary reactions, such as the child’s birthday and the date of his or her death, are examples of such reminders (Mehren, 1997: 109 – 110, Cook & Oltjenbruns, 1998: 98 – 99, Keaggy, 2002: 89). The researcher, in her own experience, believes that a parent’s grief for his or her child is life-long. While it does tend to

lessen in intensity over time, it becomes forever integrated into the parent as a part of who he or she is.

Moody and Arcangel (2002: 58 – 77) outline a number of factors related to the loss will have a profound influence on the duration and intensity of the grief process. These include:

- *Age of the survivor* – children are not always able to comprehend the permanence of death. The capacity of older people to adjust to a death is also difficult. (Compare Cook & Oltjenbruns, 1998: 109 – 110.)
- *Age of the deceased* – With the death of a parent there is a loss of history whereas with the death of a child there is a loss of future. With the death of a spouse the past, present and future are all lost. One appears to accept more a death that they and society perceive as being within the natural progression of life, which makes the death of a child all the more difficult. (Compare Cook & Oltjenbruns, 1998: 111.)
- *Relationship with the deceased* – the stronger and closer the relationship, the more profound the loss. One may also suffer a role loss with the loss of the deceased (object loss). (Compare Cook & Oltjenbruns, 1998: 110.)
- *Bereavement overload* – This term indicates that a person is weakened emotionally and/or physically as a result of multiple losses occurring within a short space of time, allowing little time for the resolution of earlier grief. (Compare Cook & Oltjenbruns, 1998: 119.)
- *Grief history* – a person's history of grieving effects future grief. One learns from his or her past experiences how to grieve and what is socially acceptable. Unresolved grief issues may arise in future grief.
- *Culture* – different cultures and religions have different mourning rituals that are considered acceptable by their societies. These may serve to help or restrict the individual in his or her grieving process. (Compare Cook & Oltjenbruns, 1998: 102 – 107.)
- *Support* – the support that one receives from his or her family, society, religion and formal structures has a profound influence on the grief process. If the support is adequate and supportive of the person's emotions and processes, he or she is more likely to adequately complete the grief process and complicated or dysfunctional grief is less likely to arise. (Compare Cook & Oltjenbruns, 1998: 118 – 119.)
- *Gender* – woman and men tend to respond differently to loss. While woman frequently become engulfed in their loss and tend to be a lot more open about their feelings, men are usually more reserved and their grief more delayed. They try to be strong as encouraged by society. (Compare Cook & Oltjenbruns, 1998: 107.)
- *Manner of death* – death may be anticipated - time is given to say good-bye and prepare but the person is left emotionally and physically exhausted. Sudden - the individual has more

energy to mourn, but the mourning is usually more intense as he or she could not say good-bye and may feel sorrow and regret as a result. Violent - innocence is lost and the person left behind is haunted by the deceased's last moments of life. The degree to which the bereaved believes that the death was preventable will also have a profound effect on his or her grieving. Mourning will be more intense if the bereaved believes that he or she could have done something to stop the death from occurring. (Compare Cook & Oltjenbruns, 1998: 113 – 118.)

The stages of the grieving process, according to Schiff (1979: 24) and Kübler-Ross (1997: 25-47), include shock, denial and isolation, anger, bargaining, depression and acceptance. Although these stages are distinct, they are overlapping and interconnected. They do not necessarily occur in a sequence and, depending on the person involved, may last for varying periods of time (Peppers & Knapp, 1980: 32). These stages will be discussed in relation to the loss of a child specifically.

2.3.1 Shock, denial and isolation

The first stage in the grief process is that of shock, denial and isolation. This stage occurs immediately on hearing of the loss of the child and continues for some time afterwards. While parents may vary in their reactions to the news of their child's death - from being totally hysterical to feeling numb, calm and distant - most will ultimately settle into feelings of total shock and denial. Denial is a form of shock that is the psyche's way of helping the parent cope with the enormity of his or her loss in the first few days, weeks, or even months, following the death of his or her child. The loss is of so great a magnitude that absorbing it all at once would be too overwhelming for the parent. Denial, thus, acts as a defence mechanism to help the parent slowly absorb the reality of his or her loss. Parents describe feelings of numbness and feelings of grief coming in waves as reality weaves its way into their consciousness. Sleeplessness, poor concentration, detachment and periods of intense pain are all symptomatic of this stage (Schiff, 1979: 24 – 25, Peppers & Knapp, 1980: 32 – 33, Rank, 1985: 48 – 49, Pregent, 1992: 32 – 34 and Kübler-Ross, 1997: 51 – 61).

Pregent (1992: 18 – 19) describes feeling totally shocked, overwhelmed, alone and afraid as she watched the hearse and the medical staff arrive at her house after her daughter had died. The researcher echoes these feelings of overwhelming disbelief. Following the death of her baby daughter, she felt, at times, that it hadn't happened at all. She felt almost drugged and 'switched off', as if she existed in surreality from which she would soon awake. At other times

the pain was so overbearing that she wanted to crawl into bed and stay there. The researcher believes that these feelings of shock and denial are so intense following the loss of a child because a parent expects to outlive his or her child. The death of a child, therefore, appears to contradict nature's 'natural' order. If the death of the child was sudden, as it most frequently is with the death of a baby, the denial may be even greater.

Coupled with denial is the feeling of intense isolation. As the grief process is highly individual in nature and involves such complex feelings, it is an individual journey and inevitably evokes feelings of isolation and loneliness. 'Nobody understands', is a feeling loved ones often express after the loss of a child as they are overwhelmed by feelings that the profundity of their loss is only understandable to themselves. With the death of a baby this is incredibly acute as, in reality, most people do not understand. Comments like 'you can always have another one' and 'it would have been worse if she was older' leave parents feeling incredibly isolated and alone in their grief. This lack of understanding for the significance of the loss by the general community, often leads to a lack of support and, therefore, inadequate, suppressed grief and intense loneliness (Rank, 1985: 56 –57 and Moody & Arcangel, 2002: 41 – 42).

The researcher felt desperately alone in her grief following the loss of her daughter. She felt as though her entire world had collapsed before her and that life would never be the same, yet everything appeared to carry on as usual. People did not appear to understand the significance of her loss and the expectation for her to quickly 'get over' her loss was often very overwhelming. She desperately wanted people to understand that Gemma-Leigh was a person too and that her life was as valuable as any other. This lack of understanding often left her feeling very isolated in her grief.

2.3.2 Anger

The second stage of grief is that of anger. Anger and bitterness are particularly common following the death of a child, as the death appears to be an injustice occurring out of the natural sequence of events (Mehren, 1997: 108). This intense emotion may be experienced externally, toward others or very often, internally, toward oneself. According to Moody and Arcangel (2002: 38) anger always seeks a target upon which to land. It needs a source of release and frequently manifests itself as bitterness, hatred, rage and resentment. Doctors, nurses, paramedics, spouses, God and even the deceased individual are often the targets of such anger (Peppers & Knapp, 1980: 35 – 37; Rank, 1985: 57 – 59 and Ingram, K. J. 1997: 73). Anger, however, is a culturally taboo emotion and parents are often left feeling guilty about these

feelings. Many religions and indeed, the parents' personal religious beliefs, frown upon anger towards God, which only heightens feelings of isolations and guilt (Rank, 1985: 57-59 and Moody & Arcangel, 2002: 38).

Most often, however, following the loss of a child, feelings of anger are turned inwardly, manifesting themselves as intense guilt. Parents instinctively assume the role of protector of their child and when they fail to be able to do so, they are left feeling responsible and guilty. One mother (Ingram, 1997: 17) succinctly summed it up when she expressed: "I was haunted by the thought that I was somehow responsible for the loss of my child. The list of my mistakes and wrongdoings was endless". Guilt is most often irrational, illogical and not grounded in fact. Despite this, the emotions associated with the guilt are very real (Schiff, 1979: 2 - 39; Peppers & Knapp, 1980: 37 – 42; Rank, 1985: 54 – 56; Mehren, 1997: 108; Moody & Arcangel, 2002: 48 and Oikonen & Brownlee, 2002: 128).

The researcher could echo the feelings of the abovementioned mother, following the death of her daughter. The bulk of her anger was reflected inwardly and she felt enormous guilt about all issues concerning the loss. She believed that she was responsible for Gemma-Leigh's illness, as the doctor's were unable to tell her how Gemma-Leigh had contracted it. She was convinced that she had either gotten it from her, or she had taken her somewhere where she had picked it up. She felt guilty for naming Gemma-Leigh's second name after her deceased aunt and godmother, and wondered if she'd somehow doomed her through doing so. She no longer subscribed to logic and felt guilty about events that were totally beyond her control.

2.3.3 Bargaining

Bargaining is the third stage of grief. According to Kübler-Ross (1997: 93 – 95) this is the phase of grief where the parent attempts to contract some sort of agreement, usually irrationally, to change what has happened. Such agreements are usually intrinsically linked to those issues about which the parent felt guilty. After the death of Gemma-Leigh, for example, the researcher found herself bargaining with God that she would no longer moan about sleeping badly at night if she could have Gemma-Leigh back. Frequently parents feel uneasy and desperate in their attempts to make what has happened, unhappen. While logically they know that nothing that they could do would change the past, logic takes a back seat in the fight for their child.

2.3.4 Depression

According to Moody and Arcangel (2002: 45) depression, the fourth stage of grief, occurs as the acknowledgement of the reality of what has occurred sinks in, and the pain of the loss begins to take its course. Depression comes in wavelike sensations of absolute devastation, usually aroused by memories. The intensity and duration of these periods is paramount and support is essential in the prevention of ongoing depression. Parents often complain of feeling listless, pessimistic and downcast in this stage and long periods of intense crying coupled with a lack of concentration and slow rhythms are common (Kübler-Ross, 1997: 97 – 100.)

The researcher found herself sitting for hours sobbing as the reality and the significance of what had happened began to dawn on her. On particularly difficult days, she didn't want to get out of bed in the morning. She felt that she had been robbed of her future and that there was nothing to look forward to.

2.3.5 Acceptance

Finally, one reaches the stage of acceptance. This is the ultimate resignation to the fact that nothing can be done to change what has happened, and that one needs to move on with one's life. Pregent (1992: 65) believes that "...healing involves the willingness to accept suffering as a part of life. You must be willing to hurt more before you can hurt less". As one has progressed through the different emotions associated with his or her grief, he or she gradually begins to accept what has happened as a part of his or her life. The researcher believes that the parent never really gets over the loss of a child, but rather learns how to integrate the grief into his or her person – as a part of who he or she is. Although all deaths will leave the individual a changed person, some choose to move beyond acceptance of the death, to the promise that one will do all that one can to further the legacy of the person who has passed away (Moody & Arcangel, 2002: 56 - 57). He or she dramatically improves him or herself as a result of the death and may go on to accomplish great things in the name of the person who is gone. Many research foundations; support groups, hospitals and other organizations have been founded in the memory of people who have passed away. Others are content to carry on their lives as they had before, but they themselves are forever changed by the loss of their loved one.

Rabbi Kushner (Mehren, 1997: 16 - 17) poignantly described his process of acceptance:

You will never be the same person you were before. In the nearly twenty years since our son died, not a day has passed that I haven't thought about him. His

life and death define who I am more than any other single event. But yes, you do reach the point where remembering does not overwhelm you as it did in the beginning. You survive to see the day when you can love and laugh and enjoy the sunshine without feeling that you are betraying your child in doing so. You realize that on the contrary, you are living his unlived years for him and with him. We heal, but we remember, and living with the memory is part of the healing.

2.4 DYSFUNCTIONAL GRIEF RESPONSES

The previous section set to describe the process and journey of grief, as a person would normally experience it. Although the actual process is highly personal and individualistic in nature, it is considered to be 'normal' if a person is able to move from being grief stricken and bereaved to accepting or becoming resigned to the loss of a loved one. According to Moody and Arcangel (2002: 96), the 'normal' or 'healthy' grief process holds the function of allowing survivors to identify, acknowledge, feel, and integrate what they love but are now without.

Grief, however, is not always 'healthy' or 'normal'. Not all people possess the coping mechanisms to deal with the grief process. 'Unhealthy' or 'dysfunctional' grief, therefore, prolongs suffering, interrupts normal activities or prevents life from being lived to the fullest (Moody & Arcangel, 2002: 96). Cook and Oltjenbruns (1998: 125) refer to dysfunctional grief as complicated grief. This they define as "...some compromise, distortion or failure of one or more of the tasks of mourning, given the amount of time since the death". (Compare Friedrichs, Daly & Kavanaugh, 2000: 302 – 304.) Complicated or dysfunctional grief, therefore, takes into account the grief work and progression through the grief process and the amount of time that has lapsed since the death. This is taken within context. Grief is more likely to become complicated if the relationship between the survivor and the deceased was conflicted; the survivor has had previous mental health problems; there is a perceived, or actual, lack of support for the survivor; the death was sudden or unanticipated; there is a perception that the death may have been preventable; the death is the loss of a child; or the survivor has unresolved past losses.

A number of signs and symptoms of 'dysfunctional' grief exist. These are discussed below (Moody & Arcangel, 2002: 97 – 116).

2.4.1 Fixated grief

The 'healthy' grief process, as discussed in section three above, involves the individual's moving through a number of stages of grief and reaching a degree of resolution at each stage regarding its challenges. Grief becomes dysfunctional or unhealthy, however, when an individual becomes stuck in a particular stage and is unable to move beyond this point. Dianne Arcangel's (Moody & Arcangel, 2002: 132 – 136) model of grief (Figure 1) describes fixated grief by means of an illustration (illustration c of Figure 1). Fixated grief results in feelings of anger, resentment, guilt, depression and other such emotions clouding the bereaved's daily functioning far beyond what is considered to be 'normal'. Continued depression and chronic mourning are examples of fixated grief (Compare Cook & Oltjenbruns, 1998: 127 and Riches & Dawson, 2000: 144.)

Leon (1990: 120 – 124) prefers to refer to fixated grief as 'incomplete' grief. He describes it by means of an illustration of a woman, Mrs. B., who following the death of her infant child at two days old, was unable to overcome the feelings of guilt and responsibility that she felt. In a subsequent pregnancy, over three years after the death of the infant, she sought help as she believed that she was overly critical of her other children and was feeling extremely depressed. Upon intervention it was found that she believed that a drug that she had taken as a teenager had been responsible for the death of her infant child years later. This guilt interfered with her life as she was unable to discipline her children without feeling guilty and suffered from a great deal of depression. Her inability to deal with this guilt had a continuing effect on her daily functioning.

2.4.2 Denial

Denial is the most common defence mechanism used by individuals in order to cope with trauma. It holds the function of protecting the psyche when the trauma of an event is too difficult to absorb at once. For this reason it may be seen as a healthy and 'normal' process in grief, however, if prolonged, it can become extremely dysfunctional. Denial may be either conscious or unconscious (Rank, 1985: 49 and Leon, 1990: 108 – 114).

Denial is conscious when the distortion of the truth is intentional. Such denial can be potentially very harmful when the literal, unconscious mind absorbs every thought and statement, unable to distinguish between reality and fiction (Moody & Arcangel, 2002: 98). Conscious deceptions are an invitation for unconscious denial and may develop into maladaptive delusions.

Unconscious denial, on the other hand, involves forgetting, escaping or disbelieving in reality (Moody & Arcangel, 2002: 101). It results in being numbed from feeling the impact of a loss and forms a shield from the grief of losing a loved one. Should this shield not be slowly shed, as it is in the 'normal' grief process, the individual is prevented from dealing with the loss and integrating it into his or her life. (Compare Peppers & Knapp, 1980, 27, Rank, 1985, 41 and Leon, 1990: 115 – 120.)

2.4.3 Reversibility of the loss

When death is considered reversible, this is a sign that grief has become dysfunctional. Closely linked with denial, is the belief that one will be able to miraculously reverse the process of death and restore the deceased individual to his or her former self. Although it is fairly 'normal' for the bereaved to daydream about, and bargain for, the return of their deceased loved one, the belief that this process can become reversible steers grief along a dysfunctional path. Acceptance and integration of the loss cannot be reached until the bereaved is able to accept that his or her loved one will not be coming back. Such an inability to comprehend the reality of the death is often tied with sudden and traumatic deaths of loved ones (Riches & Dawson, 2000: 145).

2.4.4 Mementos

There is much debate over the issue of mementos of the deceased loved one and the length of time that these should be kept for. Moody and Arcangel (2002: 104 – 107) divide these mementos into four main categories in order to simplify this debate. Transitional objects are objects that are kept by the bereaved for an initial period of time while he or she begins to come to terms with his or her loss. Wearing an item of clothing that belonged to the deceased or keeping a rose from the deceased's grave may be considered as using a transitional object. Keepsakes are objects that are permanently kept by the bereaved individual. Jewellery and photographs that belonged to the deceased are examples of keepsakes. Rejected objects are those that the bereaved discards following the death of a loved one. These are generally not objects that the bereaved holds as important.

Grief becomes dysfunctional when the bereaved becomes too invested in his or her transitional objects or keepsakes. These mementos become lifeline objects (the fourth type), which, for the person who keeps them, do not allow for the healthy processing of grief. An object becomes a lifeline object under any one of three conditions. Firstly, it is kept for the loved one upon his or

her return. Secondly, the bereaved believes that the object *is* the deceased, or, finally, ‘the emotional investment in them is so great that if they were lost, stolen, or destroyed, the survivor’s grief would equal the grief that accompanied the original loss’ (Moody & Arcangel, 2002: 105).

Cook and Oltjenbruns (1998; 127) speak of the processes of ‘mummification’ (where the survivor attempts to keep everything the way that the deceased left it when he or she was alive) and ‘memorialisation’ (where the survivor memorialises the deceased through becoming obsessive about the gravesite), tied closely with this. These processes can become incredibly destructive when they interfere with the ability of the survivor to continue with his or her everyday life. (Compare Schiff, 1979: 29.)

2.4.5 Identification / assuming the characteristics of the deceased

In an attempt to preserve the memory of a deceased loved one, survivors often, either consciously or unconsciously, absorb characteristics of the deceased. This process is known as integration and can be life enhancing and functional should the characteristics be positive and allow the individual to maintain his or her self in the process. The assumption of the deceased’s characteristics can be dysfunctional, however, when the survivor loses his or herself in the process or reproduces medical symptoms of the deceased within him or herself. Such medical symptoms are usually psychologically reproduced but do not serve to benefit the survivor and are, thus, dysfunctional. (Compare Cook & Oltjenbruns, 1998: 127.)

2.4.6 Mistaking others

It is common for bereaved individuals to mistake other people that they see in the public for their loved ones. Each episode of mistake only lasts for a short time, but usually results in a wave of sorrow engulfing the bereaved person as they once again are faced with the reality that they will not be seeing their loved one again. Although this process is fairly normal, it may become dysfunctional when the bereaved individual starts to believe that they actually did see their loved one and that such a sighting is a sort of mystical occurrence. Such denial of the loved one’s death prevents the survivor from being able to process the loss and come to terms with the fact that the person will not be returning.

2.4.7 Emotions in disguise

The grief following the death of a loved one can become problematic if it is used as a form of disguise for other underlying emotions. Moody and Arcangel (2002: 111 –112) use an illustration to describe such behaviour. They speak of a woman who decided that, after many years of watching her mother suffering as a result of cancer, decided not to try and preserve her mother's life when she eventually lay in a coma on her deathbed. This decision was made in conjunction with her mother's doctors and out of empathy for her mother who she knew had suffered painfully with the illness. As she lay dying, the woman's sister, her mother's other daughter, angrily arrived at the hospital and cursed the woman and the doctors for abusing and not caring about her mother. She began a feud and refused contact with the woman for a long time following the death of her mother. This daughter had only been in contact with her mother twice during her illness and used anger towards her family and the medical staff as a disguise for her guilt for not keeping adequate contact with her mother before she passed away.

2.4.8 Anniversary reactions

Anniversary reactions occur when certain anniversary dates of the deceased loved one (birthdays, dates of death or special occasions) arouse feelings of grief and sadness in the survivor. Such reactions are normally anticipated and the individual is able to prepare for his or her reaction to such dates. If the death was not properly mourned however, anniversary dates may be a platform for unresolved feelings to arise.

2.4.9 Replicated loss

A loss at any time may cause the survivor to revisit feelings that he or she may have had in relation to a former loss. Memories of another loss may be triggered by the loss of a loved one and initial feelings of grief about a former loss may be revisited. Such replicated loss is particularly problematic if the original loss, which is triggered by the current loss, was not properly dealt with. (Compare Davis, 2000: 55 – 56.)

2.4.10 Disenfranchised grief

Riches and Dawson (2000: 144 – 145) describe the phenomenon of disenfranchised grief as a dysfunctional grief reaction. Disenfranchised grief results from the failure of others to accept and acknowledge the severity of the loss of the survivor. This results in the survivor repressing his or

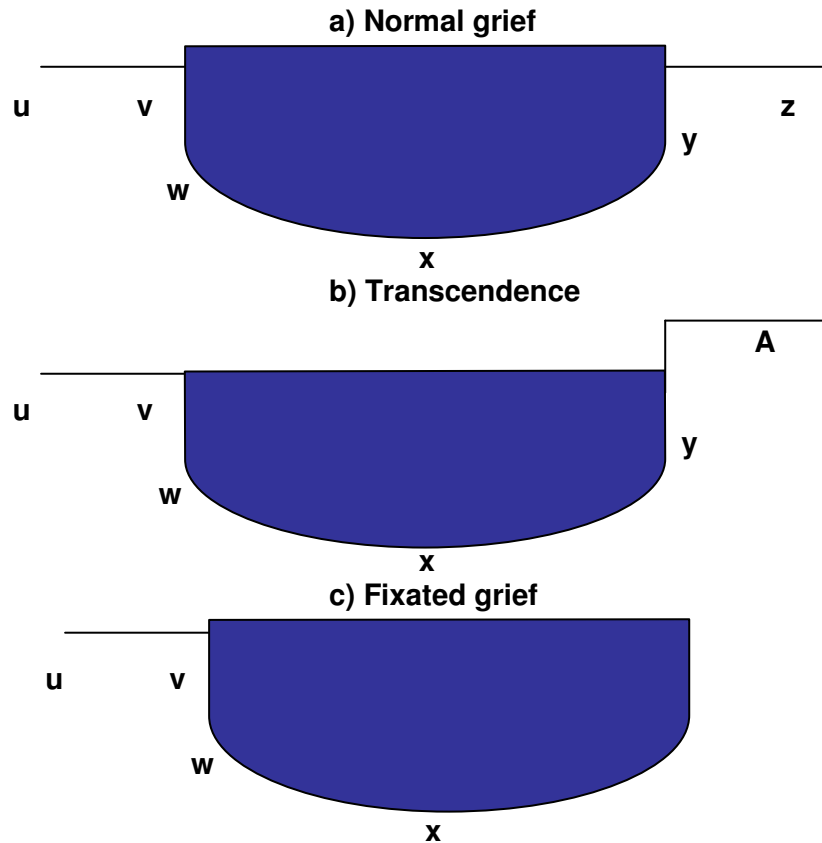
her grief reactions. The incongruence between the internal grief that the individual feels and the significance that the outside world attaches to the loss leaves the survivor feeling extremely isolated and alone, wondering if his or her intense feelings of grief are normal. As a result of a lack of social support, such grief is often prolonged and may never be adequately resolved. Disenfranchised grief is particularly significant in relation to the loss of an infant, as such a death is seldom acknowledged for its significance by the general society. It also highlights the significant role that support services play in the resolution of grief. (Compare Cook & Oltjenbruns, 1998: 120 – 121.)

2.5 MODELS OF GRIEF

A number of theorists have outlined various models of grief based on their own personal experiences of grief and on their work with other grief-stricken people. Three such models will be outlined below.

a) Dianne Arcangel's model of normal grief, transcendence and fixated grief
(Adapted from Moody & Arcangel, 2002: 132 – 136)

Figure 1. Dianne Arcangel's model of grief, transcendence and fixated grief



Key

U - Personality usually flows along a continuum

V - Loss occurs

W - Early bereavement

X - Midpoint of grief's journey

Y - Transition nears completion

Z - Personality is stabilised

A - Transcendence

According to Dianne Arcangel (Moody & Arcangel, 2002: 132 – 136) one's personality (core values and beliefs) remains on a relatively stable continuum throughout one's life (**u**). When the loss of a loved one occurs (**v**), however, there is an interruption in the stability of this continuum

and one's core beliefs and values are shaken. There is, thus, a period of transition that is entered into that can last for a number of years.

When one enters into early bereavement (**w**) and begins to face one's feelings of grief, one's personality changes and feelings of bitterness, anger, guilt, denial, arise. As these feelings are released, one enters the midpoint of grief's journey (**x**). Here, one is engulfed and overwhelmed by feelings of grief that need to be dealt with and experienced to be able to move forward. Some survivors of grief, however, are unable to move beyond this point. Normalcy for them, unfortunately, means remaining fixated in the pit of despair, anger, bitterness or sorrow (Moody & Arcangel, 2002: 136). Being perpetually traumatized by the death, they suffer from prolonged grief reactions and lack the adjustment skills to come to terms with their loss. Such 'fixated grief' is depicted in Diagram c of Figure 1 above.

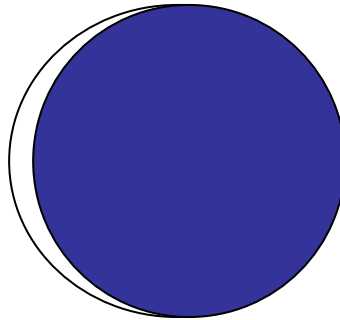
Beyond the midpoint of grief, the personality shifts and begins to move towards completion (**y**). Certain aspects of one's original personality may have noticeably changed, including fundamental conceptual beliefs and opinions. In the normal grief model, as depicted in Diagram a above, one's life following the period of grief generally restores itself to some form of normalcy. One's personal model of the world, core values, ideals and beliefs have remained relatively intact and one is able to move on with one's life absent of the loved one (**z**). In the instance of a transcendental resolution to grief, however, (diagram b of figure 1 above), resolution of grief by the survivor involves a reformation of sorts, of his or her personality. Core ideals, values and beliefs, as well as opinions and concepts are fundamentally changed, and the transcender becomes more enlightened, experiencing a greater quality of normalcy and a continual level of growth as a result of the death. The transcender has gained in wisdom, compassion, understanding and unconditional love. Transcenders feel elevated above their former selves (**A**). (Compare Davis, 2000: 56 – 57 and Moody & Arcangel, 2002: 135.) Transcendence is depicted in Diagram b of figure 1 above.

Although a relatively simple model, the researcher believes that Dianne Arcangel has managed to capture some essential grief elements in her description. The ability of one to become fixated and 'stuck' in the grief process and the contradictory ability of the individual to transcend above his or her former self as a result of grief are essential to the understanding of the grief process. Dianne Arcangel, however, fails to highlight the processes that might bring about these changes and to examine why some people return to their normal continuum, others transcend and, still others, become fixated in their grief. Despite its simplicity, the researcher believes that the model is relatively useful in the understanding of grief.

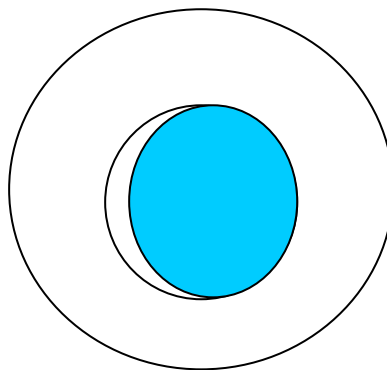
b) Raymond Moody's model of grief and transcendence (adapted from Moody and Arcangel, 2002:136 - 139).

Figure 2. Raymond Moody's model of grief and transcendence

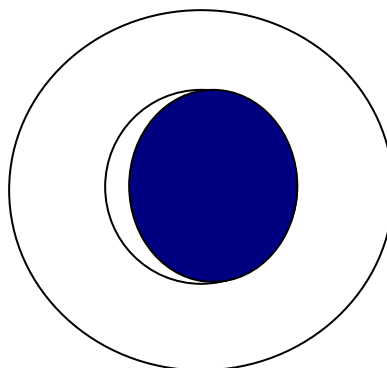
a) Grief at the time of loss



b) Transcendence 1



c) Transcendence 2



Moody (Moody & Arcangel, 2002: 137) developed his model of grief (Figure 2) following the loss of his newborn son in 1970. He describes how the model pertains, particularly to his experience of grief, and how he believes it could be used to describe the grief of other's as well. Illustration

a of Moody's model depicts grief at the time of bereavement, when the loss occurs. The circle in its entirety represents the bereaved person's entire self, while the shaded area represents his or her grief. According to Moody, one's sorrow at this time is engulfing as almost the entire self is consumed with grief. Only a tiny part of the individual remains unaffected by the loss.

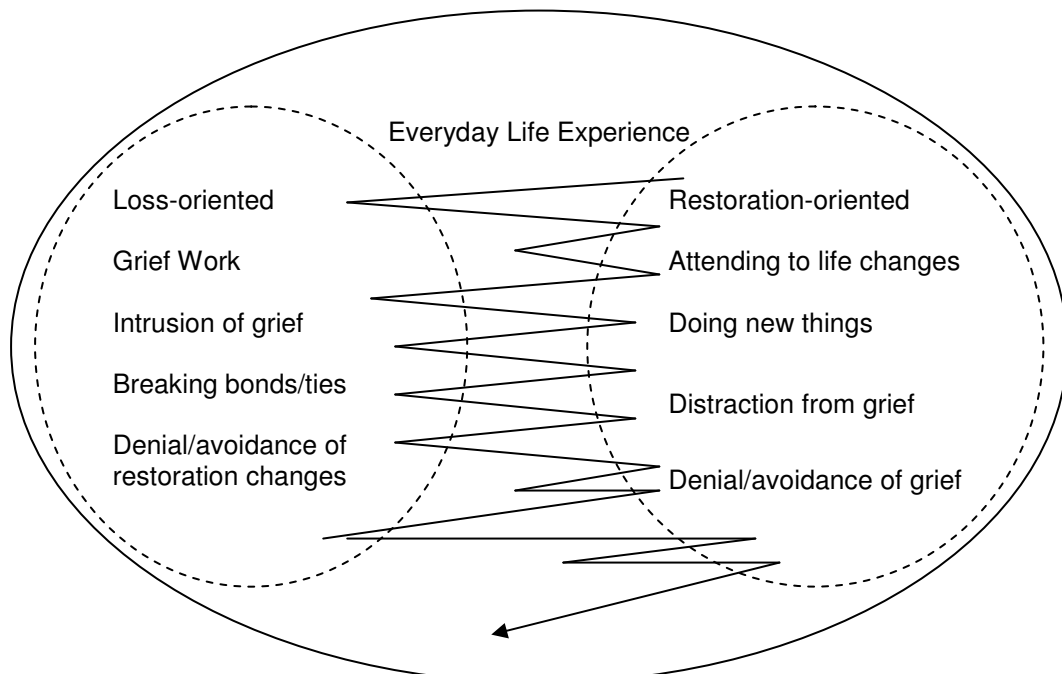
According to Moody (Moody & Arcangel, 2002: 137), in reaching transcendence, the inner circle, depicting one's grief, remains the same as it was at the time of the death of the loved one but, on an average day, becomes much lighter and less defined (illustration b). The outer circle, representing the self in its entirety, grows and continues to grow around the loss. Moody (Moody & Arcangel, 2002: 138) believes that intense grief, the kind that causes transcendence, becomes an integral part of one's psychological makeup. This grief may resurface at any time, particularly on anniversary dates of the birth or death of the loved one or on other special occasions, and may be just as intense as it was initially (illustration c). This provides for continual growth and thus, expansion of the outer circle.

Although another relatively simplistic model, the researcher asserts that Moody has still managed to capture some vital aspects of grief in his model. He has highlighted its individual nature and has expressed that, although relevant for him, this model may not be relevant for everybody who is grieving. His understanding that grief is a highly individual process is vital to all who are bereaved or work with the bereaved. Moody has also managed to capture the continual impact that grief has on the life of the bereaved individual. The incorporation of anniversary grief and the lifelong effect of grief on the bereaved is invaluable.

Despite these strengths of the model, however, the researcher believes that the model also has a number of shortcomings. As with the Dianne Arcangel's model, Moody's model is relatively simplistic and fails to outline the complex emotional processes involved in grief. In his development of the model, specifically in relation to himself, Moody has also failed to incorporate a model of grief that may be applicable for those who do not reach a level of transcendence.

c) Stroebe and Schut's dual process model of coping with loss. (Compare Cook & Oltjenbruns, 1998:100 -102, Stroebe & Schut, 1999: 197 – 224, Curren, 2001: 101 – 104.)

Figure 3. Dual-process model of coping with loss



(Adapted from Cook & Oltjenbruns, 1998:101.)

Figure 3 depicts a model of grief developed by Stroebe and Schut (1999) in order to describe the process of grief that a bereaved person follows. (Compare Cook & Oltjenbruns, 1998:100 - 102, Stroebe & Schut, 1999: 197 – 224 and Curren, 2001: 101 – 104.) According to these theorists, a bereaved person oscillates between what they call a loss orientation and a restoration orientation. Loss orientation involves the bereaved person's concentration, dealing with and processing of, the aspects that arise associated with the experience of the loss. This involves intensive and demanding grief work. Restoration orientation, on the other hand, involves the adjustment to the various changes that arise as a result of the loss. Coping with daily challenges, taking on new roles and learning new skills are examples of such changes. The core belief of this model is that, in coming to terms with a loss, the bereaved person moves between loss orientation and restoration orientation.

Central to this model is the idea that it is necessary for one to 'take time off' from the grieving process in order to recuperate and restore oneself. (Compare Cook & Oltjenbruns, 1998: 100 – 101, Davis, 2000: 57 and Curren, 2001: 103.) Grief work can be enormously engulfing and exhausting and the suggestion is made that, in certain circumstances, it is not inappropriate for

denial strategies and grief repression to come into play. Such 'time-out' allows one the opportunity to regain the strength and the sanity to deal with the difficult grief work that lies ahead.

This model is highly effective in that it takes into account the importance of culture and gender in dealing with grief (Cook & Oltjenbruns, 1998:101 –102 and Curren, 2001: 106 - 107). This has practical implications and allows the grief worker to recognize the impact of the social society in the way that one deals with his or her grief. The model also takes into account the demands of grief work and the impact of the grief, both on the person's immediate adjustment and on his or her future restoration. The model, however, fails to incorporate the understanding of dysfunctional grief.

2.6 GRIEVING A BABY

'I really don't think there can be anything more horrifying than to have your own baby breathe his last breath in your arms' (Thomas, 1993: 18).

The loss of any deeply cared for and loved child is especially painful for parents and is unique in its impact and intensity. "Losing a child is probably the most painful and devastating event that a parent can ever experience. One expects to lose one's parents, and to become a widow or widower is entirely possible, although painful. But in our society, to lose one's child to death seems out of order, unthinkable, a stunning, devastating turning of the tables" (Milo, 1997: 443). Such a death appears to be out of the natural order and most parents are totally unprepared to cope with such a loss. This is particularly relevant with the loss of a baby. According to Gensch and Midland (2000: 286), when a baby dies, the parents' dreams and hopes for that child also die. Instead of planning a nursery and a future for the child, the parents are left planning a funeral and a burial (Engler & Lasker, 2000: 228). Ingram (1997: 40) describes how she "...had dreamed of doing a million tiny things for my daughter. I would read to her every night. I would always answer her questions honestly. I would even be nice to the callow boyfriends she would bring home some day". All of these dreams for her daughter were lost when her daughter died and, although she would possibly have more children one day, the dreams that she had had for that particular child would never be realized.

According to Kohner and Henley (1997: 9) the significance of a baby's death has not been recognized in the past and bereaved parents have often struggled alone with a grief, which others have neither understood nor acknowledged. They go on to express that, while certain

grief issues are unique to parents grieving a baby, the loss of a baby is just as significant and heartbreaking as the loss of any other child or person. Gensch and Midland (2000: 290) echo this belief and express that grief is experienced in relation to the significance of the attachment, not the length of the pregnancy. One has a significant attachment to his or her child, regardless of his or her age. After interviewing many bereaved parents, Schiff (1979: 4) came to the conclusion that "...it does not appear to make a difference whether one's child is three, thirteen, or thirty when he (sic) dies. The emotion in each of us is the same". The lack of understanding for their feelings of grief, often leaves parents who are mourning a baby questioning their emotions and feeling guilty about the intensity of what they are experiencing. Very frequently, the death of a baby is also the parents' first real experience with grief. The depth of the emotions that the parents find themselves experiencing is often overwhelming and parents frequently describe themselves feeling anxious, bewildered, desperate, empty and numb. Coupled with the lack of acknowledgement for these feelings, parents are often alone in their grief and abnormal grief responses are not uncommon. According to Engler and Lasker (2000: 228) as many as 20 to 30 percent of women show some form of complicated grief in the first year following a perinatal loss. (Compare Leon, 1990: 32 – 35; Thomas & Williams, 1995; Chumbley, 1997: 107 – 109; Gensch & Midland 2000: 286 – 287; Ujda & Bendikson, 2000: 265 –266; Leh, Reiser & Pauli, 2002: 4 – 5 and Oikonen & Brownlee, 2002 125.)

2.7 MATERNAL GRIEF PREDICTORS

According to Engler and Lasker (2000: 229 - 231) a number of factors can be used in predicting whether or not a mother's grief, following the death of a baby, will be 'healthy' or complicated. It is important to note that, these maternal grief predictors by no means suggest that the mother's grief will not be painful and that the mother will be spared from doing very difficult grief work. They are solely designed to predict whether or not the mother's grief will follow a regular pattern or will become complicated in nature. These factors, which will be discussed in more detail below, include:

- *Support* –strong familial and social support, as perceived by the mother, can make a significant difference in her ability to cope with her grief.
- *Relationship satisfaction* – a strong marital or couple relationship, where there is a deep understanding of one another, aids the grief process.
- *Ways of coping* – people who cope by using their own inner strength along with the support offered by others, generally manage the grief process better than those who try to cope on their own. (Compare Rybarik, 2000: 222.)

2.7.1 Support

It is widely believed that the support received by the mother following the death of her child is the single most important factor in predicting the nature of the grief process that she will experience. According to Riches and Dawson (2000: 10) the experience of everyday support, patterns of family interactions, friends, relationships with people at work and in the neighbourhood, specialized agencies, and self-help groups, are all crucial in coming to terms with bereavement. The understanding and acknowledgment that the mother perceives she is given and the ability for her to feel free to express herself in a caring and non-judgmental environment, all have a significant impact. (Compare Engler & Lasker, 2000: 229; Miller, 1998: 64 - 65 & Rich 2000: 246.) The researcher has divided the discussion on support below into the categories of familial support and social support.

2.7.1.1 Familial support

Families are often changed by death. Some appear to be brought together in their grief while others appear to become more distant from one another. Riches and Dawson (2000: 5 – 7) outline four basic principles necessary for the understanding of the support that will be provided by families. Firstly, bereaved parents are a surviving part of a family network damaged by the loss. Secondary losses can take place if there is a breakdown in communication. This will add to the grief of the mother who often feels isolated in her preoccupation with her loss. Secondly, the reactions that the family members display towards the grief, is affected by the member's social position in the family and outside networks. As a result, misunderstandings can easily occur in the interpretations of grief responses displayed by alternate family members. Thirdly, the family's culture and the subculture of its individual counterparts affect the individual's beliefs concerning death. This can also lead to misunderstandings about other family members' feelings. Finally, grief frequently leads to an adjustment in the ways that the bereaved act and think about themselves and their families. Individual meanings concerning the death need to be reconciled into a shared picture of what has happened to the family in order for the support given to the bereaved mother to be adequate.

An open and supportive relationship with the family is an important resource for a bereaved mother. According to Nadeau (1998: 236), family dynamics, family structure, and a variety of family contextual features interact with meaning making to determine outcomes in grief. The openness with which a family discusses death and the support that they receive from one another, is of paramount importance to the nature and duration of the grief process (Nadeau,

1998: 216 – 217). Unfortunately, however, when a baby is lost, the family of the mother, while sharing her bereavement, is frequently unable to grasp the significance of her loss. For this reason, mothers often find it difficult to access adequate and helpful support from their familial resources. A mother's experience of her familial resources is largely dependant on the nature of her family and very individual and unique to each situation. While some families tend to be very supportive of the mother, others are unable to understand the depth of her grief, encouraging her (with the best intentions) to simply move on with her life. (Compare Kohner & Henley, 1997: 74 – 85; Riches & Dawson, 2000: 18 and Oikonen & Brownlee, 2002: 126 - 128.)

The researcher is of the opinion that the nature of the support provided to the mother is also largely dependant on the nature of the relationship that the mother had with her family prior to the death of the baby. A strong relationship tends to result in a more supportive and understanding response while a weaker relationship, results in a more negative response. The researcher, for example, had a close relationship with her parents and siblings prior to the death of her daughter. As a result, the support that she received from them, following the death, was extremely beneficial to her. In her grief, her family was able to sense what she needed and she was able to express to them when they were not being helpful.

2.7.1.2 Social support

'I can always find people who, when they hear about our loss, will say "Well, it was probably a blessing." I fight my rage. ...The real blessing has come in the form of kind friends who don't try to explain away my grief' (Ingram, 1997: 20).

Social support and the comments made by society following the loss of a child will, to a great extent colour the nature of the grief that the mother will experience. The importance of a strong social support network to the bereaved cannot be highlighted enough. As with families, the less support the mother receives, the more complicated her grief. Understanding, empathy and genuine concern displayed towards the mother, however, will make the grief process more bearable. (Compare Engler and Lasker, 2000: 231; Rich 2000, 246 and Currer, 2001: 118 – 120.)

According to Durlak (1998: 61) and Rybarik (2000: 222) the comments made by a mother's social network following the loss of a child become integrated as a part of her social support received. Some comments are helpful while others are extremely offensive. Ingram (1997: 77) expresses the dilemma succinctly in her description of the support received by a mother after

the loss of her daughter: "One friend, fumbling awkwardly for the words to say, murmured, 'Try to forget'. If there's one thing I don't want to do it's forget my child. I want to remember every detail of that little life, every miniature finger and toe, every curve of that baby-born-too-soon mouth. I cherish that brief moment when our baby cried, and I play that memory over and over in my mind. My friend meant well, but if I forget, I have nothing." Comments like 'you can always have another one' and 'it would have been worse if he or she was older' are also all too common and, although well intentioned, leave parents feeling even more intensely isolated.

Society in general struggles to deal with the bereaved and, even more so, those who have lost a baby. The significance of such a loss is seldom acknowledged and, although the loss of a baby is extremely devastating for all involved, those who have not experienced it, seldom understand the devastation. Parents have reported feeling abandoned and isolated by friends and the community and the lack of acknowledgement of their grief, often prolongs the grief process, leaving many lingering, unresolved issues. According to Kübler-Ross (1997: 51 – 63) feelings of isolation are normal in a response to grief. '*Nobody understands,*' is a statement that loved ones often express. With the death of a baby, however, this is very acute as, in reality, most people really do not understand. The lack of such acknowledgement and empathy has resulted in few resources being available to many mothers who have had this devastating experience. For this reason, it is of paramount importance that the community is educated on how to deal with the bereaved and which comments are helpful and which are not. The community also needs to be more informed about the devastation of parents who have lost a baby specifically and more services need to be put in place to help them to cope with the grief process. An understanding as to the significance of the loss of a child is tremendously meaningful in the recovery from such a loss. (Compare Engler & Lasker, 2000: 231 and Curren, 2001: 118 – 120.)

2.7.2 Relationship satisfaction

The death of a child changes a couple's marriage. According to Rosenblatt (2000: 5), couples dealing with the death of a child are "...likely to be beginners at dealing with the kind of grief parents feel and beginners at coming to terms, as a couple, with whatever is going on in you as individuals and as a couple". The death of a child, therefore, places a huge strain on the marital relationship. It requires a readjustment of the relationship in order to realize the role that grief will take. The death has to be dealt with by each parent as individuals and together as a couple in circumstances where it is difficult to find the outside social support of others who have experienced the depth of what the couple has. The individual needs to be aware and tolerant of the way that his or her counterpart deals with grief and non-judgmental of his or her process.

Often, because parents experience the loss simultaneously and are therefore grieving simultaneously, the mutual support that they may have offered one another is removed and the grief process can become complicated as a result. (Compare Engler & Lasker, 2000: 229.)

Although studies do not show conclusively that the divorce rate amongst those who have lost a child is higher, they do suggest that the loss of a child can demonstrate to couples the fragility of their relationship. The death of a child may allow both the individual and the couple to change and examine values and perspectives that count most for them. In so doing the couple may find that they are moving towards new perspectives on the meaning of life and on what is important in life. The changes that take place may affect the individuals in the couple differently and conflict may arise as a result. Further, such conflict may be complicated by the fact that men and women usually grieve differently. A lack of acknowledgement of these differences, can lead to misunderstandings and a breakdown in communication. This complicates the grief process and makes the loss of the child even more difficult to bear. (Compare Zucker, 1998: 63; Rich, 2000: 260, Rosenblatt, 2000: 4 – 10 and Rybarik, 2000: 222 and Wheeler, 2000: 68 – 69.)

Couples who share the loss of a child, however, often grieve together. According to Engler and Lasker (2000: 229) "...a strong marital relationship ... can smooth the grieving process after the loss and may prevent an increase in grief scores." (Compare Riches & Dawson, 2000: 18 and Rosenblatt, 2000: 10.) Comfort and support from a spouse or partner are very important grief predictors and if grief can be shared within the marital or couple relationship this can be a major resource. "Opportunities to share perceptions of joint loss with a partner, to offer mutual support and remember the details of the deceased's life that no one else is likely to appreciate, can provide enormous comfort" (Riches & Dawson, 2000: 18). The marital relationship can provide a safe and non-judgmental environment for individuals to express their strong feelings without fear of rejection.

The researcher found that, following the death of her daughter, she felt closer to her husband than ever before. In an environment where the community at large did not appear to understand the significance of her loss, she was aware that he was the only person who truly knew what she was going through. Although at times, grieving was difficult – as she preferred to speak about the loss, while he preferred to deal with it quietly within himself, the help of a support group and the understanding of each other's processes ultimately brought them closer together.

2.7.3 Ways of coping

According to Engler and Lasker (2000: 229 – 230), there are eight different types of coping strategies that mothers who have lost a child may display. These eight coping strategies may be analysed further according to three major categories. These will be discussed below:

- 1) *Confrontive coping* – The mother resolves to stand her own ground and face the grief that she is experiencing head on. According to Kübler-Ross (1986: 101 –103) this is essential to healthy grieving, but should always be done with the support of others;
- 2) *Planful problem solving* - Very similar to confrontive coping, the mother dives into the grieving process under the knowledge that it has to be done in order to resolve the grief. Grief is planned;
- 3) *Distancing* – The mother attempts to distance herself from her grief by involving herself in other activities;
- 4) *Self-control* – The mother practices self-control by keeping her emotions to herself;
- 5) *Accepting responsibility* – The mother lectures herself concerning her grief and the death and takes responsibility for the emotions that she is experiencing;
- 6) *Escape – avoidance* – The mother attempts to run away from what she is feeling by wishing the emotions away. She avoids dealing with the intensity of the emotions at all costs;
- 7) *Positive reappraisal* – The mother deals with her grief by expressing to herself that she has grown from the grief in a good or positive way;
- 8) *Social support seeking* -The mother actively seeks social support in order to cope with her grief.

The first category of analysis involves confrontive coping and planful problem solving. This category uses the person-in-environment relationship in order to deal with stress. The mother takes an active role in the grieving process. The second category involves emotion-focused grieving. Distancing, self-control, accepting responsibility, escape-avoidance and positive reappraisal are all examples of such grief. In this category, coping is attempted through diverting energy from the grief itself and changing the attention given to the problem. Finally, social support seeking fits into a category of it's own. Here the mother acknowledges the value of social support in coping with her grief and actively seeks the support needed for her to be able to do so. (Compare Ryan, 2000: 3 and Parkes, 2003: 43.) According to Engler and Lasker (2000: 230), coping with grief is most effective when one's internal coping mechanisms are used in conjunction with social support while grief is tackled head on. The use of emotion-focused coping alone generally has a negative effect on the grief process and frequently results in complicated grief. Mothers need to learn to ask for support when they need it.

2.8. SERVICES AVAILABLE FOLLOWING THE DEATH OF A BABY

The lack of understanding displayed by society for the significance of the death of a baby, has often resulted in the support services for mothers having lost a baby being of a poor standard. Consequently, bereaved mothers have often struggled alone with a grief, which others have neither understood nor acknowledged. Keeping their grief to themselves and using only emotion-focused coping mechanisms as a result, has complicated their grief and made the death of their babies all the more difficult to bare. (Compare Rank, 1985: 17 – 19, Kohner & Thomas, 1995: 1, Thomas & Williams, 1995 and Ryan, 2000: 3.)

Accessing services that offer support and acceptance is essential if the grief process is to be well reached (Rich, 2000: 246). Unfortunately, mothers seldom feel these benefits, as the services provided are not only inadequate, but poorly accessible as well. Awareness of the needs of mothers who have lost a baby and the need for helpful, accessible services to cater for them must be raised in order to aid mothers through the grief process and prevent complicated grief. Below, three important service delivery institutions: hospital services; religious services and services in the formal sector, will be discussed in more detail according to the services that are offered and those that are required.

2.8.1 Hospital services

As most babies lose their lives within a hospital setting, the supportive nature of the hospital services provided to bereaved mothers is of particular relevance. According to Kohner and Henley (1997: 47) most parents have very vivid memories of their baby's death and all the events surrounding it. The empathy and care that the mother received in the hospital where her baby lost his or her life will, generally, dictate the nature of the memories that she has. For this reason, effective hospital services for bereaved mothers are vitally important. Parents who receive adequate support after the death of a baby generally come to terms with their loss more easily and are able to carry on with their lives with more ease. This by no means suggests that their child is forgotten, but merely that they are able to integrate their grief more effectively into their lives. (Compare Gensch & Midland, 2000: 288; Ryan, 2000: 159 – 165 and Rybarik, 2000: 222.)

Although this is hospital specific, it appears that hospital support programmes are generally not sufficient and in place. According to Gensch and Midland (2000: 286 – 287) it has become increasingly apparent that many of the recommendations offered to parents experiencing a loss

actually tended to deny the existence of their baby and their identity as parents to the baby who died. Few antenatal classes offer advice on how to deal with such a loss under the mistaken belief that infant loss has basically been eliminated. This causes problems for parents who lose a baby by compounding the shock and disbelief that they feel. As a result, without the adequate support and guidance, the shock and numbness that parents feel often leads to their making decisions concerning their baby that are later regretted. Parents are in unknown territory and the way that they are dealt with following the death of their babies will influence their grieving process and have lifelong consequences. For this reason, hospital staff must be adequately informed and trained on how to deal with parents in times of loss. Understanding of the depth and significance of the loss of a baby is essential and a proper strategy and programme needs to be in place for parents following a death. (Compare Gensch & Midland, 2000: 286 – 287 and Kavanaugh & Paton, 2001: 369 – 376.)

Gensch and Midland (2000: 286 – 290) offer a number of points that should be taken into account by hospital staff when devising a strategy to deal with bereaved parents. Assisting in making memories of the deceased baby is one of the most important efforts in aiding the bereaved parents. (Compare Thomas, 1993: 8 – 16; The Child Bereavement Trust, 2000: 2; Ujda & Bendikson, 2000: 310 – 321 and Kavanaugh & Paton, 2001 369 –376.) The options that should be offered to the parents are listed below:

- Parents should be encouraged to hold or touch the baby following his or her death and this offer should remain open for a period of time. The significance of such a step cannot be emphasized enough. According to Gensch and Midland (2000: 288) preventing opportunities to see and hold the deceased baby complicates the mother's grief. (Compare Durlak, 1998: 61.) The researcher strongly agrees with this point. Although she was fortunate enough to have shared a number of weeks with her daughter at home prior to her death, she still regrets not having spent longer with her after she had died in order to say good-bye. The hospital did encourage her to hold her daughter while she died, however, and for this she will be forever grateful;
- Photos of the baby from different views should be taken. In the future, these will be the mother's only physical reminders of her child and many mothers who were not given photographs of their child go on to regret this for the rest of their lives;
- Journals, memory boxes or memory books should be provided to the parents. In these boxes footprints, handprints, locks of hair, toys, clothing worn and other significant items may be placed. The baby should also be weighed and measured and these items placed in the journals. The researcher was not offered such an option following the death of her baby.

She still regrets not having a lock of her daughter's hair as a concrete, tactile reminder of her;

- Baptisms or religious ceremonies should be offered to the parents. Parents should also be aided through funeral plans that they might need to arrange;
- Accurate and detailed information concerning the cause of death should be provided to the parents. Parents should be given the opportunity to ask any questions that they feel they need to know. Hospital staff must be honest in their descriptions of the baby's condition – even when it is poor. Ongoing communication ultimately enhances the well-being of the parents;
- Mothers who have lost their babies must not be placed in the maternity ward with other new mothers. It is too difficult for these mothers to see others with their healthy babies;
- Although contentious, many mothers have expressed that they appreciated it when the hospital staff showed their emotions and cried with them when their babies died. This showed them that their babies had had an impact on lives other than their own;
- Counselling by a trained professional should be offered to the parents prior to, if possible, and immediately after the death. Details for support groups and web site addresses must also be provided. Follow-up phone calls should be made to the parents after they are discharged from the hospital. (Compare Ujda & Bendikson, 2000: 267.)

2.8.2 Religious services

Following the death of somebody close, it is normal for one's religious beliefs to be shaken. The bereaved often question the fundamentals of their beliefs, as frequently the nature of what they once believed to be true is called into question. Many begin to form new perspectives of their religion that integrate their experience. Kübler-Ross (1986: 156) believes that religion should aid the individual in growing and transforming his or her life through his or her loss. (Compare Tattelbaum, 1980: 80 – 85.)

Biebel (1997: 29), an American pastor, describes how his 'faith had been sorely tested' following the death of his three-year old son. In his honest, sincere and poignant description of the death of his son and his grief that followed, he is able to give a unique encounter of what it is like to be a pastor who is confronted with this life-altering event. He speaks candidly about how his religious beliefs, that once were the core of his profession and being, were for the first time called into question and how he had to alter many of the viewpoints that he once had. He expresses that beliefs that he once held to be true had to be altered and how these new beliefs informed his future ministry. Pregent (1992: 41 – 44) also gives an account of how her faith was shaken

following the death of her daughter, Lisa. ‘ When Lisa died...God dies (sic) too’ is a statement she makes as she describes how she felt totally alone following the death and found no comfort, no relief and no explanation in religion. She describes a shattering of the image that God would heal her daughter, and the pain that she experienced, if her faith was strong enough and how she had to redefine these beliefs that she once held so dear.

According to Nadeau (1998: 184 - 190), following the death of a family member, people tend to take on one of four main approaches towards religion in order to make sense of the death: -

- *Revelation, reunion and reward* – People taking this viewpoint generally believe that, while they are unable to understand the death of their loved one now, some day, usually in the afterlife, it will make sense to them;
- *Death as a test* – People taking this viewpoint believe that their loved one passed away as some sort of test of faith, courage and strength. This test may be for the loved one or for the bereaved;
- *God caused the death* – In their search for meaning in the death of their loved one, people may take on the stance that God was responsible. Resultant statements made about God may be positive, for example ‘God wanted her for an angel’, or negative, for example ‘God didn’t save him’. Many display great anger towards God;
- *General statements about faith and God* – Asking questions concerning the meaning of the death, often results in many statements being made about faith and God in general. One’s faith following the loss of a loved one is often shaken and one begins to struggle with the core questions posed by one’s religion.

The experience of the mother of the religious support that she received following the death of her baby is of great significance. Questions concerning death and the afterlife have suddenly become painfully significant and much of what she believed has been shaken. The tolerance that her religious institution has for her changing emotions and for the depth of her grief, despite the religious beliefs, may dictate her future feelings towards her religion. Religious institutions need to become more aware of the needs of mothers following the death of a baby and need to adapt their services so as not to alienate, but rather support them. Leaders need to be tolerant of the mother’s questioning her religion and possible anger towards God, and answer all questions as honestly and caringly as they can. Unhelpful statements including ‘she’s in a better place’, ‘she is with God now’, ‘it all happened for a reason’ and ‘don’t grieve - he wouldn’t have wanted that. Your crying holds his spirit back’, should be avoided at all costs. These statements are, as Lewis (1966: 24) put it, a “...comfort to the God-aimed eternal spirit within her. But not to her motherhood”. A lack of acknowledgement by her religious institution for the grief that the

mother is experiencing and allowance for her to experience it can complicate grief for the mother. As one's religion often dictates one's way of looking at the world and one's philosophy of life, this is of absolute paramount importance if the mother is to recover from her loss. (Compare Tatelbaum, 1980: 80 – 85; Rank, 1985: 43; Kübler-Ross, 1986: 156 and Kissane & Bloch, 2002: 87 – 90.)

Although the researcher found her church and minister enormously supportive and understanding following the death of her daughter, some of the religious stances expressed to her were not helpful at all. People, possibly in their own quest to understand the death, constantly appeared to be surmising the reason for her passing. Many of these reasons, the researcher felt, insulted the significance of her daughter's life. The researcher also struggled to integrate many of the religious teachings into her new perception of reality and found much of what those, who had never experienced a major loss in their lives, believed, very naive.

2.8.3 Formal services

Counselling services, support groups and support networks provided for the mother following the death of her baby can have a significant impact on the healing process. Most mothers find it enormously beneficial to speak with other mothers who have also lost a baby and truly understand what they are going through. This kind of support allows mothers to normalise their feelings and work through their grief in a supportive and caring environment. The opportunity for the mother to talk freely and honestly without feeling angry, guilty or ashamed about her feelings provides emotional support. Such emotional support of the mother is necessary in order for her to be able to cope with the grief process. Many mothers, however, have found support from the formal sector strikingly absent. Support services for mothers who have lost babies have been few and far between and, mothers are generally totally unaware of those that are available. With a greater body of knowledge being provided concerning the significance of the loss of a baby, however, this is changing. (Compare Kohner & Thomas, 1995: 32 – 36; Riches & Dawson, 2000: 18; Ryan, 2000: 3 and Ujda & Bendikson, 2000: 266-269.)

It is now known that formal counselling services provided to the mother following the death of a baby can have a significant impact on her grief process. According to Thomas (1993: 21 – 23), there are a number of skills that bereavement counsellors, whether in an individual or group setting, must possess in order to adequately aid the bereaved:

- A counsellor must be empathic, trained and self-aware. (Compare Stillion, 1998: 62 – 63.)

- A counsellor must have a thorough knowledge of the grief process so as to be able to help parents identify and normalise their feelings. He or she must know where the bereaved is in the process and what is required of him or her to be able to move on with his or her life. (Compare Jacobsen, Kindlen & Shoemark, 1997:179; Gensch & Midland, 2000: 288 – 289; Riches & Dawson, 2000: 18 and Curren, 2001: 130 – 135.)
- A counsellor must always be non-judgmental and all of the mother's feelings must be validated in a caring environment. (Compare Kavanaugh & Paton, 2001 369 – 376.)
- A counsellor must be up to date on the advances in bereavement research.
- A counsellor should help the mother to identify her ways and means of coping and her social support structure so that she is better able to cope when her counsellor is not available. (Compare Kavanaugh & Paton, 2001 369 – 376.)
- A counsellor should be willing to listen, without making comment, to the mother's story. According to Nadeau (1998: 240) people make sense of their experience by telling stories over and over again. (Compare Jacobsen, Kindlen & Shoemark, 1997: 179 and The Child Bereavement Trust, 2000: 1.)
- Without providing answers, the counsellor needs to allow the bereaved to access their own innate wisdom concerning their grief in order to recover. The counsellor needs to withhold advice about what he or she believes is best and be non-directive.
- A counsellor must not try to remove the pain of the mother, but rather help her to become aware of the pain that she feels and progress through the grieving process. (Compare Curren, 2001: 141 – 143.)
- A counsellor should be receiving supervision, or have his or her own professional support network.
- A counsellor should coordinate remembrance activities for the mother. He or she must help the mother to create memories of the child that she has lost. (Compare Gensch & Midland, 2000: 288 – 289.)

As many babies lose their lives in a hospital, many of the counselling services are provided to parents by hospital appointed counsellors. Alongside the abovementioned skills of a counsellor, these counsellors need to: (Compare Thomas, 1993: 21.)

- Be available to offer support as soon as possible after the death of the baby, if not before. (Compare Curren, 2001: 130 – 135 and Kavanaugh & Paton, 2001: 369 – 376.)
- Provide the parents with all options concerning their child and make sure that all options are explored before decisions are made.

- Be prepared to clarify information for the mother and, if necessary make contact with the medical staff responsible for the baby in order to do so. (Compare Kavanaugh & Paton, 2001: 369 – 376.)
- Provide home visits and follow-up counselling services after the mother has been discharged from the hospital. (Compare Currer, 2001: 130 – 135.)
- Remember anniversary dates of the baby's birth and death and contact the mother to provide support on these days.
- Train medical staff on how to deal with mothers who loose a baby and make sure that a proper procedure and structure is in place should such an eventuality occur.
- Communicate with parents who are having a new baby of the loss of a previous one. (Compare The Child Bereavement Trust, 2000: 3 and Wheeler, 2000: 310 – 326.)

The researcher acknowledges the benefit of being offered the opportunity to, not only speak to professionals, but also other mothers who share the same experience following the loss of a baby. This cathartic exercise allowed her to better cope with the grieving process. In fact, so much so, that she and a friend, who had also lost a baby, set up a support network for mothers in the same situation. Currently, The Compassionate Friends offer the support group itself, a group that was of great benefit to the researcher.

2.9. CONCLUSION

It has been clearly demonstrated by the discussion above that the death of a baby is an emotional and difficult time in a mother's life. The grief process, often called *grief work*, is enormously taxing to experience and takes a great deal of time to recover from. It is paramount, in order to prevent the mother from experiencing complicated grief, that support is offered to her to aid her through the grief process. Three major services that offer support to the mother have been discussed. These services need to be of a high standard and easily accessible to mothers if their benefits are to be reaped.

CHAPTER 3

EMPIRICAL STUDY

3.1 INTRODUCTION

This chapter seeks to present the findings of the study that the researcher has conducted. The findings will be presented both quantitatively (making use predominantly of percentages and graphs) and qualitatively (making use of themes and sub themes). As the identified research approach was the dominant-less-dominant approach (quantitative being dominant and qualitative, less dominant) this is the necessary analysis (Creswell, 1994: 173 – 190, De Vos, 1998: 360 - 361 and De Vos, 2002a: 366).

The researcher conducted her study with fifteen mothers who had lost their babies to a stillbirth or neonatal death within the last five years. The names and telephone numbers of these mothers were received from their various support networks and so the researcher was able, with confidence, to know that the mothers had a constant support backing should they feel that they needed extra debriefing following the interview. Obtaining a research sample from the research population, however, was not easy. Understanding the sensitive nature of the information being discussed, and staying within the ethical confines of the study, the researcher had to allow mothers to turn down the opportunity to be involved in the study. This was indeed the case with many of the mothers and, in each instance, the researcher explained to these mothers that they were fully within their rights to turn down the request should they feel they could not manage the interview.

The interview sessions conducted with the mothers were also very time-consuming. Again, the researcher attributed this to the sensitive nature of the information under discussion and, on each occasion, allowances of time for the mothers to digress from the questions being asked and for the mothers to be debriefed following the interviews, needed to be made. All of the mothers involved, however, were extremely interested in the research and many had suggestions concerning the ways in which the research could inform the different services that they had experienced.

In her capacity as the researcher, the interviews were found to be emotionally exhausting. Despite the schedule's avoidance of discussing the deep-seated emotional concerns of each parent, these inevitably arose in many of the interviews and frequently

required that the researcher debriefed the mother being interviewed. The researcher was very grateful to have the support of her network following such interviews and the occasional debriefing that she received from them, when she felt the need, was invaluable.

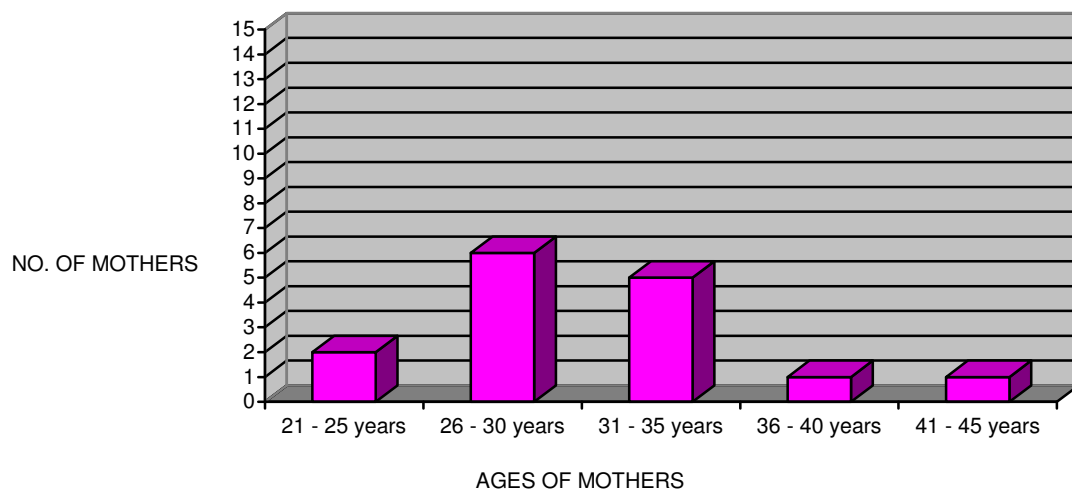
3.2 FINDINGS OF THE STUDY

As mentioned above, the findings of the study will be represented both quantitatively (predominantly by means of percentages and graphs) and qualitatively (by means of themes and sub themes). These findings are presented according to the six different sections of the administered schedule and are discussed in detail below.

3.2.1 Section A: The demographic data of the study

The fifteen mothers who were interviewed ranged from the ages of twenty-three years old to forty-one years old, with a mean age of thirty-one years. Their ages are represented in Figure 4 below.

Figure 4: Ages of the mothers interviewed (n = 15)



As depicted in Figure 4, two (13.33%) of the mothers interviewed were between twenty-one and twenty-five years of age, six (40%) of the mothers were between twenty-six and thirty years of age, five (33.33%) of the mothers were between thirty-one and thirty-five years of age, one (6.67%) mother was between thirty-six and forty years of age and one (6.67%) mother was between forty-one and forty-five years of age.

Four (26.67%) of the mothers interviewed only have the child who has passed away. Six (40%) of the mothers have two children, four (26.67%) have three children and one (6.67%) has four children. All of these numbers are including the baby/babies who passed away. Three of the mothers were pregnant, one with her second child and two with their fourth child. Two of the mothers lost twins.

In total, there were seventeen babies who had passed away. Twelve (70.59%) of these babies were male and five (29.41%) were female. Five (33.33%) of the mothers interviewed had lost their baby within the last year. Three (20%) of the mothers had lost their baby two years previously, five (33.33%) had lost their baby three years previously and two (13.33%) had lost their baby four years previously.

For ten (66.67%) of the mothers interviewed, the baby who had passed away had been their first child. Five of these mothers had gone on to have another child and one had gone on to have two more children. Four (26.67%) of the mothers interviewed had one child already at the time of their baby's death. One had a one-year-old at the time of the death, two had two-year-olds and one had a four-year-old. Two of these mothers had gone on to have other children, one of them having adopted another child. Finally, one (6.67%) of the mothers had two children at the time of her baby's death – a five-year-old and a two-year-old. She is currently pregnant with her fourth child.

Five (29.41%) of the babies were stillborn. Three mothers were aware of the reasons for the stillbirth and two were not. Five (29.41%) babies died as a result of prematurity and related consequences. One of these babies was five days old, one was three days old and three were two days old when they died. Three (17.65%) of the babies died as a result of genetic abnormalities. One of these babies was five days old, one was three days old and one was two days old at death. Three (17.65%) babies died as a result of illness. One of these babies was one day old at the time, one was nine days old and the oldest baby was twenty days old at the time of her death. Finally, one (5.88%) of the babies died as a result of asphyxia during the birth process. He lived for a day. The mean age of the babies at the time of their death was three days old.

3.2.2 Section B: Support

All of the mothers interviewed felt that they had needed support in order to help them to cope with the loss of their babies. One of the mothers expressed that she does not turn to people for support and that the support needed to be initiated by them. When asked to whom the mothers turned to for support, three major themes emerged. These included their husbands/partners, their families and their friends.

All of the mothers interviewed described the support that they had received from their husbands/ partners. Two major sub-themes emerged in this support where mothers' descriptions were that their husbands/partner were totally supportive or totally unsupportive. Four of the mothers, however, were ambivalent about the support that they had received from their husbands/ partners.

Some of the mothers simply said that their husbands / partners had been very supportive of them following the death of their baby. While these mothers acknowledged that their husbands/partners were grieving too, they felt that the experience had brought them closer together through their mutual support of one another.

Most of the mothers, however, felt that their husbands had not been supportive at all. Some of these mothers went on to explain this lack of support as their husband's/partner's denial of his own grief feelings. They wondered if their husbands/partners grieved differently and if this accounted for the lack of support that they received. Some felt that their husband's grief was probably not as intense. One mother felt that, rather than meaning to be unsupportive, her husband simply did not know how to offer her the kind of support that she needed.

The remaining mothers had mixed descriptions of the support that they received from their husbands/partners. One described her husband as having been supportive in that he offered strength in a time where she felt totally lacking in that regard. She felt, however, that he was unsupportive in that he did not speak about the loss and she so desperately needed to discuss it. Another mother said that her partner was supportive following the loss, but a month thereafter, was too overwhelmed and left her. Similarly, the third mother said that her husband had been extremely supportive at first, but as time wore on, she felt that he had heard enough and was tired of dealing with the grief. Finally, the last mother said that her husband, although supportive of her, had a

breakdown following the death of their son and so was unable to offer the support that she needed, as he needed support himself.

Chapter 2 (pages 45 – 46) discusses the marital relationship and grief following the loss of a child. Rosenblatt (2000: 4 – 10) believes that grief has a significant impact on the marital relationship. Members of a couple need to grieve the loss of a child both individually and together. The different ways in which women and men grieve often complicates this process and there needs to be an understanding and tolerance by both partners of these differences in order to smooth over the grief process and allow the couple to grieve together (Zucker, 1998: 63; Engler & Lasker, 2000: 229 and Rich 2000: 260). These differences in the grief process may well explain the high incidence of mothers feeling unsupported by their husbands/partners. Rather than meaning to be unsupportive, the support offered may be considered insufficient by the mothers as a result of a lack of knowledge about the grief process. Their husbands/partners may simply be unaware of how to offer adequate support and, in grieving differently, may be interpreted as being distant and unsupportive. It would be interesting, in this instance, to consider the husbands'/partners' interpretations of the support offered to them at the time of the loss of their babies by their respective wives/partners.

The second theme that emerged from the question was that many of the mothers interviewed said that they had turned to their families for support following the loss of their babies. Most of these mothers described their families as being very supportive, some focusing specifically on their mothers as having been supportive and one focusing on her sister as her support. Three of the mothers, however, described their families as not having been supportive at all. Two of these mothers felt that the lack of support was as a result of their families being bereaved themselves and, thus, unable to offer support to them. One mother felt that the support that she received was too suffocating and that her family tried to force their ideas on how best to cope with the grief onto her. She found this kind of 'smothering' support very unhelpful.

According to Nadeau (1998: 216 – 217) the family can be an enormous support to the bereaved mother if they are able to adequately understand her process and communicate openly about the death, and her needs, with her. A mother's experience of the support that she receives from her family, therefore, is largely dependant on the nature of her actual family, the dynamics of the family and the relationships that she shares with the different members of her family. (Compare Kohner & Henley, 1997: 74 –

85; Riches & Dawson, 2000: 18 and Oikonen & Brownlee, 2002: 126 - 128.) On the whole, the mothers interviewed found the support of their family was a strong resource following the death of their baby.

Thirdly, a number of the mothers interviewed expressed that they turned to friends for support following the loss of their babies. All of these mothers described these friends as having been enormously supportive, one of them going on to say that the fact that they were able to simply listen to how she felt was most important.

Some of the mothers also described other support systems that they had turned to following the loss of their babies. Two of the mothers said that they had turned to their psychologists for support. Both of these mothers found them to be extremely supportive as both of the psychologists were present at the hospital when their baby died. Both appreciated that the psychologists had given them procedural guidance and emotional support. One mother said that she had turned to her clients for support and found them very supportive. One mother said that she had turned to the sister who ran her antenatal classes for support and that this had been very helpful and another mother said that she had turned to God for support and that she felt that He had pulled her through. Finally, one mother said that she had turned to her child for support and that this had been extremely helpful as he had kept her busy and given her time away from her grieving.

Twelve (80%) of the mothers interviewed felt that society at large did not grasp the profundity of their loss. Two (13.33%) of the mothers felt that it did and one (6.67%) mother felt that some people did while others didn't.

All of the twelve mothers that believed that society in general did not understand the profundity of their loss, and the mother who felt that some people did and others did not, described feeling hurt and angered by insensitive comments made by people. This was a definite theme that emerged. These comments included:

- 'You can always have another one'
- 'Just get over it'
- 'Your baby is better off now'
- 'What if you can't have another one?'
- 'It was just a baby'
- 'You're lucky you have other children'
- 'It's not so bad'

- 'It would have been worse if he/she was older'
- 'At least you didn't know him/her'
- 'You are lucky he/she was so young'

One of the mothers described feeling very hurt when her sister-in-law who had lost her child who was twelve years old said 'Now you understand a little bit of what I feel'. This mother expressed that she felt that, in general, people quantified her loss based on the amount of time that she had spent with her baby rather than the significance of the person who was lost. She said that she believed that, in general, society does not seem to understand that the loss of a child is devastating at any time, and that time is of no relevance when a child dies. Part of the tragedy, she believed, when losing a baby, is that so little time was spent with the child. By the comments made to the mothers, it does appear that this is indeed the case. Unfortunately, offensive comments like these that are made to the mother, become integrated into her perceptions of the social support that she has received. (Compare Durlak, 1998: 61 and Rybarik, 2000: 222.) This may be seen that all, except one, of the abovementioned mothers described that society at large did not understand the profundity of their loss, and that they received poor societal support as a result.

Another theme emerging from the mothers who felt that society did not grasp the profundity of their loss, was the description of many mothers of their workplaces, specifically, as being very unsupportive. These mothers said that colleagues were avoidant of the topic of the baby and preferred not to discuss him or her. Three of the mothers expressed that their colleagues had told them that they needed to 'get over it' and one mother described being asked by a colleague why she was so sad. Two of the mothers also described a lack of support and understanding by their workplaces in subsequent pregnancies. One felt, however, that women colleagues, in general, were more understanding than men.

Two of the mothers who felt society did not understand the profundity of their loss felt hurt that people did not mention their baby's name and were offended that people, generally, did not remember their baby's birthday and the anniversary of their baby's death. One of these mothers also did not appreciate that her deceased child was not acknowledged by society as a member of her family. Similarly, another mother felt that society demonstrated their lack of understanding by not acknowledging her as a mother

and stripping her of her motherly role. She felt that this denied the existence of her child as well as patronising the bond that she had with her.

Two mothers that felt that society at large did not understand the profundity of their loss expressed that they believed that society, in general does not know how to deal with the bereaved. Grief clichés, inappropriate remarks and avoidance are all symptomatic of this. One said that she could always see those who had lost somebody close to them because they did not cringe when she mentioned her deceased baby's name. These mothers believed that society should be better educated on grief and how to best support the bereaved.

One mothers did not appreciate being singled out by society and treated as though she was not 'normal'. She expressed that she felt that she was treated like somebody who was unable to function and frequently, as a result, was avoided by people who did not feel they knew how to deal with her.

As expressed above, two of the mothers interviewed felt that society, in general, had understood the profundity of their loss. One of these mothers described her workplace as being very understanding while the other said that, although some insensitive statements had been made, she had surrounded herself by the right people and so felt very supported. She described that her son's school had been especially supportive, supplying her with meals and emotional support. She added that all of the flowers that she had been sent had also made her feel very supported. It is very interesting that these two women, the only two who felt that society in general had understood the profundity of their loss, both lost their babies within the last two months. It would be helpful to conduct a longitudinal study into people's perceptions of social support over time and see whether or not these two women would feel the same way as time moved on. Conversely, it would be interesting to see whether the twelve mothers who found society at large lacking in understanding would have felt the same way had they been interviewed closer to the time of their baby's death.

3.2.3 Section C: Hospital services

All of the mothers interviewed lost their babies within a hospital setting. Ten (66.67%) of the mothers described the hospitals that they were at as having been generally

supportive and five (33.33%) of the mothers described the hospitals as not having been supportive at all.

According to Gensch and Midland (2000: 286 – 290) hospitals should assist parents who have lost a baby in making as many memories of the baby as possible as, frequently, the contact that the mother has with the baby at the hospital is the only time that she will ever get to spend with him or her. Making memories aids the grief process and should be encouraged by all hospitals (Thomas, 1993: 8 – 16; The Child Bereavement Trust, 2000: 2; Ujda & Bendikson, 2000: 310 – 321 and Kavanaugh & Paton, 2001 369 –376). In so doing, a number of important options should be offered and, indeed encouraged, of parents. These will be discussed below.

Parents who have lost a baby should be encouraged to hold him or her. This offer should remain open for a period of time. Preventing such opportunities can complicate the grief process. (Compare Durlak, 1998: 61 and Gensch & Midland, 2000: 288.) Fourteen (93.33%) of the mothers interviewed did hold their babies when or after they died. All of these mothers greatly appreciated being able to do so. Seven of these mothers, however, expressed that they would have liked to be given longer time with the baby and felt that they would have liked the hospital to encourage them to do so. They were unsure of how long was socially accepted and did not feel that they were able to ask the staff if they could keep the baby for a longer period. One of these mothers was not given an opportunity to hold her baby in her own room and expressed that she would've liked time alone with her baby. Four of the mothers expressed that they were given as long as they wanted to with the baby, one adding that they also allowed her parents to spend time with the baby and that she greatly appreciated this. One (6.67%) of the mothers did not hold her baby. She expressed a great deal of regret and remorse in this regard. This mother explained that her deceased child was the first dead body that she had come into contact with and that she felt afraid and unsure of holding him. She explained that the staff members were very insensitive in this regard and that it was not explained to her that it was okay to hold him, even though he had died. She deeply regretted that she was not encouraged to hold him.

Photos of the baby, from different viewpoints, should be taken by the hospital. These will, frequently, be the mother's only physical reminders of her child. Only one (6.67%) of the mothers interviewed expressed that the hospital had taken photos of her baby as a part of their procedure and one (6.67%) mother expressed that a nurse had taken photos of

her baby in her own capacity, but not as a part of the hospital procedure. Despite this, however, nine (60%) of the mothers interviewed were able to take photos of their baby at the hospital. Four (26.67%) of these mothers were encouraged to do so by the hospital and the other five (33.33%) did so of their own accord. Six (40%) of the mothers did not take any photos at the hospital, nor were they encouraged to do so. One of these mothers had photos of her baby already as she had taken her baby home for three weeks prior to her death and one of these mothers took photos of her baby at his funeral. Five of the six mothers, however, felt that they would have liked to be encouraged by the hospital to take photos of their baby.

Mementos including memory books/boxes, journals, hospital bands, items of clothing, footprints, handprints and locks of hair should be provided for the mother. These may provide concrete and tactile memories of the baby who has passed away. None (0%) of the mothers interviewed were given a memory box or a memory book by the hospitals in which their babies died. Twelve (80%) of the mothers were given footprints and two (13.33%) of the mothers were given handprints. Two (13.33%) of the mothers were given a lock of their baby's hair and four (26.67%) of the mothers were given the armbands that their baby had been wearing. One of these mothers, however, described how she had to get her doctor to search for it after her baby had died, as the nurses had not given it to her. One (6.67%) was given a poem that a nurse had written on a card for her and another (6.67%) was given the hat that her baby had been wearing in the neonatal intensive care unit. One (6.67%) was given a flag and another (6.67%) was given a pamphlet on grief. Three (20%) mothers received no mementos of their babies at all from the hospital. Two of the mothers expressed a great deal of remorse in this regard as they were not offered these mementos at all and one mother expressed that she was offered mementos but, at the time, did not want them. Eleven (73.33%) of the mothers expressed that they specifically regret not having been given a lock of their baby's hair as a tactile reminder of their child.

Four (26.67%) of the mothers interviewed had their babies baptised in the hospital. Three of these mothers arranged the baptism themselves and one of the hospitals arranged it for the mother after giving her the option to do so.

Detailed, accurate and honest information concerning the child's condition and cause of death should be provided to the parents at all times. The hospital staff should be approachable and parents should feel that they are able to ask any questions of the staff.

There should be a great deal of communication between the different staff members and the parents. Of the mothers interviewed, seven (46.67%) said that they were given information concerning the death of their babies. Of these seven, five felt that the information provided to them was sufficient. All of these mothers felt that the doctors were approachable and would have answered any questions that they were able to if asked. Three of the mothers said that they did ask questions, three said that they did not think of any questions at the time and one mother said that she did not want to know any more than she was told. Three of the seven mothers expressed that they later contacted the medical staff that had dealt with their child to obtain more information and two said that they had researched their baby's condition themselves. The remaining eight (53.33%) mothers expressed that they were not provided with information about their baby's death. Four (26.67%) of these mothers expressed that this was a result of the reason for the death being unknown to the medical staff. Two of these mothers were offered an autopsy for their baby, but neither took up the offer. One of the mothers greatly regretted her decision not to have an autopsy and felt angered that she was encouraged by her gynaecologist not to do so. She expressed that she believes that autopsies should be encouraged when the cause of death is unknown in order to give the mother some closure. All of these mothers, however, felt that they could have asked questions of their doctors and that they were approachable. The remaining four (26.67%) of the eight mothers felt that they were not provided with adequate information concerning the death of their babies. Three of these mothers described the doctors as being unapproachable and insensitive. They felt unable to ask questions and all three later contacted experts in order to find out more about the conditions from which their babies died. One mother described finding out about the cause of her child's death when she received the death certificate. The fourth mother expressed that she was provided with no information about the cause of her child's death because the doctor was not present when he died. She too, later called a medical expert to obtain further information.

All of the mothers interviewed were given rooms separate from the maternity ward when it was discovered that their babies were going to die / had died.

When asked to describe their experiences of the staff at the hospitals, three major themes emerged according to the descriptions provided by the mothers. The mothers either found the staff totally supportive, totally unsupportive or some of the staff totally supportive and others totally unsupportive.

- A third of the mothers interviewed described the staff at the hospitals as all being supportive. These mothers expressed that the staff was compassionate, kind, friendly, helpful, empathic and understanding. All five of the mothers expressed that the nursing staff in particular were very compassionate, two added that their gynaecologists were supportive and one felt that her midwife and the cleaning staff, along with the nurses and doctors were very supportive.
- Six of the mothers felt that some of the staff was very supportive while other staff was very unsupportive. All of these six mothers described the nursing staff, particularly those in the neonatal intensive care unit as being enormously caring, supportive and understanding. Three of the mothers, however, found the maternity ward staff unsupportive. These mothers described them as friendly, but insensitive in that they gave inaccurate information concerning their child's condition and assured them consistently that their baby would be fine. They felt the nurses knew that their baby's condition was serious and, as a result, found this inaccurate information insensitive. They described the staff as untrained in dealing with bereaved mothers. One mother found all of the maternity staff unsupportive and explained how they had avoided her and any discussion about her deceased child. She was given no acknowledgement by the maternity staff for her loss. Two of the mothers felt that their doctors were unsupportive. They described them as being uncaring, flippant, insensitive and lacking in empathy. One mother felt that her gynaecologist was unsupportive. She described her as being very procedural and uncaring and said that she felt that the gynaecologist treated her as if she was euthenasing a pet, rather than losing a child.
- Four of the mothers interviewed described all of the staff at the hospitals where they lost their babies as being unsupportive. Words used in their descriptions of the staff included: uninterested, unsupportive, lacking in empathy, unhelpful, avoidant, distant, irritable and uncompassionate.

According to Kohner and Henley (1997: 47), parents often have very vivid memories of their baby's death and all the events surrounding it. The empathy and care that the mother received in the hospital where her baby lost his or her life will, generally, dictate the nature of the memories that she has. It is interesting that the description of the mothers of their general hospital experiences seems to be very dependant on the perceptions they have of their treatment by the hospital staff. As mentioned previously, five of the mothers interviewed described their hospital experiences as being unsupportive in general. Similarly, four mothers felt that all of the hospital staff was unsupportive (all four of these mothers, having described unsupportive hospital experiences). Although many of these

mothers were given the opportunity to hold their babies and were given mementos of the babies, the mothers seemed to rate the support that they received based on the caring and compassion that they were shown by the hospital staff.

Three (20%) of the mothers interviewed said that they found nothing at the hospital supportive. The remaining twelve (80%) mothers outlined various points that they felt offered them some kind of support following the death of their babies.

A major theme arising out of the twelve mothers' descriptions of what they found most supportive at the hospital, was the support of the various staff members that dealt with them and their various qualities. The staff members' honesty, kindness, empathy and genuine caring were all very important to the mothers. Two mothers described how the nurses cried when their babies had passed away. This was very important to them as it showed that the lives of their babies had touched others. Gensch and Midland (2000: 286 – 290) believe that staff showing emotions at the death of a baby may be enormously supportive to the parents for precisely this reason. One mother described how the staff members simply saying: "I'm so sorry", meant so much to her. Many of the mothers felt a great deal of comfort in the knowledge that the staff was competent and was doing everything that could be done for their child. They appreciated having procedures and equipment explained to them and felt the continuity of staff for their baby was very helpful. One mother found it very helpful that the midwife explained the procedural dynamics of planning a funeral and selecting undertakers as well as the grief process itself. The same mother also appreciated that, throughout the process, she was given decisions that she was allowed to make. For example, after her baby was stillborn, she was allowed to decide how she wished to deliver him. This she found helpful in that it gave her a sense of control in a situation over which she felt she had no control at all.

Another major theme emerging from the mothers being asked what they had found most supportive at the hospitals, was the contact that they were allowed with their babies and the mementos of their babies that they were given. The mothers found holding their babies while or after they had died enormously supportive and many found it supportive that they were given various mementos by the hospitals to remember their babies by. One mother greatly appreciated that she was given the opportunity to bath her baby who had recently passed away.

Finally, a number of other descriptions were given by the mothers of the aspects that they had found most supportive at their hospitals. Four of the twelve mothers found it supportive that they were allowed visitors in. They appreciated that their visitors did not have to stick to the specific visiting hours and as a result, they could be provided with constant support from family and friends. One of these mothers appreciated that the hospital had called her family when her baby was dying to allow them to come and say good-bye to her.

Two mothers found sympathy cards that they received from the hospitals following the deaths of their babies very supportive and one mother felt supported in that she had put a soft toy above her son's incubator which remains there today. This, to her, allowed her child's memory to remain alive.

Only one mother (6.67%) said that there was nothing at the hospital that she found unsupportive. The remaining fourteen (93.33%) mothers outlined various things at the hospitals that they found unsupportive.

It became evident in their description of what they had found most unsupportive at the hospitals, that the staff members very much defined the mothers' hospital experiences. Thematically, as in their descriptions of what they had found most supportive, many the mothers mentioned different staff members who they felt did not offer the support that they needed. Some of the mothers found their doctors to be unsupportive. This ranged from the lack of emotional support that they were given by the doctors to the honesty of the doctors in describing the condition of their child. Others described the nursing staff as being unsupportive. Some felt that they were unrealistic in their descriptions of the condition of the baby and insensitive to their needs, while others found them uncaring, insensitive and avoidant. Two of the mothers felt that the nursing staff was too rough and insensitive when dealing with the bodies of their babies. One mother said that she would have liked them to treat her child like a baby and not an object while the other thought it insensitive that the nurses roughly ripped out the pipes attached to her baby while she was still holding him after he had died. One mother resented that the nurses were unable to answer any of the questions that she asked of them and another resented that she was not informed of her baby's deteriorating condition. She felt that she did not know what was happening until he was about to die and believed that the nurses' decision not to tell her because she had had a traumatic birth was unfair. This denied her the right to spend valuable time with her son before he died. Finally one mother felt hurt when told

by the reception staff on her way home from the hospital that she should 'go home and enjoy her baby.' She understood that the staff had meant no harm, however, believed that communication between the maternity staff and the other staff in the hospital should be better.

A second theme that emerged from the discussions of what they had found most unsupportive at the hospital, was the mothers' regretting that they were not given more mementos of their babies and longer time with them. One mother said that she would have liked time alone with her daughter to say her good-byes and another said that she would have liked to be offered to bath and dress her child. One mother deeply regretted having no photos of her child and, while she said that she would never forget what she looked like, she said that she would have liked a more tangible reminder. Similarly, another mother felt regret that she did not have a lock of her daughter's hair.

Finally, the mothers gave a number of other descriptions of what they had found unsupportive at the hospitals. Three mothers found it unsupportive that they were not given more information about the cause of their baby's death. One of these mothers expressed that she had not understood the medical terminology used in the description of his condition and would have preferred the information to be user-friendlier. One mother resented that she was given so much medication at the time of her baby's death. She felt that the medication clouded her memories and, because his life was so short, she would have liked to adequately remember every moment. She said that less medication would have also allowed her to deal with the death more constructively by confronting it head-on. Another mother felt it unsupportive that she was not given enough pain medication. She explained that, as a result of the nursing staff avoiding her, she was not consistently supplied with pain medication for the caesarean section.

One mother said that she found it extremely unsupportive that, after her baby had died in utero, the theatre caesarean was only scheduled for the following day. She expressed that it was very difficult for her to carry the baby for the night, knowing that she was dead. She added that, while in hospital after delivering the baby, she would have liked a bed to be supplied for her husband to sleep in, as he was a strong support for her. One mother said that she would have liked to be referred to a counsellor by the hospital and she would have liked the hospital to do follow-up services with her.

It is very interesting to compare the major themes arising out of what the mothers felt most supportive at the hospitals and that which they found least supportive. In both instances, the mothers thematically described the hospital staff and the time with their babies, and mementos of their babies, that they were given, as having been supportive or unsupportive. Clearly this demonstrates that, a mother who is given as much time as possible with her baby, is provided with as many mementos of her baby as possible and is shown compassion and understanding by honest and competent hospital staff, will leave the hospital having found her stay very supportive.

Figure 5: Ways in which mothers feel hospitals could improve their services to bereaved parents

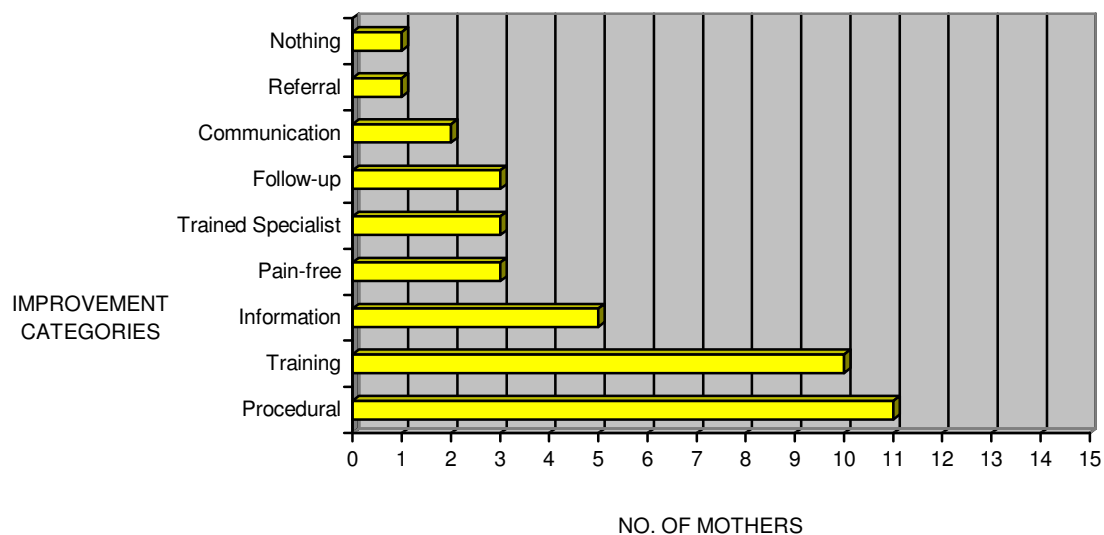


Figure 5 depicts the ways in which the mothers interviewed felt that the hospitals could improve the services that they offer to bereaved parents. Eleven (73.33%) of the mothers interviewed felt that the staff at the hospitals needed to have a specific procedure set in place in order to deal with parents who are recently bereaved. These mothers felt that it was important that staff automatically not only offered, but also encouraged parents to hold their babies for as long as they want to and as often as they want to, take photos of their babies and collect mementos of their babies. One mother expressed that she felt that the hospitals should have a digital camera set-aside specifically for this purpose, and that the staff should be trained in how to take photographs of babies, both alive and deceased. Another mother added that the staff should take photos of the baby from different angles and should keep these photos even if the parents express that they do not want them. Parents should be told that they can collect these photos should they

change their minds and an archive should be kept in this regard. These mothers expressed that hospital staff needs to acknowledge that parents are totally ill prepared for the death of their infants and so are not aware of what they want or don't want. For this reason it should be explained to them that holding the baby, taking photographs and so forth, are all important in the grieving process. Hospital staff members need to take the macabre out of the death of the baby and encourage the parents to practice their maternal instincts on the child, regardless of whether or not he or she is still alive. The mothers also felt that memory boxes/books with footprints, handprints, locks of hair, hospital bands and any other mementos must be provided by the hospital as a part of their procedure.

Ten (66.67%) of the mothers interviewed felt that the hospital staff, in general, need to be better trained to deal with bereaved parents. They felt that all hospital staff should have a grief-counselling course as a part of their training. Hospital staff should call the babies by name and treat the babies as if they were still alive – with tenderness and care. They should display more compassion and empathy towards the parents.

Five (33.33%) of the mothers felt that hospitals should provide more information to bereaved parents. Three of these mothers felt that written information specifically on the cause of the child's death should be provided to the mother while two of the mothers felt that information on the grief process and how specifically to deal with it should be given. One of these mothers also felt that, as so frequently the loss of a baby is the parents' first real contact with the death of somebody close, procedural information about undertakers and funeral arrangements should be provided.

Three (20%) of the mothers interviewed felt that hospitals needed to make sure that mothers remain pain-free after their baby has died. They felt that it was very difficult for mothers to experience the pain following childbirth when they did not have the baby to show for it.

Three (20%) of the mothers felt that the hospitals needed to appoint somebody specifically trained as a specialist to deal with bereaved parents. One of these mothers felt that hospitals should have a specific division set aside to deal with such cases and others felt that simply one person, who could provide them with information and answer all of their questions would be helpful.

Three (20%) of the mothers interviewed believed that the hospitals should provide follow-up services and two (13.33%) mothers felt that hospitals needed to improve their communication services, amongst themselves and with the parents. Both of these mothers felt that the hospitals need to be better equipped to answer the questions that mothers may have of them and that staff members needed to be more honest in their conveyance of the condition of the babies.

One (6.67%) mother felt that hospitals should provide referral information to parents for counselling when they leave the hospital and one (6.67%) mother felt that there was no particular way in which hospitals could improve their services to bereaved mothers.

3.2.4 Section D: Religious services

All (100%) of the mothers interviewed were Christian. Thematically, mothers either felt that their religious views had not been affected by their loss or that they had been affected.

Five of the mothers felt that their religious views were not affected by the loss. One mother felt that the death of her child had not affected her religious views at all. Four felt that their religious views, on the whole, had not been affected by the loss, however, added to this by outlining the role God had played in their grief. Two of these mothers felt that they were now closer to God than they had been before the loss of their babies. One went on to say that, although she had a number of questions, she did not blame God and felt that it was Him who had kept her together and supported her during this difficult time. One mother felt that her loss had made her more accepting of other people's pain and the last felt that, although she had initially been very angry with God, she had since let go of this anger and felt that her views had not changed from what they had been before.

The remaining ten mothers felt that the death of their babies had definitely affected their religious views. Three sub themes were identifiable in the mothers' descriptions of the ways in which their religious views were affected by their losses. Firstly, two of these mothers felt incredibly angry with God and blamed Him for not saving their babies. Both felt that they could make no sense, from a Christian perspective, out of the death of a baby and one mother expressed that she could not understand why God allowed abused and unwanted children to live while He let desperately wanted and loved babies die. Both mothers remain angry with God and, while they did attend church prior to the

deaths of their babies, they no longer do. These two mothers see God as having caused their babies deaths as outlined by Nadeau (1998: 184 – 190) in chapter two. This is part of the way in which they make meaning of the deaths.

Secondly, three mothers described the experience as having brought them closer to God. These mothers felt that God was a strength and support through the ordeal and that he had carried them through this difficult time. They believed that the experience had made them realise how real God is and explained that they did not blame God for the death but felt that death is simply a part of life. One of these mother expressed that the death of her daughter had lead her to read a great deal more Christian literature and that this had brought her closer to God. She also described how she had been able to feel the support of the prayer chains offered by her church and that this, too, had brought her closer to Him.

Thirdly, five of the mothers who felt that their religious views had been affected by the loss of their baby displayed ambivalent feelings towards God. Three of these mothers expressed that they had felt feelings of anger and resentment towards God straight after the loss of their babies. They had questioned the reasons for the loss of their babies and were unable to make sense of their losses. One mother expressed that she had lost trust in God and his desire to protect her and her family. All three of these mothers felt that they had since reconciled with God and no longer had any anger towards Him. One mother was able to come to this point through the reading and understanding of literature, another felt that she was only able to do so when she let go of her need to control her surroundings and left things in God's hands. The last mother, however, explained that she had reconciled with God out of fear. She expressed that she was afraid that if she remained angry with God, He would punish her again and she felt that she would be unable to endure this. This mother saw the death of her baby as a test from God as described by Nadeau (1998: 184 – 190). Two mothers felt that the loss of their babies had made them feel closer to God as, in so doing, they had felt closer to their babies. One of these mothers, however, expressed that, as time had moved on, she had become gradually angrier towards God for taking her son. She expressed that she still felt a great deal of this anger and still had a lot of questions. The other mother expressed that, although feeling closer to God had made her feel closer to her child, she also felt more alone than she had felt before. She said that she no longer believed that God intervenes in the world. She said that she finds the notion of God offering protection

to people as naïve and said that her views, on the whole, have become much more realistic and holistic.

A number of themes arose out of the mothers' descriptions of the support that they had received from their religious institutions. Although some mothers expressed that they had found their religious institutions supportive, predominantly, the support offered was described as poor.

Only five of the fifteen mothers interviewed described their religious institutions as having been supportive following the death of their babies. These mothers described phone calls and visits from different members of the congregation as having been very helpful, and one mother found the prayer chains particularly uplifting. One mother expressed that the members of her church had kept up the visits for three to four months and had taken them up again with the birth of her next child. She said that the congregation had also provided cooked meals for her family for the first two or three week and that this was extremely helpful at a time when she felt unable to do these household chores. She expressed that she enjoyed the fact that those offering support appeared to be trained and knew when to approach her and when to keep their distance. One of these mothers, however, expressed that, although her congregation had been very supportive initially, this support waned fairly quickly and she felt that she would have liked it to continue for a longer period of time.

The remaining ten mothers found the support of their religious institutions lacking. Two sub themes arose in the mothers' interpretations of the poor support. Firstly, some of these mothers felt that this was a result of the congregation being unaware of what had happened. They described being disappointed in their religious institutions and expressed that, while initially their religious institutions had offered no support to them, once they had found out about the loss, the institutions were very supportive. One of these mothers said that, as a result of her experience, she has since helped the church to institute a programme aimed at keeping in touch with the congregation and its new members.

Secondly, many mothers felt that they had received no adequate support at all from their religious institutions and made no excuses for this. All of these mothers said that they had not received regular calls or visits. One of the mothers went so far as to say that the institution that she belonged to blamed her for the death of her child. She said that she

had been on depression medication when she had fallen pregnant and that, although she had stopped this medication when she had found out about the pregnancy, her congregation had said that this was the reason for her son's death. They expressed that she was being punished for being a 'drug addict' and told her that her depression was a curse placed on her by God. This mother had found these comments enormously damaging and complicating in her grief, as her religion was a cornerstone of her being. She had been plagued with guilt as a result and, only through therapy, was she able to overcome this.

Interestingly, both of the mothers who found that they were angry with God and who had stopped going to church as a result of the death of their babies, fell into the above category. The anger that they felt, compounded with the lack of perceived support that they received from their religious institutions, left them feeling resentful and turning away from the church. This is frequently the case and highlights the necessity for religious institutions to provide as much support to bereaved parents as they are able (Tatelbaum, 1980: 80 – 85; Rank, 1985: 43; Kübler-Ross, 1986: 156 and Kissane & Bloch, 2002: 87 – 90).

A sub theme arising out of the discussion of the support that the mothers had received from their institutions was the use of clichés by community members. Five mothers described being offended by religious grief clichés and other comments made to them by members of their congregation and of the public. Comments like: 'S/he is in a better place'; 'It's God's will'; and 'God always takes the prettiest flower' were offensive and unhelpful to these mothers. One mother, who lost twins, was upset by comments made by her congregation that she was lucky that both had died because it would have been difficult for them to live without each other and that she was lucky they had died because twins are very expensive and exhausting. She expressed that she had not felt lucky at all and thought that these comments were extremely insensitive. Another mother explained that a colleague had called her as she was being wheeled into theatre to deliver her stillborn daughter and had prayed aloud on the phone that God should raise her daughter from the dead as he had done so with Lazarus. She found this remark very insensitive and unhelpful. One mother found it offensive that members of her church continually offered her menial reasons for her daughter's death that she felt patronised the value of her daughter's life. She believed that this demonstrated their lack of understanding for the depth of her loss and, as a result, felt totally unsupported by them. Insensitive statements made to mothers following the deaths of their babies, can serve to

define their grief experiences. The ease with which they move through the grief process is greatly determined by the support that they perceive they are receiving. Insensitive and unhelpful statements, like these described by the mothers, only serve to further alienate them (Tatelbaum, 1980: 80 – 85; Rank, 1985: 43; Kübler-Ross, 1986: 156 and Kissane & Bloch, 2002: 87 – 90).

Despite the poor support that mothers described receiving from their religious institutions, almost half of the mothers interviewed found their religious leaders supportive following the death of their babies. Flowers sent, visits, phone calls, baptisms, services and continual emotional support were all described as being helpful and supportive qualities in a religious leader. Very important to these mothers, however, was the ability to ask questions of their religious leaders without feeling judged. These mothers also appreciated that their questions were answered honestly and that their religious leader, when unable to answer a question, expressed that s/he could not do so.

The remaining mothers, however, expressed that they had received little or no support from their religious leaders. These mothers felt that, despite being members of the church, they had not been approached by their religious leaders and were not supported by them at all (again both mothers who were angry with God and no longer attended church as a result, fell into this category). One mother felt that, although she had received little support, she was not a regular churchgoer and so this was not really relevant for her. Another described how she had used the same religious leader who had baptised her baby in the hospital to conduct the baby's funeral service. As a result, her regular religious leader had been offended and so had offered her no support.

Table 1: Support offered by religious institutions that mothers found helpful (n=15)

| Type of support received | Number of responses | Percentage % |
|---------------------------------|----------------------------|---------------------|
| Support from Religious leader | 6 | 40.00 |
| Nothing | 5 | 33.33 |
| Visits and Phone Calls | 5 | 33.33 |
| Prayer Chains | 2 | 13.33 |
| Practical Support | 2 | 13.33 |
| Support with Next Child | 1 | 6.67 |

Table 1 depicts those things that the mothers interviewed felt were most supportive in their religious institutions following the death of their babies. Six (40%) of the mothers found that the religious leader was very supportive of them. Three of these mothers specifically enjoyed the fact that their religious leaders were approachable and that they were able to ask them questions without fear of judgement. They felt that questions were answered honestly and that their religious leaders admitted to not knowing the answers to those questions that s/he was unable to answer. Two of these mothers appreciated the funeral services offered by their religious leaders and one, specifically, felt moved that he had made the service very personal for her child. Two mothers appreciated specifically the emotional support offered to them and the leader's ability to maintain a balance in this regard and one mother felt it supportive that she simply knew that should she need the support of her religious leader, she would be able to contact him.

Five (33.33%) of the mothers expressed that they had found nothing helpful in the support offered to them by their religious institutions and five (33.33%) of the mothers said that they had found the visits and phone calls made to them helpful. These included visits from various members of the congregation and, one mother specifically, found a phone call made to her by a member of her congregation who had also lost a baby, very supportive. Two (13.33%) mothers found prayer chains, one through the church and the other through her son's nursery school, very supportive. Two (13.33%) mothers found the practical support offered to them helpful. One specifically appreciated the help she received in arranging her son's funeral and another found the meals that she received from the church for the first three weeks after her son's death very helpful. Finally, one (6.67%) mother found the support that she received from her congregation at the birth of her next child, very supportive.

Table 2: Ways in which mothers felt religious institutions could be more supportive of them (n=15)

| Type of Support | Number of responses | Percentage % |
|----------------------|---------------------|--------------|
| Emotional Support | 6 | 40.00 |
| Visits / Phone Calls | 6 | 40.00 |
| No ways | 4 | 26.67 |
| More Proactive | 4 | 26.67 |
| Answered Questions | 4 | 26.67 |
| Practical Support | 3 | 20.00 |
| Follow-up | 3 | 20.00 |
| More Sensitivity | 3 | 20.00 |
| More Awareness | 2 | 13.33 |

Table 2 depicts the ways in which the mothers interviewed felt that their religious institutions could have been more supportive of them following the loss of their babies. Six (40%) of the mothers felt that their religious institutions could have been more emotionally supportive of them. Four of these mothers said that simply by 'being there' they would have felt more supported and that, providing a listening ear, would have made a significant difference to them. Six (40%) of the mothers felt that they would have appreciated visits and telephone calls from either their minister or members of their congregation. One mother said that even a simple cell phone message would have shown support, as she did not often feel like talking on the phone anyway.

Four (26.67%) mothers felt that there was no way that their religious institution could have improved its services to them, and four (26.67%) felt that their religious institutions need to be more proactive when dealing with bereaved mothers. They felt that they had been so lacking in energy and struggled to make the first move and approach the institutions for help. They agreed that they would have greatly appreciated the religious institution approaching them first. One of these mothers added that she believed that the congregation should not leave all of the reaching out to the religious leader and that they, too, should be more proactive. Four (26.67%) mothers felt that they would have appreciated their religious leaders and prominent members of their religious institutions being more approachable and answering their questions. All four mothers felt that they were left with so many questions and so few answers after the loss of their babies and they would have appreciated answers to these questions from a Christian perspective.

Three (20%) of the mothers expressed that they would have appreciated practical support from their religious institutions. Meals and transport, as they were unable to drive after the births, would have been helpful. They expressed that they struggled, at the time, to maintain their daily chores and it would have been helpful not to have to cook. Three (20%) mothers felt that support needed to be sustained and that follow-up visits or calls to check on their progress would have been appreciated.

Three (20%) mothers felt that their religious institutions needed to be more sensitive in their dealings with the bereaved. They felt that religious grief clichés should be avoided at all times and two felt that people should not try to make meaning for them out of their loss. One of these mothers also felt that religious institutions should remain non-judgemental and not attempt to point fingers and blame the mothers for their loss. Two (13.33%) mothers felt that there should have been more awareness within their congregation about what is happening in the lives of its members. This in turn, they believed, would have led to more acknowledgement of their loss.

3.2.5 Section E: Formal services

3.2.5.1 Hospital counselling

According to Gensch and Midland (2000: 286 – 290), counselling by a trained professional should be offered to bereaved parents by the hospital following the death of their baby. Follow-up phone calls should also be made to the parents after they are discharged from the hospital (Ujda & Bendikson, 2000: 267). Despite this, however, only two (13.33%) mothers reported being approached by hospital counsellors following the loss of their babies and only one (6.67%) of these mothers actually had a session with the counsellor. Eleven of the remaining mothers (73.33%) expressed that they would have liked to be given the opportunity to see a hospital counsellor and only two (13.33%) said that they did not feel that, at the time, they would have appreciated such an offer.

Both mothers who were approached by the hospital counsellors were unsure of their qualifications and simply referred to them as such. One mother chose not to pursue counselling sessions with the counsellor as she found her to be too enthusiastic and unrealistic at a time when she was not feeling very optimistic. She expressed that she got the distinct expression that the counsellor had never experienced grief herself and

felt that she was band-aiding her situation. The other mother had one session with the hospital counsellor. She expressed that, as she had just delivered her baby by caesarean section she was still very 'drugged-up' on pain relief medication when approached. She explained that she does not, as a result, remember much of the one session that she had with the counsellor. For this reason, she was unable to provide benefits of the therapy and felt that, a possible shortcoming would be that she was approached at the wrong time. She said that she would have appreciated being provided with written information by the counsellor that she could peruse when more conscious and that a possible follow-up after her discharge from the hospital would have been appreciated.

Gensch and Midland (2000: 286 – 290) also believe that details for support groups and web site addresses should be provided for mothers following their discharge from the hospital. (Compare Ujda & Bendikson, 2000: 267.) Five (33.33%) of the mothers interviewed expressed that they were given details of support networks/ counsellors upon discharge from the hospital. Two of these mothers were told about the Compassionate Friends, one receiving a booklet in this regard, and a representative of Baby Angels, who they believe was contacted by the hospital, visited two mothers at the hospital. The other mother was given the details of a hospital counsellor who she could contact should she feel the need. She expressed that she would have liked to have seen this counsellor, but was not able to mobilise herself to make the phone call to her. She said that she would have appreciated, rather, the hospital getting the counsellor to contact her. Eight (53.33%) of the mothers were not given any details of support networks, web sites or counsellors upon discharge and two (13.33%) of the mothers expressed that, as a result of the medication they were given, they were unable to remember whether they were or not.

3.2.5.2 External individual counselling

Eleven (73.33%) of the fifteen mothers interviewed did receive external individual counselling following the deaths of their babies. The remaining four (26.67%) mothers who did not, all expressed that they would have liked to. One mother said that, as her baby had only passed away within the previous two months, she might still choose to do so. Another mother said that she had not done so because she was afraid that the counsellor may have different views from her own and, as a result, may be more harmful than helpful. The remaining two said that, while they had wanted to see a counsellor,

they struggled to mobilise themselves to make the first contact with one. One mother added that she felt that there might be financial constraints involved in counselling as well.

Of the eleven mothers who received counselling, five (45.45%) saw psychologists, one seeing two different psychologists; two (18.18%) saw psychiatrists; two (18.18%) saw Christian counsellors; one (9.09%) saw a maternity nurse acting in a counselling capacity and one (9.09%) saw a social worker. Five (45.45%) of these mothers were referred to the counsellors by their gynaecologists. Two (18.18%) were referred by their work. Two (18.18%) were referred by family members. One (9.09%) was referred by her church and one (9.09%) was referred by her support group. One mother saw two psychologists and was referred to the second by a friend.

Figure 6: The length of time that the mothers received counselling

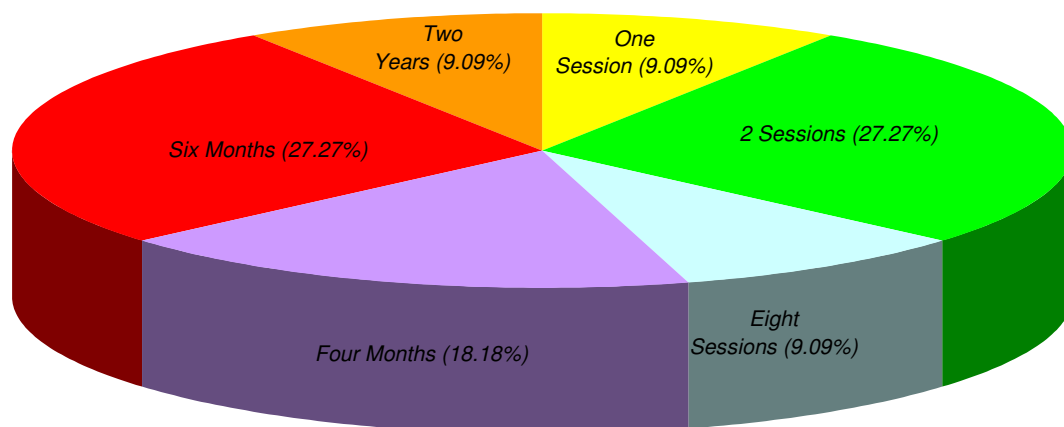


Figure 6 depicts the length of time that the mothers saw their counsellors for. This ranged from one session to two years with modal numbers of two sessions and six months. One (9.09%) of the eleven mothers who sought counselling saw the counsellor for only one session. She explained that the counselling was offered as a free service by her workplace and, as she and her husband felt he was more in need of counselling than herself, he took the remainder of the sessions offered to them. Three (27.27%) of the mothers saw the counsellors for two sessions, one expressing that she intended having more sessions in the future and one (9.09%) mother saw her counsellor for eight sessions. Two (18.18%) mothers saw their counsellor's for four months and three (27.27%) saw their counsellors for six months, one expressing that she intended seeing him for longer. One (9.09%) mother saw her counsellor for two years.

When the eleven mothers who sought counselling were asked to describe the benefits of the counselling that they had received, four major themes emerged. Three of the mothers, however, felt that there were no benefits for them from the counselling. Two of these mothers were unimpressed by the actual counsellors and their methods used, and the other simply felt that she did not really need the counselling and would be able to cope better on her own.

The first major theme identified was many of the mothers' feelings that the counselling was beneficial in that it was cathartic and allowed them the opportunity to simply speak about the grief that they were feeling. These mothers expressed that they appreciated having somebody who would genuinely listen to the way that they were feeling without judgement and without making clichéd and unappreciated remarks. According to Stillion (1998: 62 – 63) a counsellor must be empathic and trained. The therapeutic environment should allow the client the opportunity to express him or her self openly and without judgement. In grief counselling particularly, the ability to tell one's story, over and over again, is very cathartic. (Compare Jacobsen, Kindlen & Shoemark, 1997: 179, Nadeau, 1998: 240, The Child Bereavement Trust, 2000: 1 and Kavanaugh & Paton, 2001: 369 – 376.)

A second identified theme was that mothers found the intellectual support, in terms of information offered to them by their therapists, very beneficial. They appreciated being given information on the grief process and practical tips on how to cope with it. Two found that the therapists' ability to answer their questions was very helpful and two found that the normalising of their feelings, based on the grief process information provided, was greatly beneficial. One mother felt that this was so beneficial in that it allowed her to see that she would have to move through the grief process before she could achieve the same level of normalcy in her life that she had had before. She realised that there was no 'quick fix' for grief. A counsellor must have a thorough knowledge of the grief process so as to be able to help parents identify and normalise their feelings. He or she must know where the bereaved is in the process and what is required of him or her to be able to move on with his or her life. The counsellor should also help the bereaved to identify ways and means of coping with the grief process (Jacobsen, Kindlen & Shoemark, 1997:179; Gensch & Midland, 2000: 288 – 289; Riches & Dawson, 2000: 18, Currer, 2001: 130 – 135 and Kavanaugh & Paton, 2001: 369 – 376).

Other mothers found the emotional support offered by their counsellors particularly beneficial – a third theme that emerged. Simply having somebody to hold their emotions and display genuine empathy was helpful. Two of these mothers struggled particularly with feelings of guilt and found that the ability to work through this was extremely helpful. One felt similarly about her ability to work through her anger in the therapeutic setting.

Finally, a fourth identified theme amongst the mothers was the therapists presence at the hospitals, immediately following the death of their babies, as being very beneficial. Although this was the reality for fewer mothers, all those who had experienced this were grateful. This allowed them to receive immediate emotional support and one mother, in particular found that the practical help offered by the therapist at the hospital was supportive. According to Currer (2001: 130 – 135) therapists, particularly hospital appointed therapists should be available to offer support as soon as possible after the death of the baby, if not before. (Compare Kavanaugh & Paton, 2001: 369 – 376.)

When asked for the shortcomings of the therapy they had received, nearly half of the mothers felt that there had been no shortcomings and were completely content with the services that they were offered. With the remainder of the mothers, two major themes emerged. Firstly, some of the mothers felt that their counsellors were religiously dogmatic and felt that they tried to force their opinions and views onto them. One described her therapist as making continuous biblical references (the therapist was not a Christian counsellor) and telling her that ‘everything happens for a reason’ and that, although she would not know the reason now, one day she would. This mother felt that such views were inconsistent with her own and thought that these clichés should have been avoided within the therapeutic environment. The other mother felt that her therapist left her with many regrets as, in the initial stages following the death of her son, the therapist had projected her views on what she should do onto her. While she wanted to bury her son, the therapist felt she should cremate him, and while she wanted to take photos of her son, the therapist felt she should not as this was too ‘morbid’. The therapist also informed her that she would be unable to baptise him (which she so desperately wanted to do) as he was already dead. She only later found out that this was not the case. This mother felt a great deal of anger towards the counsellor as she felt that her guidance had been dogmatic and, ultimately, damaging to her.

Secondly, mothers found the counsellors to be insufficient in the services that they offered to them. One mother felt that the information that the counsellor provided for her

was too simplistic and not particularly helpful, and another felt the counsellor provided no answers to her questions and would have appreciated being given information on the grief process and practical tips on how to move through it.

Two other shortcomings were identified. One mother felt that she would have appreciated follow-up services from the therapist and one felt that, although her therapist was pleasant, she was unable to help her.

3.2.5.3 Support Groups

All of the mothers interviewed had been, or were currently, a part of either the 'Compassionate Friends' or 'Baby Angels' support groups. Fourteen (93.33%) of the mothers felt that they had needed the support of others who had shared a similar experience to them following the loss of their babies and one (6.67%) mother felt that she did not feel that she did. This mother expressed that she felt that she already had a strong enough support system and that other bereaved mothers would simply hold her back in the grief process. These mothers, she believed, would not allow her to move on with her life and would be a constant reminder of that she had lost. One of the mothers who had initially felt that she wanted the support of other bereaved mothers, also now felt that they held her back and prevented her from moving on with her life.

The fourteen mothers who had felt that they needed the support of somebody who had shared a similar experience with them expressed different reasons for feeling this way. Five major themes became evident in their reasoning. Firstly, and predominantly, most of the mothers felt that they wanted to speak with somebody who truly understood how they feel. They felt that contact with somebody who felt the same way as they did and appreciated the profundity and depth of their loss would be enormously helpful. Secondly, many mothers felt that they needed somebody to normalise the way that they felt and thirdly, some felt that, contact with other bereaved mothers would provide them with reassurance and hope for the future. These mothers felt that they needed the comfort of knowing that they were not alone and that they would, one day, recover a sense of normalcy in their lives. Fourthly, many mothers felt that contact with other mothers who were bereaved would, possibly, provide them with information that they so desperately sought. Such information included information on the specific cause of death of their child and information relating to the grief process and how to move through it. Finally, a handful of the mothers felt that they needed to make meaning out of the loss of

their babies and so wanted to make contact with other bereaved mothers to offer them guidance and support.

Six (40%) of the fifteen mothers interviewed were contacted by the support groups and were unsure how the support groups had obtained knowledge of their details. Three (20%) of the mothers found out about the support groups through the media, one through the newspaper and two through magazines. Two (13.33%) of the mothers learned of the support groups from the hospitals that they were at. One (6.67%) mother had previous knowledge of the support group, one (6.67%) learned of the support group from her medical aid, one (6.67%) learnt of the support group from a colleague and, finally, one (6.67%) mother was told of the support group by a family member. One of the mothers also joined an Internet support group, which she had found beneficial.

A number of themes arose in the benefits outlined by the mothers of the support networks that they had been a part of. Predominantly, the mothers found the support networks particularly beneficial in that they were cathartic, allowing them to share their experiences with other mothers who truly understood what they were going through. They felt emotionally supported as a part of the network and did not feel judged in anything that they said or did. The group did not expect these mothers to explain themselves. One mother described the group as a forum for her grief and another expressed that she felt free to cry without believing that she was being an 'emotional burden.'

A second theme arising was that mothers appreciated the regular phone calls that they received from the support network and many added that they appreciated that the networks were approachable and they could contact them at any time should they feel the need. One mother expressed that, even though she had not actually done so, she found comfort in the knowledge that she could.

A third theme arising was that mothers found the support networks offered them hope for the future. This was at a time when many of them felt so hopeless and could not see the way forward. Fourthly, mothers felt that the groups helped them, to normalise the feelings that they had. Fifthly some found the speakers at their support groups very helpful and well selected and sixthly others enjoyed that they were able to make good friends as a result of being a part of the network.

A seventh, and final, theme in the mothers responses to the benefits that they had found of their support groups was that many mothers appreciated that the groups had been proactive and made first contact with them. One of these mothers attributed her having photos of her baby to the group member who had visited her at the hospital. She expressed that, had she not come and encouraged her to do so, she would not have done so. She found this early contact, straight after the loss of her baby, beneficial.

Other benefits were described by the mothers, which did not present themselves thematically. Two mothers felt that they were never forced to attend group meetings when they were not up to it. They appreciated this and found it beneficial. One mother expressed that it had been good for her to feel that she was helping other bereaved mothers. She expressed that this gave meaning to the life of her baby, and one found website support particularly helpful in that it was easily accessible and maintained the right balance of support and distance.

When asked for the shortcomings of the support groups, six of the mothers felt that there were none. The remaining mothers outlined a number of issues where two major themes were identified. Firstly, many mothers found the logistics of the groups difficult. The location and times of the meetings were inappropriate for the mothers and one mother also found it difficult that she was not able to take her other children to the meetings. Secondly, mothers found the meetings very heavy and emotionally exhausting for them. Although one admitted that this was possibly necessary in order for her to confront her grief, two felt that, as a result, they held them back and kept them fixated in their grief.

Four other shortcomings of the support groups emerged. Two of the mothers did not like the name of the support network: 'Baby Angels' and what they felt this connotated. One mother described it as glorifying her dead baby when she felt that she wanted to think of him as a baby and not an angel. One mother felt that the website responses were sometimes slightly slow and another resented that her son's name was placed on the Internet memorial site wall under the heading 'stillborn'. She felt that she did not like the connotations of the word 'stillborn' and that, seeing his name there had made the experience very real for her. She said that she was not ready for this and suggested that the groups allow mothers to fill their babies names in themselves. Finally, one mother found that the support group meetings were very dogmatic. She felt that some of the guest speakers tried to force their beliefs onto her and that she had found this very upsetting. She described being told by a guest speaker that she was closed minded for

not embracing her belief system and that she would keep getting such signs if she did not turn to spiritualism.

Figure 7: Mothers' suggestions on how support groups could better their services

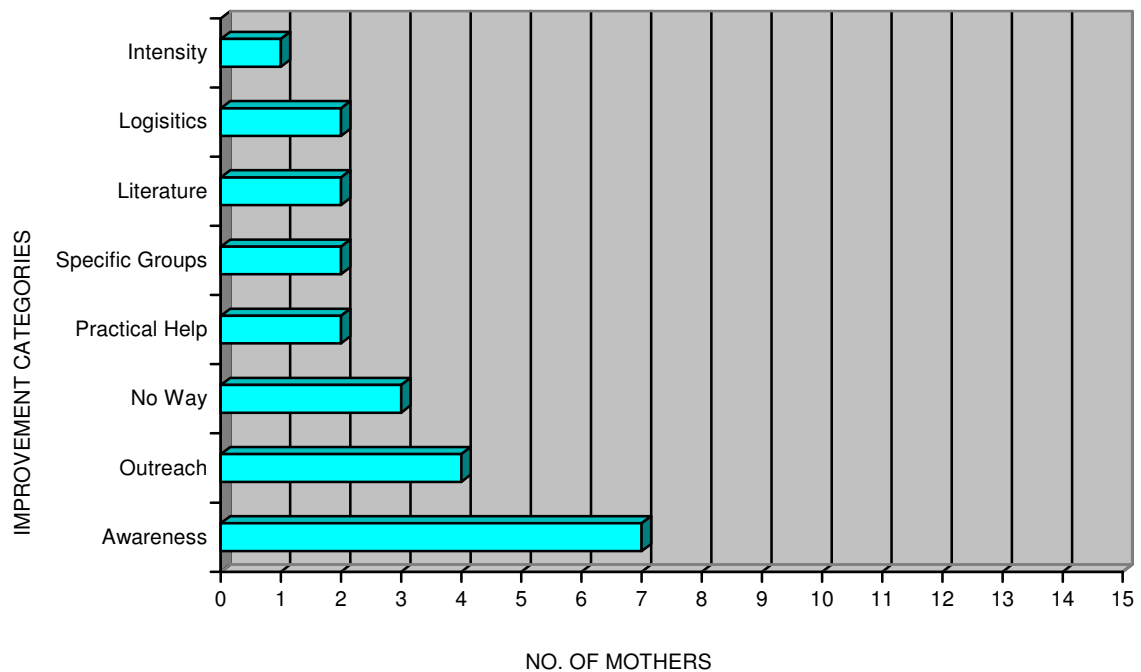


Figure 7 depicts the ways in which the mothers feel support groups could provide a more constructive service to the community. Seven (46.67%) of the mothers felt that the support groups needed to be more conspicuous and that the community needed to be more aware of their existence. Four (26.67%) mothers felt that the support groups needed to do more outreach with recently bereaved mothers and, three specifically felt that they needed to visit the mothers as soon as possible after their babies deaths. These mothers believed that the support groups could provide them with valuable information in making memories of their children, for example: holding them, taking photos of them and so forth, before the opportunity passes. Two mothers also felt that, as they felt so exhausted following the loss of their babies, they would have appreciated the support groups making the first move in contacting them.

Three (20%) of the mothers felt that there was no way that the support groups could offer a better service and two (13.33%) mothers felt that support groups should offer more

practical help in selecting undertakers and planning the funerals of the babies. Two (13.33%) mothers felt that they would have liked their groups to be split up to deal with more specific kinds of death. They felt that they would like to have a group devoted to mothers who had lost babies as they felt that there were specific and unique issues related to such a death. Two (13.33%) of the mothers said that they would like their groups to supply them with more literature, specifically around the death of a baby and the different causes of death. Two (13.33%) felt that the logistics of the groups could be improved. Specifically they suggested that the groups meet at more appropriate times and that they had their meetings more often and one (6.67%) mother felt that the groups should lessen in intensity and not be so emotionally charged. She felt that the mothers should also meet occasionally to simply have fun and that not all meetings should focus on the deaths.

3.2.6 Section F: General

Figure 8: Mothers' ratings (out of ten) of the support that they received following the death of their babies

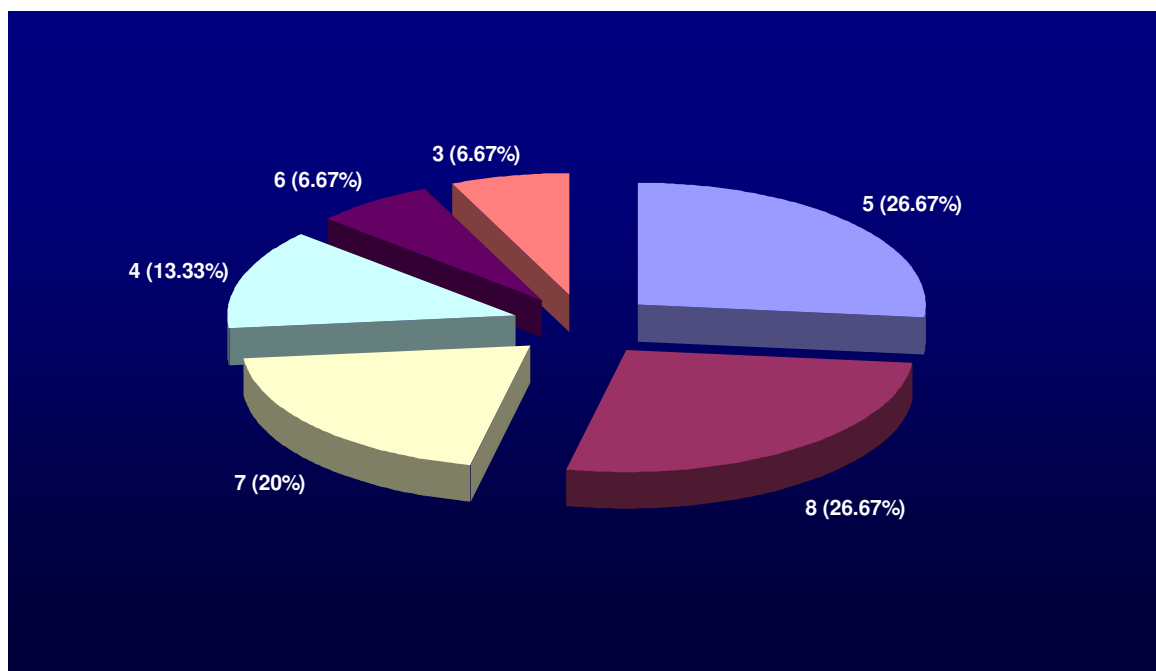


Figure 8 depicts the mothers' overall ratings (out of ten) of the support that they received following the deaths of their babies. The ratings that the mothers gave ranged from three to eight, with an average rating of six and modal ratings of both eight and five. Four

(26.67%) of the mothers said that they would rate the support that they received as eight out of ten. These mothers expressed that they had found that services and the community had been very supportive of them. Although they acknowledged that there were glitches in some of the services, on the whole they had felt supported. Three (20%) of the mothers gave a rating of seven and one (6.67%) gave a rating of six. Four (26.67%) of the mothers gave a rating of five saying that the support they received was average. Some of these mothers expressed that, while some of the support was very strong, support in other arenas was weak and so they averaged each other out. Two (13.33%) mothers gave their support a rating of four and one (6.67%) mother gave the support that she received a rating of three saying that she felt generally unsupported following the loss of her baby.

Figure 9: Mothers' ratings (out of ten) of the ease with which they were able to access services following the death of their babies

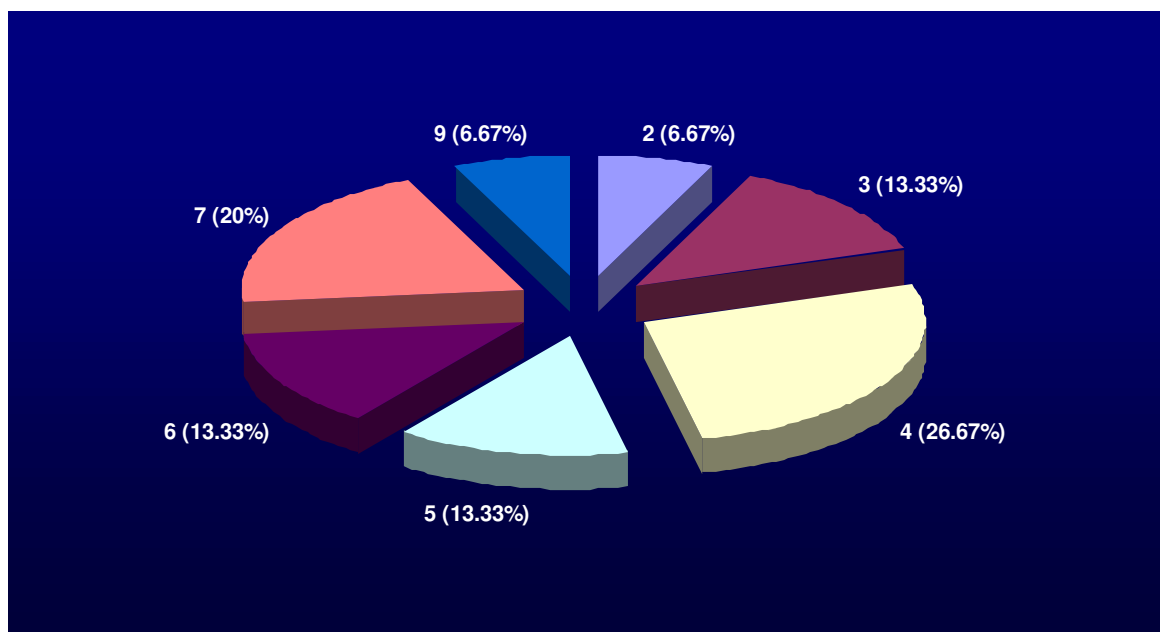


Figure 9 represents the mothers' ratings (also out of ten) of the ease with which they were able to access services to offer them support following the deaths of their babies. The ratings that the mothers gave ranged from two to nine, with an average rating of five and a modal rating of four. One (6.67%) of the mothers gave a rating of nine, saying that she had found services very easily accessible. Three (20%) of the mothers gave a rating of seven, two (13.33%) of the mothers gave a rating of six and two (13.33%) mothers

gave a rating of five. Four (26.67%) of the mothers gave a rating of four, two (13.33%) gave a rating of three and one (6.67%) mother gave a rating of two.

Although not specifically asked as a part of the question, a theme that did seem to arise was that, while a number of the mothers had found that the support offered to them was valuable, many of them expressed that they struggled to gain access to the support. This would account for the lower mean and modal scores arising out of the ratings for the ease with which they were able to gain access to the support services as apposed to the nature of the support that they received.

When asked how the mothers felt services in general could be improved, three major themes arose from their responses. Most predominantly, mothers felt that awareness needed to be raised amongst society in general about the significance of the loss of a baby and the emotional trauma that a mother experiences as a result. This ties back to the general agreement amongst the mothers, as discussed previously, that society at large was unable to appreciate the significance of their loss. Some mothers expressed having felt very alone following the loss of their babies because people were unable to appreciate the depth of their loss. Further, these mothers also felt that their needed to be more awareness within society of the services that are available to bereaved mothers. Only one mother had heard of the compassionate friends prior to her loss and the rest said that it would have been beneficial to them to have some knowledge of the various support networks already.

The second theme arising out of the question was that mothers felt that, in general, staff at hospitals, churches and funeral parlours should be better trained in handling the bereaved. These mothers felt that inadequate protocols and procedures within these institutions for dealing with bereaved parents compounded their grief and left them with many regrets. One mother also felt that it could be beneficial to introduce grief and the handling of the bereaved into the school guidance syllabus. She felt that society in general is inadequately trained in dealing with grief and that, given that death is inevitable, such skills would be invaluable.

Thirdly, mothers felt that the services offered to bereaved mothers needed to be more proactive in their approach. Many mothers described feeling exhausted and lacking in motivation following the death of their babies and felt that having the support networks contact them, rather than expecting them, to make the first move, would have been to

their benefit. A few of these mothers went so far as to suggest that contact from support groups should be initiated while they were still in the hospital so as to provide them with immediate, compassionate care.

Other suggestions made by mothers were that more literature for bereaved mothers be made available and that more websites for bereaved mothers be established.

Six of the mothers interviewed felt that there were no extra services that needed to be offered to bereaved mothers following the death of a baby. Of the nine remaining mothers, however, two major themes arose. Firstly, mothers felt that, in antenatal classes, information should be provided to them on the loss of a baby and what one should do should such a situation arise. These mothers believed that it is vitally important that such training exists as, when a baby dies, in most cases mothers are totally unaware of what to do. They believed that mothers should be taught that they should hold their babies, take photos of their babies, collect mementos from their babies and engage in other memory making experienced in such a situation. One mother expressed that avoiding discussing the possibility that one's baby might die, would not prevent it from happening.

The second theme arising from this question was that the mothers felt that hospitals should employ a specially trained person to make contact with the parents immediately following the death of their baby who would contain their grief and guide them through the different steps. One mother felt that these hospitals should also have contact networks on their websites specifically for this purpose. These networks should contain information specific to different types of deaths and provide mothers with contact details of others who shared a similar experience and support groups that they could attend. She felt that this programme should have a coordinator dedicated specifically to this purpose.

3.3 SUMMARY

In summary, the findings of the study have been depicted both quantitatively and qualitatively. Although the significance of the findings will be discussed in more detail in the next chapter, it appears that the parents overall experiences of accessing services and the quality of the services that they were provided with, has been average. Some mothers have described the services as being enormously supportive and very easily

accessible, whereas others have described them as being unsupportive and inaccessible. On the whole, however, the mothers appear to have had average experiences of the services that they received and obtaining access to these services. While some aspects of the various services were described as helpful, others were not seen as helpful at all.

CHAPTER 4

SUMMARIES, CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This chapter seeks to present the overall conclusions and recommendations of the study based on the literature investigation done and the findings of the study as presented in chapters two and three. It will present the conclusions and recommendations for each chapter, beginning first by providing a brief summary of what each chapter entailed. Recommendations for the study process, the findings and future investigations will be provided.

4.2 SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.2.1 Chapter 1

4.2.1.1 Summary

The topic that the researcher investigated was mothers' experiences of accessing services following the death of a baby through stillbirth or neonatal death. The first chapter aimed to provide the reader with a comprehensive understanding of the research motivation, procedure and methodology used by the researcher in her investigation of the said topic.

The researcher motivated her choice of topic in the knowledge that between three and five percent of new mothers each year face the devastation of the loss of their babies. In August 2002, the researcher lost her three-week-old daughter, Gemma-Leigh, to meningitis. Subsequent to her loss, the researcher and a friend, who had also lost a baby, started a support network for people who had lost babies. Through her contact with other bereaved mothers, the researcher began questioning the accessibility of adequate and supportive services to mothers who had lost babies. Her choice of research topic was, therefore, made out of personal interest and social concern. Further, the researcher believed that, should she be able to gain information from the mothers concerning their experiences of the services, this information would be invaluable in

informing the running of her support group. The findings would, therefore, affect the researcher's day-to-day activities.

The problem that the researcher formulated through her contact with bereaved mothers was that, to a large degree, the services offered to mothers who have lost a baby are of poor quality and are not easily accessible. Specifically, the researcher looked at hospital services, religious services, social support and services within the formal counselling sector. Support is acknowledged to be vital in the mothers' successful movement through the grief process and in the prevention of grief complications. For this reason, the support offered to bereaved mothers by the relevant services, play a significant role in the outcome of their grief.

The aim of the study conducted was to explore the experiences of mothers in accessing the services that are available to them following the death of a baby through stillbirth or neonatal death. The objectives, therefore, were: -

- To do an investigation into the emotions of mothers following the loss of a baby through stillbirth or neonatal death;
- To assess the services that are available to mothers following the death of a baby through stillbirth or neonatal death;
- To assess the accessibility of the services available;
- To provide conclusions and recommendations for practice and for future research on the services offered to mothers who have lost a baby through stillbirth or neonatal death.

The research question asked was: **What are mothers' experiences of accessing services following the death of a baby through stillbirth or neonatal death?**

The research design was exploratory in nature in that previous research into the experiences of bereaved mothers in gaining access to support services following the death of a baby through stillbirth or neonatal death, in Gauteng had not yet been explored. The research was applied in type as it built on past research and, the researcher hoped, would be able to provide information for the practical improvement of support services for such mothers. The researcher used a combination of the quantitative and the qualitative approaches in the form of the dominant-less-dominant model (quantitative research being more dominant). The procedure that she used to collect the data was the semi-structured interview schedule that allowed her to gain insight, in propinquity, to the mothers'

perceptions, beliefs and personal accounts of their experiences in gaining access to support services. Quantitative information obtained was analysed by means of percentages and graphs and qualitative information obtained was analysed according to themes and sub themes.

A pilot study of the literature, the experts that could be consulted the feasibility of the study and pilot testing of the interview schedule was discussed. The literature study and the pilot test were to inform the interview schedule.

The sampling method used for the research was a non-probability sample. This accidental sample was chosen based on the availability of mothers and was not at all random. Certain criteria for the sample were also defined, making it purposive in nature.

These included:

- The respondents were all be mothers, of any age, who had lost a baby;
- The baby was lost through stillbirth or neonatal death;
- The baby passed away within the last five years;
- The mothers were all members of a support group, either the *Compassionate Friends* or *Baby Angels*.

Ethical issues were then discussed. It was mentioned that the researcher would need to obtain informed consent for the study and was to ensure that the respondents details remained confidential at all times. No harm was to come to the mothers. This was ensured through the sampling criteria making it necessary for all mothers to have access to a support group network. Further, the researcher undertook to do any debriefing that was necessary. The need for the limitations of the study methodology to be outlined was mentioned along with the possibility of publishing the research.

Finally the concepts of *stillbirth*, *neonatal death* and *support groups* were defined.

4.2.1.2 Conclusions

The conclusions to this chapter will be provided in point form. They are as listed below:

- The researcher maintains that this study is of significant value in a field that, as yet, has not been widely researched - even less so in South Africa. As the loss of a baby affects an estimated three to five percent of mothers each year, the need for such

research is self-evident. Further research, on a much greater scale would be invaluable.

- The information provided from the study, will be able to inform the running of the researcher's support group. The information also holds the potential of informing the services offered by hospitals, religious institutions and other counselling services.
- Although the researcher believes that the defined categories of service examination were vital, a more in-depth examination of each particular service might provide even more detailed and valuable information.
- The aims and objectives of the study were met. The researcher was able to explore the experiences of mothers in accessing the services that are available to them following the death of a baby through stillbirth or neonatal death. Further and in depth literature study into the emotions of mothers following the loss of a baby through stillbirth or neonatal death was conducted. An assessment of the services that are available to mothers following the death of a baby through stillbirth or neonatal death and their accessibility was conducted through the interview schedule and conclusions and recommendations for practice and for future research on the services offered to mothers who have lost a baby through stillbirth or neonatal death are hereby given.
- The research question namely, 'What are mothers' experiences of accessing services following the death of a baby through stillbirth or neonatal death?' is not simply answered, but does so through the presentation of the findings in chapter three.
- Although the researcher believes that the dominant-less-dominant model of research was effective in the conducting of this study, further, more qualitative and more quantitative research into the field would only add value.
- The semi-structured interview schedule was effective in gaining the information needed and, the required number of mothers was found to be involved in the study. Despite this, however, it must be mentioned that obtaining mothers willing to be involved in the research was a lengthy procedure as the subject matter involved is highly personal. It is possible that, had the researcher conducted purely quantitative research, where a questionnaire could be sent out and mothers did not have to elaborate too deeply on their answers, that a higher response rate might have been achieved. It must, however, be noted that such research would also have ethical challenges in this regard and quite possibly, the sensitive nature of the material might mean that questionnaires are not a possibility.
- Interestingly, one mother expressed to the researcher that she had enjoyed the interview in that she had found it cathartic and informative. She expressed that she felt that she had been able to 'organise' her emotions better as a result of the

discussion. This was a positive side effect of the research that the researcher had not considered. It may have been a similar experience for other mothers.

- The sample, as a result of its size and general uniformity, has not provided generalisable information.
- Being a non-probability sample based on availability, the researcher found that many of the mothers interviewed shared similar backgrounds and all were of the same ethnicity. The researcher, thus, believes that a shortcoming of the research is the relative uniformity of the selected sample. Further research into the experiences of mothers from different backgrounds and ethnicities would be valuable. Also, as all of the mothers lost their babies at private hospitals, the experiences of those using government facilities would be valuable.

4.2.1.3 Recommendations

The recommendations of this chapter will be provided in point form. They are as listed below:

- It is strongly recommended that the researcher endeavours to provide feedback to the various services discussed of the findings of the research. Such information may prove valuable in the services that they offer to bereaved mothers.

Recommendations for further research are listed as follows:

- It is recommended that more quantitative research into mothers' experiences in accessing resources following the death of a baby through stillbirth or neonatal death, would be invaluable. A questionnaire format that could be distributed throughout South Africa, thus reaching a larger number of mothers from different walks of life, would provide a new dimension to the already gained information.
- It is recommended that further, more in depth research be conducted into the individual categories of service evaluations. Such research may be conducted quantitatively, on a large scale to obtain generalisable data, or qualitatively, with one or two mothers, to obtain information rich data on the experiences of mothers.
- It is recommended that further research be done into the experiences of mothers of varying ethnicities and with different backgrounds, of accessing services following the loss of a baby through stillbirth or neonatal death.
- Similar research into the services offered by government as opposed to private hospitals should be conducted.

- The researcher believes that it would be invaluable to conduct the same study on the experiences of fathers. Unfortunately it appears that their needs are, for the most part, neglected in such circumstances.

4.2.2 CHAPTER 2

4.2.2.1 Summary

Chapter two sought to discuss, in detail, the literature informing the study. The discussion of the literature as outlined by the researcher, was set in a logical progression – beginning with a discussion on grief and the grief process itself, then moving onto a discussion of the grief following the loss of a boy and maternal grief predictors and ending in a discussion on the services available to bereaved mothers.

The chapter began with definitions of grief, mourning and bereavement being provided. It then moved onto a discussion of the grief process. Although there has, in the past, been some argument between experts as to the path that grief follows, most agree that there is a grief process. It is suggested that a number of issues will influence how long a bereaved parent will take to move through this process. The age of the survivor and the age of the bereaved both play a significant role in the grief process. The issues relating to the loss of a child, for example, are vastly different from those relating to the loss of a parent. The relationship that the bereaved had with the deceased and the bereaved person's grief history also play a role. Bereavement overload, the culture and gender of the bereaved and the manner in which the deceased died, may have a profound influence of the grieving process. Finally, and most important to this study, the support that the bereaved receives from his or her support networks significantly impacts on the outcome of his or her grief process.

The stages of grief were then outlined and discussed in detail. These included the stages of shock, denial and isolation; anger (towards oneself and others); bargaining; depression and, ultimately, acceptance.

Dysfunctional grief responses were outlined in detail. These responses are particularly pertinent in their definition of the grief process and determine the quality of the life of the bereaved. Fixated grief, unhealthy denial, reversibility, mementos, identification/ assuming the characteristics of the deceased, mistaking others, emotions in disguise,

anniversary reactions, replicated loss and disenfranchised grief were discussed. Disenfranchised grief is particularly relevant in relation to the loss of a baby and the subsequent support that a bereaved mother receives. Mothers who feel that the depth of their grief is not accepted by society at large may repress their grief and complicate it as a result.

Models of grief, particularly Dianne Arcangel's model of normal grief, transcendence and fixated grief (Adapted from Moody & Arcangel, 2002: 132 – 136); Raymond Moody's model of grief and transcendence (adapted from Moody & Arcangel, 2002:136 - 139) and Stroebe and Schut's dual process model of coping with loss were outlined. (Compare Cook & Oltjenbruns, 1998:100 -102, Stroebe & Schut, 1999: 197 – 224, Curren, 2001: 101 – 104.) These models were chosen according to their particular qualities and highlighted different aspects of grief. The first highlighted the movement of the grief process and one's ability to become either fixated in the grief or to transcend the grief. The second shows that the grief following the loss of a child, although sometimes waning in intensity, becomes incorporated into the individual as a part of who he or she is and does not ever become removed. The third, amongst other things, highlights the need for time out in the grieving process.

Despite the intense grief that parents experience following the loss of a baby, this grief is seldom acknowledged and understood by society at large. People tend to quantify loss based on time rather than significance, leaving many bereaved mothers of infants feeling isolated and alone, and, frequently, complicating their grief as a result (disenfranchised grief). Three major categories are outlined in predicting the outcome of the grief process in bereaved mothers. These include the perceived support that they receive from the community and their families; their satisfaction within their marital/partner relationship (bereaved parents need to be supportive, tolerant and understanding of each others' grief process) and the ways in which they cope with loss. Mothers that cope by using their own inner strength along with the support offered by others, generally manage the grief process better than those who try to cope on their own.

Finally, three major categories of services available to mothers following the loss of a baby were discussed: hospital services, religious services and formal counselling services. Hospital services need to be tolerant. Briefly, as most babies pass away within a hospital setting, the services offered to bereaved mothers following their baby's death are of particular relevance. Mothers should be encouraged to hold their babies, take

photos of their babies and gather as many mementos of their babies as possible. They should be offered a baptism of their babies, be provided with adequate and detailed information on the cause of their baby's deaths and should be allowed to stay in a private room. Mothers should be offered immediate hospital counselling.

Religious institutions and religious leaders should be supportive of bereaved mothers and their grieving process. Answers should be provided to their questions, when possible, in a non-judgemental and compassionate environment. Counsellors offering formal counselling to bereaved mothers should be empathic and non-judgemental. They should be aware of the grief process and be able to provide the bereaved mothers with practical tips for moving through this. They should be up to date with theory in this regard. Such counsellors should receive constant supervision.

4.2.2.2 Conclusions

The conclusions to this chapter will be provided in point form. They are as listed below:

- Although the researcher believes that the information provided in the literature study was sufficient for this investigation, there are certain areas in the literature that she believes would provide a great deal more informative information and, in which, she believes detailed literature studies could be conducted in their entirety. For example, a more detailed look into the marital relationship following the death of a baby would be hugely informative.
- It is worth mentioning that the process of conducting the literature study was both difficult and cathartic for the researcher herself. The information required that she examine her own personal experiences and emotions and, although this was at times difficult, she believes that, on the whole, it was a beneficial experience for her.

4.2.2.3 Recommendations

The recommendations of this chapter will be provided in point form. They are as listed below:

- It is recommended that a detailed literature study into the effects of the loss of a baby on the marital relationship be conducted. Such a study would also need to focus specifically on the differences in the grieving processes of men and women as, in the researcher's experience, it appears that much of society and, indeed, many mothers believe that the grief of fathers is not as intense as their own. The researcher does

not believe that this is the case at all and wonders if the differences in grieving styles between mothers and fathers could account, rather, for this perception.

- It is recommended that a detailed literature study into the effects of the loss of a baby on the father be conducted.
- It is recommended that research be conducted into the mothers' coping strategy in relation to her perception of the support that she received following the loss of a baby through stillbirth or neonatal death.

4.2.3 Chapter 3

4.2.3.1 Summary

This chapter endeavoured to present the findings of the study that the researcher conducted. The research was a combination of quantitative and qualitative approaches, set in the dominant-less-dominant form – the former being more dominant and the latter, less. Fifteen mothers were interviewed ranging from the age of twenty-three to forty-one years with a mean age of thirty-one years. As two of the mothers had lost twins, there were seventeen babies who had passed away. Five of the babies were stillborn, five were born prematurely and died of related consequences, three passed away as a result of genetic abnormalities, three passed away from illnesses and one died as a result of asphyxia during the birth process. The mean age of the babies at the time of their death was three days old.

All of the mothers interviewed felt that they had needed support following the loss of their babies. The mothers primarily turned to their husbands, their families or their friends for support. Of those who had turned to their husbands, most were unsatisfied with the support that they had received. While some mothers had mixed experiences of this support, most found their husbands totally unsupportive. Some of these mothers felt that this might be because their husbands simply did not know how to support them and others felt that their grief must have been more intense than that of their husbands. A handful of mothers described their families as grieving themselves and therefore, not very supportive, however, most of the mothers found the support offered by their families, very beneficial. Others described the support offered by friends as being very helpful.

Eighty percent of the mothers interviewed felt that society at large had not understood the profundity of their loss. Two themes arose out of their explanations for this. Firstly, and most predominantly, the mothers felt hurt and angered by insensitive, clichéd comments that had been made to them that they felt undermined the value of their babies and the significance of their loss. Secondly, many described their workplaces as being particularly unsupportive. Interestingly, the mothers who felt that society had grasped the profundity of their loss both lost their babies within the last two months.

All of the mothers interviewed lost their babies within the hospital setting. Sixty-seven percent of the mothers interviewed described their stay at the hospital as being, generally supportive and thirty three percent felt that it was not. Ninety-three percent of the mothers interviewed were given the opportunity to hold their babies while, or after they died. Many of these mothers expressed regret that they had not been able to do so for longer. Only one mother had her baby's photo taken by the hospital as a matter of protocol. The rest of the mothers, save six, either took their own photos or had somebody take photos for them. Although eighty percent of the mothers were given footprints of their babies as mementos when leaving the hospitals, most of the mothers expressed that they would have liked more mementos of their babies to be given to them. Particularly, the mothers regretted not being given a lock of their baby's hair. Twenty-seven percent of the mothers had their babies baptised at the hospital, in only one case did the hospital arrange the baptism. All of the mothers were put in their own rooms.

Forty-seven percent of the mothers interviewed felt satisfied with the information provided to them on the cause of their baby's death and found the doctors to be approachable. Fifty-three percent of the mothers were not provided with such information. Some of these mothers felt that their doctors were unapproachable and insensitive and that this was the reason for their lack of information, while others felt that the information was not provided to them because it was unknown to the doctors. None of the babies were given autopsies although one mother regretted this decision.

Three major themes arose out of the mothers' descriptions of the hospital staff. They were either viewed as totally supportive, compassionate and understanding, totally unsupportive, or as some being supportive and others not. Interestingly, the number of mothers who saw the staff as being totally unsupportive was very close to that of the mothers describing the hospital experience as unsupportive.

Eighty percent of the mothers described ways in which the hospital was supportive of them. Thematically, they felt certain staff members, the opportunities provided to them to make memories of their babies and the allowance for them to have visitors at any time, very supportive. In contrast, the ninety-three percent of mothers who gave accounts of what they had found unsupportive at the hospitals, thematically found certain staff members and the lack of opportunities provided to them to make memories of their babies, unsupportive.

When asked how they felt hospital could improve the services offered to mothers all but one mother gave suggestions. Seventy-three percent felt that they should have a more structured procedure in place for dealing with bereaved mothers. Sixty-seven percent felt that hospital staff needs more training and thirty-three percent expressed that they would have appreciated receiving more information – both on the grief process and their baby's cause of death. Twenty percent of the mothers felt that bereaved mothers should be kept pain-free and a further twenty percent felt that hospital should employ a person specifically trained to deal with bereaved mothers. Twenty percent of the mothers felt that hospitals should follow-up on bereaved mothers. Other suggestions included the improvement of communication and the offering of referral information upon discharge.

All of the mothers interviewed were Christian. Thirty-three percent of the mothers felt that the loss of their babies had not affected their religious views. Sixty-seven percent of the mothers felt that it had affected their religious views. Three themes arose as explanation. The mothers either blamed God for the death of their baby, feeling angry with Him and drifting from the church as a result; felt closer to God as a result of the death; or felt ambivalent in their views of God and the church.

Sixty-seven percent of the mothers interviewed described their religious institutions as being unsupportive following the loss of their babies. Two themes arose in their explanations for this. Firstly, some mothers felt that their churches were unaware of their loss and so, as a result, offered no support. Secondly, other mothers felt that their churches simply chose not to support them or were outright unsupportive. Nearly half of the mothers found their religious leaders to be supportive in offering emotional support and intellectual guidance. A sub theme arising out of the discussion on the support was the mothers' resentment of the religious clichés told to them by their religious communities.

When asked what they had found most supportive in their religious institutions, thirty-three percent of the mothers interviewed said that they had found nothing supportive. Forty percent expressed their religious leaders were supportive, thirty three percent felt the visits and phone calls they received were supportive, thirteen percent found prayer chains supportive and a further thirteen percent appreciated the practical support that they had received. Seven percent felt supported when her next child was born.

Twenty-seven percent of the mothers interviewed felt that there was no way that their religious institutions could improve the services offered to them. Forty percent, however, felt they could offer more emotional support and a further forty percent felt they could make more visits to them. Twenty-seven percent felt religious institutions need to be more proactive in approaching bereaved mothers and twenty-seven percent expressed that they would have liked to be able to ask questions and have their religious leaders answer them as best they could. Twenty percent of the mothers would have appreciated a follow-up, twenty percent would have appreciated practical support and twenty percent would have appreciated more sensitivity for the profundity and significance of their loss. Thirteen percent felt that churches needed to be more aware of what is happening within their congregation.

Only one of the mothers interviewed received counselling from the hospital. This was only one session, which she was unable to remember as a result of the medication she had been given, and she expressed that she would have appreciated being approached at a more appropriate time. Seventy-three percent of the mothers expressed that they would have liked to be given the opportunity to see a hospital counsellor. Thirty three percent of the mothers were given the details of support structures by the hospitals – support groups visited thirteen percent at the hospital, thirteen percent were given details of support groups and seven percent were given the details of a counsellor.

Seventy-three percent of the mothers interviewed sought external individual counselling. All the remaining mothers expressed that they would have liked to see one, but didn't for various reasons. Forty five percent of these mothers saw a psychologist; eighteen percent saw a psychiatrist; eighteen percent saw a Christian counsellor, nine percent saw a maternity nurse acting in a counselling capacity and nine percent saw a social worker. The mothers were referred to the counsellors by different people, most having been referred by their gynaecologists. The length of counselling time for the mothers

ranged from one session to two years, with a modal number of two sessions and six months.

Benefits of the external individual counselling were expressed as: catharsis in a non-judgemental environment; intellectual support with the providing of information on the grief process, normalising of feelings and tips on how to deal with their grief; Emotional support; and having the counsellor present at the hospital when the baby passed away. Nearly all of the mothers felt there were no shortcomings to their therapy. Two themes, however, emerged amongst those who did. Firstly, some mothers described their counsellors as having been religiously dogmatic in their approach. This they found extremely unsupportive. Secondly, some mothers found the information provided to them insufficient.

Ninety-three percent of the mothers interviewed felt that they had needed the support of other mothers who had also lost a baby. A number of reasons were provided for this. Some felt that they wanted contact with somebody who truly understood their grief and some felt that they wanted to normalise their feelings. Further mothers needed hope for the future in a time where they felt so hopeless and wanted to see others who had managed to move on with their lives. Some mothers wanted more information on the grief process and the cause of their baby's death and others wanted to help bereaved mothers in order to make meaning out of their loss. Although mothers learnt of the groups from different sources, the groups themselves contacted forty percent of the mothers. Twenty percent found out about the groups through the media and thirteen percent were told about the groups by the hospitals.

Seven themes arose in the mothers' descriptions of the benefits of the support groups. These were: Catharsis – the ability to share their experiences with others who truly understood; Regular phone calls and the ability to contact the group at any time; hope offered for the future; the ability to normalise feelings; the quality of guest speakers; the friends made through the group; and the proactive nature of the groups in making the first contact. While forty percent of the mothers felt that there were no shortcoming in the support groups, two themes emerged in the critique given by the others. Firstly, the logistics (location, time and frequency of meetings) associated with meetings were a problem for some and, secondly, some mothers found the meetings very emotionally heavy and draining.

Three mothers felt that there was no way that the support groups could improve their services. Forty-seven percent felt that there needed to be more awareness around the existence of the groups and that they need to be more conspicuous to communities. Twenty seven percent felt that they needed to be more proactive in their approach. Other suggestions included the offering of practical help; having groups focused on specific types of deaths, the provision of more literature by the groups, meeting more frequently and at better times, and lessening the intensity of group meetings.

Overall, the ratings that the mothers gave the support that they had received scores between three and eight. The average score was six and the modal scores were five and eight. When rating the ease with which they were able to access the services to offer them this support, the scores ranged from two to nine. The average score was five and the modal score was four.

Three major themes arose in the ways that mothers felt services in general could be improved. Firstly, and predominantly, they felt awareness around the support services available to bereaved mothers need to be increased. Equally, they felt awareness amongst the community about the significance of the loss of a baby and the depth of emotional trauma experienced by the mothers of the baby need to be increased. Secondly, mothers believed there needed to be more training of the support networks and that procedure and protocols need to be set in dealing with bereaved parents. Thirdly, mothers felt that support services needed to be more proactive in their approach to bereaved mothers rather than leaving the mothers to make the first move.

Finally, although six of the mothers felt no extra services needed to be made available to bereaved mothers, two themes arose in the suggestions offered by the other mothers. Firstly, mothers felt that antenatal classes should include in their syllabus a discussion on the death of babies and what should be done should such an eventuality occur. Secondly, mothers felt that hospitals needed in their employ, specialists to deal with bereaved mothers and to help them through their grief.

4.2.3.2 Conclusions

The conclusions to this chapter will be provided in point form. Although (based on the sample size and nature of the study) the findings are not generalisable, the findings still

provide valuable information from which conclusions may be drawn. They are as listed below:

- Although, for the purposes of this study, it was necessary to limit the study to stillborn and neonatal deaths, the researcher believes that a study examining the experiences of mothers who have lost their babies to cot deaths or miscarriage would also be invaluable. The researcher found that, when interviewing the mothers, many spoke about a friend or family member who had had horrific experiences gaining support services after a cot death or a miscarriage particularly. Cot death in that police investigations have to take place, and miscarriage in that the existence of the baby is seldom acknowledged.
- Mothers need support following the loss of a baby through stillbirth or neonatal death.
- Mothers turn primarily to their spouses/partners; families and friends for support following the loss of a baby through stillbirth or neonatal death.
- Mothers, in general, do not find their spouses/partners very supportive following the loss of a baby through stillbirth or neonatal death. Although tentative, it may be considered as a result, that fathers' grief is not adequately acknowledged and that they do not receive the support from their spouse that they might need.
- Mothers find their families and close friends most supportive following the loss of a baby through stillbirth or neonatal death.
- Society at large does not understand the profundity and significance of the loss of a baby. It appears that society believes that grief is time dependant, despite this not being the case.
- Insensitive and clichéd comments made to mothers following the loss of a baby through stillbirth or neonatal death are damaging and hurtful and may hinder the grieving process.
- Many mothers feel unsupported by their workplaces following the loss of a baby through stillbirth or neonatal death.
- It is possible that time plays a significant role in the mother's perceptions of the support that she has received.
- Hospital services provided to mothers who have lost a baby through stillbirth or neonatal death are not adequate. Although sixty-seven percent of the mothers described their hospitals as having been supportive, based on the literature outlining the procedures that should be in place for bereaved mothers and the mothers descriptions of the services that they actually received, they appear to be inadequate.
- Most hospitals do not have a procedure in place for dealing with bereaved mothers.

- Many hospital staff members are not adequately trained on how to deal with bereaved mothers.
- Most mothers, whether defining their hospital experiences as supportive or not, have regrets pertaining to their hospital stay. This particularly relating to their making memories of their deceased babies.
- The most important factors defining the hospital experiences of mothers is the support of the staff and the opportunities provided to the mothers to make memories of their babies.
- Most mothers' religious views are affected following the loss of a baby.
- Most mothers do not find support from their religious institutions easily accessible.
- Most mothers found their religious institutions unsupportive following the loss of their babies.
- The support given to a bereaved mother by her religious institution and leader has a profound effect on her grief process and her religious views.
- Mothers find the emotional support and the ability to be asked and answer various questions very helpful in a religious leader.
- Visits, phone calls, prayer chains and practical support are all important in the support offered by religious institutions to mothers following the death of a baby.
- In general, mothers are not provided with counselling by their hospitals following the deaths of their babies at the hospitals. This despite the general desire amongst mothers to receive such counselling.
- The formal counselling services offered to mothers following the loss of a baby through stillbirth or neonatal deaths are, for the most part, supportive of the mother.
- Most mothers receive external individual counselling following the loss of a baby through stillbirth or neonatal death. These mothers, generally, find such counselling beneficial.
- Mothers found catharsis, information given, emotional support and the presence of their counsellors at the hospital immediately following the death of their babies, supportive.
- Mothers find religious dogma and insufficient information provided by their counsellors unsupportive.
- Mothers feel that they need the support of other mothers who share a similar experience after the loss of a baby through stillbirth or neonatal death. Particularly, mothers want to find somebody who understands their experience and allows them to normalise their feelings, offering them hope for the future.

- Mothers find support groups very beneficial following the loss of a baby, however, frequently struggle with the logistics of attending meetings.
- Mothers often find support group meetings too heavy and emotionally draining.
- Overall, mothers find the support that they receive following the loss of a baby through stillbirth or neonatal death, slightly above average. They find the access to such support, however, difficult.

4.2.3.3 Recommendations

The recommendations of this chapter will be provided in point form. They are as listed below:

- The researcher again asserts that the lack of support that mothers find from their husbands/partners, results from a lack of understanding between the two of each mothers' grief process. For this reason, both should be better educated, possibly through counselling, on these discrepancies and ways in which to overcome them.
- It is recommended that society at large be better educated on the profundity and significance of the loss of a baby.
- It is recommended that the workplace of a recently bereaved mother who has lost a baby through stillbirth or neonatal death, be informed of how to best support her prior to her returning to work. Any trained professional within the workplace may do this.
- Recommendations for hospital services are as follows: -
 - Hospitals staff must be better trained on the significance of the loss of a baby and how to deal with bereaved mothers.
 - A procedure must be put into place at hospitals concerning what to do should a mother lose her baby. All staff members dealing with the mother should be trained in this regard. Mothers should be encouraged to hold their babies, photos should be taken by the hospitals of the babies, all possible mementos of the babies should be collected, mothers should be provided with information concerning the death of their babies and the grief process, mothers should be offered a baptism of their babies and mothers should be given a separate room.
 - Mothers should be kept pain-free following the death of their baby.
 - Hospitals should follow-up on mothers who have lost a baby there.
 - Hospitals should refer mothers for outside support upon discharge.
 - Hospitals should consider employing or contracting to grief experts to help them deal with bereaved mothers.

- Recommendations for religious services are as follows: -
 - Religious institutions need to be more aware of what is happening in the lives of the members of their congregations.
 - Religious leaders must be available and approachable to bereaved mothers to offer emotional support and answer their questions.
 - Religious institutions must offer practical support.
- Recommendations for formal counselling services are as follows: -
 - Counselling must be provided by hospitals for bereaved mothers.
 - It is recommended that bereaved mothers receive external individual counselling following the death of a baby through stillbirth or neonatal death.
 - Counsellors should refrain from expressing their own personal religious views and ideas in counselling sessions.
 - Bereaved parents must be provided with information on the grief process and practical tips on how to work through it during the counselling session.
 - Mothers should be referred to support groups following the loss of a baby through stillbirth or neonatal death. They should be encouraged to join them.
 - Support groups need to examine with their members, their needs in terms of times of meetings, locations of meetings and frequency of their meetings.
 - Support groups need to be sure that their members are adequately debriefed when leaving group meetings.
 - Support groups need to make themselves more conspicuous within the community.
 - Support groups need to initiate contact with bereaved mothers and do so as soon as possible following the death of the baby.
 - Support groups need to provide more literature for bereaved mothers.
- In general, services need to be more proactive in their approach to dealing with the bereaved. They must acknowledge that bereaved mothers usually lack energy and drive to mobilise themselves and, thus, make the first move in helping them.
- In general, more awareness needs to be raised about the resources available to bereaved mothers.
- Antenatal classes should include, as a part of their syllabus, a discussion on the loss of a baby, what one should do in such circumstances and the grief process.
- Literature on the different causes of deaths in babies needs to be more readily available.

Recommendations for further research are listed as follows:

- It is recommended that research be conducted into the experiences of mothers in accessing resources following the death of a baby through cot death be conducted.
- It is recommended that research be conducted into the experiences of mothers in accessing resources following the death of a baby through miscarriage be conducted.
- It is recommended that a longitudinal study into the mothers' perceptions of the support that she has received over time be conducted.
- It is recommended that research be conducted into the experiences of mother from religions, other than Christianity, of obtaining resources following the death of a baby through stillbirth or neonatal death.

4.4 SUMMARY

The researcher firmly believes that the research conducted will be invaluable in the practical contributions that it will be able to make to the services that are available to bereaved mothers. It is clear that, while the mothers feel that the services that they receive are just over average, they do not find these services very accessible to them. More awareness needs to be raised, not only about the significance of the loss of a baby and the emotional trauma that follows such a loss, but also about the services that are available to bereaved mothers. Adequate support is essential to a bereaved mother's overcoming her grief and being able to move on with her life. Without such support, her grief may become complicated and her quality of life will suffer as a result. For this reason, support services need to be of a high quality and need to be easily accessible to bereaved mothers. The study suggests that a drastic improvement in both the quality and the accessibility of these services will need to take place in order for them to sufficiently meet the needs of mothers who have lost a baby through stillbirth or neonatal death.

REFERENCE LIST

- Alexander, H. 1993. *Bereavement. A Shared Experience*. London: Lion Publishing.
- Author Unknown. "Perinatal Education Programme."
http://www.pepcourse.co.za/newborncafe/Unit38_p8.html (2003).
- Author Unknown. "South Africa People – 2002." The 2002 World Fact Book of the United States Central Intelligence Agency.
http://www.greekorthodoxchurch.org/wfb2002/south_africa/south_africa_people.html (2002).
- Author Unknown. "Training Manual for the Death Notification Form (BI 1663) 1999."
<http://www.doh.gov.za/nhis/vital/docs/deathmanual.html> (1999).
- Babbie, E. & Mouton, J. 2001. *The Practice of Social Research*. Oxford: Oxford University Press.
- Bates, R. 2003. *Interview with Ms R. Bates, Parklane Clinic*. Johannesburg, June 2003.
- Biebel, D. B. 1997. *Jonathan You Left too Soon*. Grand Rapids: Baker Book House Company.
- Bless, C. & Kathuria, R. 1993. *Fundamentals of Social Statistics; An African Perspective*. Cape Town: Juta and Co, Ltd.
- Chumbley, J. 1997. *Cot Death: The Facts*. London: Ward Lock.
- Collins, K. 1990. Social Work Research. In McKendrick, B. W. *Introduction to Social Work in South Africa*. Pretoria: HAUM Tertiary.
- Cook, A. S. & Oltjenbruns, K. A. 1998. *Dying and Grieving: Life Span Perspectives*. 2nd ed. Orlando: Harcourt Brace and Company.

Corey, M. S. & Corey, G. 1997. *Groups: Process and Practice*, 5th ed. Pacific Grove: Brooks/Cole Publishing Company.

Creswell, J. W. 1994. *Research Design: Qualitative and Quantitative Approaches*. California: SAGE Publications.

Creswell, J. W. 1998. *Qualitative Inquiry and Research design: Choosing Among Five Traditions*. California: SAGE Publications.

Currer, C. 2001. *Responding to Grief: Dying, Bereavement and Social Care*. New York: PALGRAVE.

Dane, F. C. 1990. *Research Methods*. California: Brooks/Cole Publishing Company.

Davis, K. 2000. Suffering and Gains in Loss. *Contemporary Psychology*, 45 (1). 55 – 57.

De Beer, K. 2004. *Interview with Mr K. De Beer, Lombardy East Methodist Church*. Johannesburg, February 2004.

De Kock, J. 2003. *Interview with Ms J. De Kock, The Compassionate Friends*. Johannesburg, June 2003.

De Vos, A. S. 1998. Combined Quantitative and Qualitative Approach. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

De Vos, A. S. 2002a. Combined Quantitative and Qualitative Approach. In De Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

De Vos, A. S. 2002b. Intervention Research. In de Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

De Vos, A. S. & Fouché, C. B. 1998. General Introduction to Research Design, Data Collection Methods and Data Analysis. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

De Vos, A. S. & Van Zyl, C. G. 1998. The Grounded Theory Methodology. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

De Vos, A. S., Schurink, E. M. & Strydom, H. 1998. The Nature of Research in the Caring Professions. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

De Wet, L. 2005. *Interview with Ms L. De Wet, Baby Angels*. Pretoria, May, 2005.

Durlak, J. A. 1998. Dealing with Traumatic Deaths. *Contemporary Psychology*, 43 (1). January: 61.

Durrheim, K. 1999. Research Design. In Terre Blanche, M. & Durrheim, K. (Editors), - *Research in Practice: Applied Methods for the Social Sciences*. Rondebosch: University of Cape Town Press.

Elmes, D. G., Kantowitz, B. H. and Roediger, H. L. 1999. *Research Methods in Psychology*, 6th ed. Pacific Grove: Brooks/Cole Publishing Company.

Engler, A. J. & Lasker, J. N. 2000. Predictors of Maternal Grief in the Year after a Newborn Death. *Illness, Crisis and Loss*, 8 (3). July: 227 – 243.

Fouché, C. B. 2002a. Problem Formulation. In De Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Fouché, C. B. 2002b. Selection of a Researchable Topic. In De Vos, A. S. (Editor), *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Fouché, C. B. and De Vos, A. S. 1998a. Problem Formulation. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

Fouché, C. B. and De Vos, A. S. 1998b. Selection of a Researchable Topic. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

Fowler, F. J. and Mangione, T. W. 1990. *Standardised Survey Interviewing: Minimising Interviewer-Related Error*. California: SAGE Publications. (Applied Social Research Methods Series, Vol 18).

Friedrichs, J., Daly, M. I. & Kavanaugh, K. 2000. Follow-Up of Parents Who Experience a Perinatal Loss: Facilitating Grief and Assessing for Grief Complicated by Depression. *Illness, Crisis and Loss*, 8 (3). July: 296 – 309.

Gensch, B. K. & Midland, D. 2000. When a Baby Dies: a Standard of Care. *Illness, Crises and Loss*, 8 (3). July: 286 – 295.

Greef, M. 2002. Information Collection: Interviewing. In De Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Grinnell, R. M. 1993. *Social Work Research and Evaluation*, 4th Ed. Itasca: Peacock Publishers.

Guy, R. F., Edgley, C. E., Arafat, I. & Allen, D. E. 1987. *Social Research Methods: Puzzles and Solutions*. Massachusetts: Allyn and Bacon, Inc.

Hendrick, T. E., Bickman, L & Rog, D. J. 1993. *Applied Research Design: A Practical Guide*. California: SAGE Publications.

Hornby, A. S. 2000. *Oxford Advanced Learner's Dictionary of Current English*, 6th Ed. Oxford: Oxford University Press.

Howe, D. 1995. *Attachment Theory for Social Work Practice*. London: McMillan Publishers.

Ingram, K. J. 1997. *Always Precious in our Memory: Reflections after Miscarriage, Stillbirth or Neonatal Death*. Chicago: ACTA Publications.

Jacobsen, F. W., Kindlen, M. & Shoemark, A. 1997. *Living Through Loss: A Manual for Those Working with Issues of Terminal Illness and Bereavement*. London: Jessica Kingsley Publishers.

Kavanaugh, K. and Paton, J. 2001. Communicating with Parents who Experience a Perinatal Loss. *Illness, Crisis and Loss*, 9 (4). October: 369 – 380.

Keaggy, B. 2002. *Losing You too Soon: Finding Hope after Miscarriage or the Loss of a Baby*. Oregon: Harvest House Publishers.

Kimmel, A. J. 1988. *Ethics and Values in Applied Social Research*. California: SAGE Publications.

Kissane, D. W. & Bloch, S. 2002. *Family Focused Grief Therapy*. Buckingham: Open University Press.

Kohner, N. & Henley, A. 1997. *When a Baby Dies: The Experience of Late Miscarriage, Stillbirth and Neonatal Death*. London: HarperCollins Publishers.

Kohner, N. & Thomas, J. 1995. *Grieving after the Death of your Baby*. Buckinghamshire: The Child Bereavement Trust.

Kübler-Ross, E. 1986. *Death: The Final Stage of Growth*. New York: Simon and Schuster, Inc.

Kübler-Ross, E. 1997. *On Death and Dying*. New York: Simon and Schuster, Inc.

Leh, P. L., Reiser, C. A. & Pauli, R. M. 2002. *When Your Baby is Stillborn*. Wisconsin: Wisconsin Stillbirth Service Programme.

- Lehohla, P. J. 2002. *Recorded Live Births 2001*. Pretoria: Statistics South Africa.
- Leon, I. G. 1990. *When a Baby Dies: Psychotherapy for Pregnancy and Newborn Loss*. Binghamton: Vail-Ballou Press.
- Lewis, C. S. 1966. *A Grief Observed*. London: Faber and Faber.
- Loewenberg, F. & Dolgoff, R. 1988. *Ethical Decisions for Social Work Practice*. Itasca: Peacock Publishers.
- McCracken, G. 1990. *The Long Interview*. California: SAGE Publications. (Qualitative Research Methods, Vol 13).
- Mehren, E. 1997. *After the Darkest Hour, the Sun will Shine Again: a Parent's Guide to Coping with the Loss of a Child*. New York: Simon and Schuster Inc.
- Miller, E. D. 1998. It's Not that Easy to Let Go: Living with Loss. *Contemporary Psychology*, 43 (1). January: 64 – 65.
- Milo, E. M. 1997. Maternal Responses to the Life and Death of a Child with a Developmental Disability: a Story of Hope. *Death Studies*, 21 (5): 443 – 476.
- Moody, R. & Arcangel, D. 2002. *Life after Loss: Finding Hope Through Life after Life*. London: Ebury Press.
- Nadeau, J. W. 1998. *Families Making Sense of Death*. London: SAGE Publications.
- Oikonen, J. & Brownlee, K. 2002. Family Therapy Following Perinatal Bereavement. *Family Therapy*, 29 (3). 125 – 140.
- Oliviere, D., Hargreaves, R. & Monroe, B. 1998. *Good Practices in Palliative Care*. Aldershot: Ashgate.
- Parkes, C. M. 2003. Acquainted with Grief. *Illness, Crisis and Loss*, 11 (1). January: 37 – 46.

Peinemann, F. "Prenatal Mortality Rate Criteria by Country." <http://frank.peinemann.bei.t-online.de/medicine/pmcountry.htm> (1st April 2003).

Peppers, L. G. & Knapp, R. J. 1980. *Motherhood and Mourning Perinatal Death*. New York: Praeger Publishers.

Poggenpoel, M. 1998. Data Analysis in Qualitative Research. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers

Pregent, C. 1992. *When a Child Dies*. Notre Dame: Ave Maria Press.

Rank, M. 1985. *Free to Grieve: Healing and Encouragement for Those Who Have Experienced the Physical, Mental and Emotional Trauma of Miscarriage and Stillbirth*. Minneapolis: Zondervan Bible Publishers.

Rich, D. E. 2000. The Impact of Postpregnancy Loss Services on Grief Outcome: Integrating Research and Practice in the Design of Perinatal Bereavement Programmes. *Illness, Crisis and Loss*, 8 (3). July: 244 – 264.

Riches, G. & Dawson, P. 2000. *An Intimate Loneliness: Supporting Bereaved Parents and Siblings*. Buckingham: Open University Press.

Robson, C. 1995. *Real World Research: a Resource for Social Scientists and Practitioner-Researchers*. Oxford: Blackwell Publishers, Ltd.

Rosenblatt, P. C. 2000. *Help your Marriage Survive the Death of a Child*. Philadelphia: Temple University Press.

Ryan, A. 2000. *A Silent Love: Personal Stories of coming to Terms with Miscarriage*. Victoria: Penguin Books.

Rybarik, F. 2000. Perinatal Bereavement. *Illness, Crisis and Loss*, 8 (3). July: 221 – 226.

Schiff, H. S. 1979. *The Bereaved Parent*. London: Souvenir Press.

Schurink, E. M. 1998a. Designing Qualitative Research. In De Vos, A. S. (Editor) - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

Schurink, E. M. 1998b. The Methodology of Unstructured Face-to-Face Interviewing. In De Vos, A. S. (Editor) - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

Schwandt, T. A. 1997. *Qualitative Inquiry: A Dictionary of Terms*. California: SAGE Publications.

Singleton, R. Straits, B. C., Straits, M. M. & McAllister, R. J. 1998. *Approaches to Social Research*. New York: Oxford University Press.

Sister Wendy, 2003. *Interview with Sister Wendy, Parklane Clinic*. Johannesburg, March 2003.

Stillion, J. M. 1998. Exploring Empathy: A Journey Through Pain. *Contemporary Psychology*, 43 (1). January: 62 – 63.

Stroebe, M. & Schut, H. 1998. Culture and Grief. *Bereavement Care*, 17 (1): 7 – 11.

Stroebe, M. & Schut, H. 1999. The Dual Process Model of Coping with Bereavement: Rationale and Description. *Death Studies*, 23: 197 – 224.

Strydom, H. 1998a. Ethical Aspects of Research in the Caring Professions. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. 1998b. Pilot Study. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. 2002a. Ethical Aspects of Research in the Social Sciences and Human Service Professions. In De Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. 2002b. The Pilot Study. In De Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. & De Vos, A. S. 1998. Sampling and Sampling Methods. In De Vos, A. S. (Editor), - *Research at Grass Roots: a Primer for the Caring Professions*. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. & Delpont, C. S. L. 2002. Sampling and Pilot Study in Qualitative Research. In De Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Strydom, H. & Venter, L. 2002. Sampling and Sampling Methods. In De Vos, A. S. (Editor), - *Research at Grass Roots: For the Social Sciences and Human Service Professions*. 2nd ed. Pretoria: J. L. Van Schaik Publishers.

Tatelbaum, J. 1980. *The Courage to Grieve*. London: Cedar Books.

The Child Bereavement Trust. 2000. *The Child Bereavement Trust: Support and Counselling for Grieving Families*. Wycombe: The Child Bereavement Trust.

Thomas, J. 1993. *Supporting Parents When Their Baby Dies Before or Soon After Birth: a Guide for Staff Antenatal, Labour Ward, Postnatal Gynaecological and Neonatal Teams*. London: Expression Printers Ltd.

Thomas, J. & Williams, B. 1995. *When our Baby Died*. Video Recording: Surrey Media Services.

Toseland, R. W. & Rivas, R. F. 1998. *An Introduction to Group Work Practice*, 3rd ed. Needham Heights, Massachusetts.

Ujda, R. M. & Bendiksen, R. 2000. Health Care Provider Support and Grief after Perinatal Loss: A Qualitative Study. *Illness, Crisis and Loss*, 8 (3). July: 265 – 285.

Van der Merwe, H. 1996. The research process: Problem Statement and Research Design. In Garbers, J. G. (Reds.) *Effective Research in Human Sciences*. Pretoria: J. L. van Schaik Publishers.

Van Niekerk. 2003. *Interview with Ms. Van Niekerk, Statistics South Africa*. Pretoria, May 2003.

Wheeler, S. R. 2000. A Loss of Innocence and a Gain in Vulnerability: Subsequent Pregnancy After a Loss. *Illness, Crisis and Loss*, 8 (3). July: 310 – 326.

Zucker, A. 1998. Was Donne Only Half Right? *Contemporary Psychology*, 43 (1). January: 63.

APPENDICES

APPENDIX A

LETTER SUBMITTED TO MOTHERS: MOTHERS' EXPERIENCES OF ACCESSING SERVICES FOLLOWING THE DEATH OF A BABY THROUGH STILLBIRTH OR NEONATAL DEATH

Dear ...(Bereaved Mother).....

Thank you so much for agreeing to partake in my study concerning the services that were available to you following the loss of your baby. I have undertaken to research this topic, under the guidance of my supervisor, Dr C.E. Prinsloo, and the University of Pretoria, in order to better understand both the nature and the availability of the services that were offered to you, and other mothers like you, following the death of your baby. I am hoping that the outcomes of the research may be used to help inform the future functioning of some of these services.

I obtained your details from the support network (Baby Angels/ Compassionate Friends) that you are a part of. These details, however, will remain strictly confidential and will not be printed with the research. I understand that the subject matter to be discussed is highly personal and would like to inform you that, should you at any time feel that you wish to withdraw from being involved in the study, you may do so, without prejudice, at your discretion. Should you wish to obtain a copy of the final written work, this will also be provided.

Thank you, once again for your time.

Yours sincerely
Jennifer Conry

APPENDIX B

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR RESEARCH: MOTHERS' EXPERIENCES OF ACCESSING SERVICES FOLLOWING THE DEATH OF A BABY THROUGH STILLBIRTH OR NEONATAL DEATH

A. IDENTIFYING DETAILS

1. Age of respondent:
2. How many children (including the baby who passed away) do you have?
.....
3. Please mark the age, sex and age at the time of your baby's death, of each child in the space provided below (please circle the baby who passed away).

| | Sex | Age (in chronological order) | Age at Time of Baby's Death |
|---------|-----|------------------------------|-----------------------------|
| Child 1 | | | |
| Child 2 | | | |
| Child 3 | | | |
| Child 4 | | | |
| Child 5 | | | |

4. Please indicate your age at the time of your baby's death:
.....
5. Please indicate the cause of your baby's death:
.....
.....
.....
.....

B. SUPPORT

6. Did you feel that you needed support to help you deal with the loss of your baby?

| | |
|-----|----|
| YES | NO |
|-----|----|
7. If **yes**, whom did you turn to for support and how would you describe the support that you received?
.....
.....
.....
.....
.....
8. Do you feel that society at large understood the profundity of your loss?
.....
.....
.....
.....

19. How did you find the support offered by your religious leader following the loss of your baby?

.....

20. What, if anything, did you find helpful in the support offered to you by your religious institution?

.....

21. In what ways, if any, do you feel your religious institution could have been more supportive of you?

.....

E. FORMAL SERVICES

1. Hospital Counselling

22. Were you provided with any counselling by the hospital following the death of your baby?

| | |
|-----|----|
| YES | NO |
|-----|----|

If **yes**, please answer questions 23 -25. If **no**, please answer question 26.

23. Was the counsellor a:

| | |
|------------------------|--|
| Psychologist | |
| Social worker | |
| Psychiatrist | |
| Counsellor | |
| Other (please specify) | |

24. For how long did your counselling last?

.....

25. Please describe the counselling that you received in terms of its benefits and shortcomings

.....

26. Would you have liked to be given the opportunity to have seen a hospital counsellor?

| | |
|-----|----|
| YES | NO |
|-----|----|

27. Were you given any details of support groups/ support web sites or outside counsellors by the hospital when you left?

| | |
|-----|----|
| YES | NO |
|-----|----|

Please elaborate

.....

2. External Individual Counselling

28. Did you see a professional counsellor external of the hospital in order to help you cope with the loss of your baby?

| | |
|-----|----|
| YES | NO |
|-----|----|

If **yes**, please answer questions 29 - 32. If **no**, please answer question 33.

29. Was the counsellor a:

| | |
|------------------------|--|
| Psychologist | |
| Social worker | |
| Psychiatrist | |
| Counsellor | |
| Other (please specify) | |

30. Who referred you to the counsellor?

.....

31. For how long did your counselling last?

.....

32. Please describe the counselling that you received in terms of its benefits and shortcomings.

.....
.....
.....
.....
.....
.....
.....
.....

33. Would you have liked to see a counsellor?

| | |
|-----|----|
| YES | NO |
|-----|----|

If **yes**, what were your reasons for not seeking counselling?

.....
.....
.....
.....

3. Support Groups

34. Did you feel that you needed the support of others who had shared a similar experience with you in order to help you cope with the loss of your baby?

| | |
|-----|----|
| YES | NO |
|-----|----|

Elaborate:.....

.....
.....
.....

35. How did you learn about the support group?

.....
.....
.....

36. Please describe your experience of the support group that your were a part of in terms of its benefits and shortcomings.

.....
.....
.....
.....
.....
.....
.....

37. In what ways do you feel support groups could improve in order to provide a more constructive service to the community?

.....
.....
.....
.....

F. GENERAL

38. In general, on a scale of 1 – 10 (1 being totally unresponsive and 10 being totally responsive) how would you rate the overall support that you received following the loss of your baby?
.....

39. On the same scale, how would you rate the ease with which you were able to access the services that provide this support?
.....

40. In what ways do you think the services could be improved?
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....

41. What other services should be provided?
.....
.....
.....
.....

**I thank you for your time
Jennifer Conry**