PSYCHOSOCIAL IMPLICATIONS OF STILLBIRTH FOR THE MOTHER AND HER FAMILY: A CRISIS-SUPPORT APPROACH

by

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Declaration

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ABSTRACT

According to South African annual statistics, stillbirth is a relevant issue and National health policies, social welfare services and health care providers should place special focus on pregnant women to avoid the possible occurrence of a negative pregnancy outcome such as a stillbirth.

An event that should have been a joyous birth, ended in a tragic death, forcing the mother to deal with the emotions of birth and death simultaneously. The bereaved mother needs to receive special care and support as soon as possible and the crisis intervention approach is seen as being helpful to regain a sense of equilibrium in her and the family's life before starting to adapt to the new situation.

This study explores and describes the lived experience of 25 mothers who experienced a stillbirth. Focus was given to the psychosocial implications of stillbirth on mothers and their families. This study examined the mothers' feelings about the stillbirth six months or longer after the event, as well as its impact on relationships with partners and other children. By adopting a crisis intervention approach, the effectiveness of crisis intervention shortly after the stillbirth could be investigated.

This study used a combination of quantitative and qualitative research approaches and assumed an exploratory and descriptive research design to provide a detailed description of the phenomenon being studied, i.e. the psychosocial implications of stillbirth. A questionnaire was used to obtain demographic (quantitative) data and a semi-structured questionnaire – the design based on information from literature - was administered during individual interviews. Obtained data was both measurable and rich in description and revealed that mothers still longed for their stillborn babies after a period of six or more months had passed. It also indicated that the father or partner of the baby and other children were affected by a stillbirth. Gender differences in how stillbirth is experienced by each partner, consequently adds extra tension on the relationship.

Most of the mothers experienced the stillbirth as a crisis and found support in their mothers, family and a counsellor. Significantly, mothers felt crisis-intervention was

beneficial, but preferred that crisis intervention be followed by on-going therapy. The stillbirth also resulted in feelings of alienation from community, friends and family - who did not know how to approach them. Generally, mothers were satisfied with medical care received but several issues regarding autopsy consent and guilt feelings surrounding this are highlighted.

Important recommendations resulting from the study indicate that the crisis-intervention approach as method in social work is effective when rendering service for bereaved mothers and families after a stillbirth. It helps to regain a sense of equilibrium, but further intervention is recommended to facilitate the grief process. In addition, the study emphasizes the importance of social workers being aware that the stillbirth causes tension in partner- and family relationships. Receiving social work intervention is not only highly effective, but allows bereaved mothers to feel empowered and encouraged to openly grieve for their stillborn babies - much needed in an environment where a stillbirth is seen as a silent birth.

OPSOMMING

Volgens jaarlikse Suid-Afrikaanse statistieke, is stilgeboorte ‘n relevante onderwerp en die Nasionale gesondheidsbeleid, maatskaplike welsynsdienste en gesondheidssorgverskaffers moet fokus op swanger vroue ten einde moontlike negatiewe swangerskapuitkomstes, soos stilgeboorte, te voorkom.

Tydens ‘n stilgeboorte, eindig die heuglike vooruitsig van ‘n geboorte in die tragiese afsterwe van die baba en word die moeder geforseer om emosies van geboorte en sterfte gelyktydig te hanteer. Sulke moeders benodig spesiale versorging asook ondersteuning so spoedig moontlik. Krisis intervensie is ‘n effektiewe metode om die moeder te help om ‘n mate van balans in haar en haar gesin se lewe te herwin voordat hulle kan begin aanpas by die nuwe situasie.

Hierdie studie ondersoek en beskryf ervarings van 25 moeders wat ‘n stilgeboorte ervaar het. Fokus word geplaas op die psigososiale effek van stilgeboorte op moeders en hul gesinne. Moeders se gevoelens rakende die stilgeboorte ses maande of langer na die geboorte, is ondersoek, asook die effek daarvan op hul verhoudings met lewensmaats en ander kinders. Deur die krisis intervensie benadering te gebruik, kon die effektiwiteit daarvan kort na die stilgeboorte ondersoek word.

Kwantitatiewe en kwalitatiewe navorsingsmetodes is in hierdie studie gebruik. Die studie veronderstel ’n verkennende en beskrywende navorsingsontwerp om sodoende ’n uitvoerige beskrywing van die psigososiale implikasie van stilgeboorte te verskaf. Data word verkry deur ’n vraelyste - demografiese (kwantitatiewe) data, asook semigestruktureerde vraelyste (kwalitatief) wat tydens individuele onderhoude toegedien is. Die ontwerp van die semi-gestruktureerde vraelys is gebaseer op inligting vanuit die literatuurstudie. Die bevindinge van die empiriese ondersoek dui aan dat moeders na ses maande of langer steeds hunker na hul stilgebore babas. Geslagsverskille rakende die wyse waarop moeders en vaders die stilgeboorte ervaar dra gevolglik by tot ekstra spanning in die verhouding.

Die meeste moeders het die stilgeboorte as ‘n krisis ervaar en het ondersteuning gevind by hulle moeders, gesinne en ‘n berader/maatskaplike werker. ‘n Beduidende bevinding was dat moeders krisis intervensie as voordelig beskou het, maar verkies dat dit opgevolg moet word deur deurlopende terapie. Die stilgeboorte veroorsaak ook dat die moeders ‘n gevoel van vereensaming van die gemeenskap, vriende en familie ervaar het. Volgens hulle was mense te bang en onseker in hoe om hulle te benader. In die algemeen was moeders tevrede met die mediese sorg wat hulle ontvang het, maar kwessies rakende toestemming en skuldgevoelens rondom nadoodse ondersoeke word uitgelig.

Belangrike aanbevelings dui aan dat krisis intervensie as metode in maatskaplike werk effektief is ten opsigte van dienslewering vir ‘n moeder en haar gesin na ‘n stilgeboorte. Dit help om ‘n mate van balans te herstel, maar verdere intervensie word aanbeveel om die rouproses te fasiliteer. Die studie beklemtoon ook dat dit belangrik is dat maatskaplike werkers bewus moet wees dat ‘n stilgeboorte spanning veroorsaak in huweliks- en gesinsverhoudings. Die ontvangs van maatskaplike werk intervensie is nie net hoogs effektief nie, maar bemagtig en motiveer moeders om openlik te rou vir hulle stilgebore babas, iets wat nodig is in ‘n samelewing waar stilgeboorte as ‘n geboorte beskou word waaroor daar nie gepraat word nie.

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CHAPTER 1

INTRODUCTION

1.1 PRELIMINARY STUDY AND RATIONALE

"We grieve all that cannot be spoken, that for which there is no name (Griffin, 1978, cited in Cacciatore, 2009)."

The death of a fetus or newborn infant prompts a grief response which has numerous unique aspects. It affects not only the parents of the demised baby but also has an impact on the family and friends of the parents as well as the socio-economic environment of the parents.

The perinatal mortality rate in South Africa during 2006-2007 was approximately 38/1000 births (birth weight 500 g and above). Stillbirths alone extrapolate to approximately 8000 annually in health care institutions in South Africa (Pattinson, 2009:28). In contrast, the perinatal mortality rate is less than 10/1000 births in all industrialized countries of Western Europe and North America; a significant difference when compared to the rates in South Africa. The World Health Organization (WHO) estimates that there are 22 000 neonatal deaths in South Africa every year (Stephen & Patrick, 2008:83).

Stillbirth defies the modern expectation of a healthy outcome for pregnancy and has been demonstrated to be as profound and significant as any other type of bereavement (Chan, Lou, Arthur, Cao, Wu, Li & Lui, 2008:509). Grief experienced during this time is complex and individualistic. Main reasons contributing to the fact that this specific type of grief is so complex are: 1) lack of memories surrounding the baby, 2) sense of biological failure, especially felt by the mother of the baby, 3) minimization by others as well as lack of validation from others and 4) uncertainty regarding further pregnancies or parental future hopes (Hutti, 2005:630).

Various authors like Brier (2008:451) and Hughes and Riches (2003:108) agree with Capitulo (2005:390) and Hutti (2005:630) that for a stillborn baby, as in any loss, a period of grieving is required, but that this grieving can be a very lonely process owing to a lack of understanding of this unique and complex loss. Grief following miscarriage,

stillbirth or infant death is particularly susceptible to being disenfranchised, as only parents may have known the baby, felt it move, or observed it by ultrasound.

Brownlee and Oikonen (2004:526) did a review on perinatal bereavement and recommended that further research was necessary to address the social context of perinatal bereavement and the impact of factors compounding grief, such as financial resources, culture and social identity. These issues have been neglected in the literature, but may greatly influence people's style of grieving and the meaning they attribute to their loss. Brownlee and Oikonen (2004:526) further stated that social workers, by virtue of their knowledge of the social environment in which a person lives and its impact on social problems and emotional well-being, are in a good position to address these issues and make a substantial contribution to the theoretical and practice literature on perinatal bereavement.

Cacciatore (2009:93) also believes that the social worker has a prominent role in the macro culture to sway attitudes, beliefs and values about women experiencing stillbirth. This position is congruent with social work values such as advocacy, social change and self-determination.

Research regarding the psychosocial implications of stillbirth not only for the parents but also the impact of the loss on their families and themselves as a "total person" functioning in different systems is scarce. The literature review suggested a need for insight regarding whether different cultural and religious beliefs affect the way a person experiences the bereavement process. Do bereaved parents have a need for further support and in what form? As Cacciatore (2009:91) points out, there is an increased awareness of the psychosocial impact of stillbirth on the mother, and a holistic approach from the crisis intervention perspective needs to be done to understand stillbirth as experienced in a South African context where cultural and socio-economic factors are vital in forming an individual. Callister (2006:231) indicated a need for more qualitative data documenting cultural influences on perinatal loss, as well as the examination of paternal and sibling grief. A systematic review indicated that there is a paucity of research in this area, with no randomized trials documenting benefits of specific interventions (Callister, 2006:231). Further empirical investigation of the effects of parental exposure to the baby they have lost, needs to be conducted (Badenhorst & Hughes, 2007:256).

A literature study was conducted regarding this topic and it was found that little information is available about the follow-up of bereaved persons and that the focus is mainly on the period shortly after the stillbirth has occurred. To know whether support provided during the crisis period was beneficial for the person concerned, it is necessary to evaluate the functioning of that person a few months after the loss occurred.

The researcher gained a personal interest in the perinatal research field during an orientation period at Tygerberg Hospital in the Western Cape, before starting work there. Through-out the orientation period and during current duties at the Safe Passage Research Study, the researcher became closely involved with parents, especially mothers who have experienced a stillbirth. The researcher's task was to assist the parents emotionally through the stages of loss and grief. During this time it was noticed that, although research has been done on the impact of stillbirth on the parents as well as the family, this research had mainly been undertaken in industrialized countries of Western Europe and North America, with little research done in a South African context. The research that was done focused on the impact of stillbirth on the mother, but this was done before the onset of democracy in South Africa and during a time when stillbirth was not recognized as important enough to grieve about. Thus the need has arisen for a more recent study with special focus on social work intervention and the effectiveness thereof in a fast changing South Africa. The researcher's interest was further stimulated by existing conditions facts and a literature search. According to Pauw, publications dealing with the role of the social worker in infant death are few (Pauw, 1991:292).

The great need for a better understanding of the psychosocial implications of stillbirth for parents has been clearly perceived by the researcher during bereavement counselling of participants after stillbirth. This counselling entails an important follow-up call or visit a few months after the loss for all participants in the Safe Passage Study who have experienced a perinatal loss. Information from these follow-up visits provides the social worker with valuable details regarding participants' ability to maintain an acceptable level of functioning after the loss. In addition, opportunity is given for reflection on the crisis period. (Feelings about giving consent/or not giving consent for autopsy, holding the baby/or not holding the baby are normally reflected on.)

Providing emotional support and bereavement counselling to parents who have experienced a loss forms part of the tasks of the social worker of the Safe Passage Study at the clinical site at Tygerberg Hospital, Stellenbosch University. The following data can be provided regarding interviews which were conducted with prospective study participants.

During intervention the mourning process should be facilitated and appropriate support be provided. Unfortunately very few proper support groups for bereaved parents of stillbirths or infant deaths exist in South Africa. Internationally the Stillbirth Alliance and SANDS (Stillbirth and Neonatal Death Society) actively provide support to this specific group of parents. In South Africa the Compassionate Friends support group is actively providing support to bereaved parents (Ndlovu, 2009), but this is for any bereaved parent and not just for parents experiencing perinatal loss. This makes it less accessible for parents who might think their loss cannot be compared to the loss of a child that was much older.

The perceived lack of support groups motivated the researcher to explore the effectiveness of support to bereaved parents and to determine the feasibility of specialized support groups. From the above it can be reasoned that social workers play an important role in offering support to parents and families after the loss of a baby/infant, taking into account the psychosocial implications of such a loss on the entire family system. According to Pauw, publications dealing with the role of the social worker in infant death are few (Pauw, 1991:292). The need for the proposed study is therefore based on the above-mentioned rationale. Furthermore, after a comprehensive literature study of national and international literature it was found that there was a need to explore the implications of perinatal loss from a crisis intervention approach and a social worker's perspective. The value of the research will be to explore the psychosocial implications of stillbirth and to clarify the importance of social work intervention in this field of practice. The proposed research can therefore be seen as relevant.

1.2 PROBLEM STATEMENT AND RESEARCH HYPOTHESIS

A miscarriage or perinatal loss is a psychologically challenging event. Unlike with the loss of other family members, the grieving individual has had few direct life experiences or actual times with the deceased to review, remember and cherish (Brier, 2008:455).

While stillbirth affects all socio-economic groups, races, and ethnicities world-wide, they disproportionately afflict socio-economically disadvantaged populations. This correlates with the high perinatal mortality rate mentioned above.

Research on the psychosocial implications of stillbirth on the parents has mostly done in European countries, Australia and the United States of America (Callister, 2006:231, Badenhorst & Hughes, 2007:255, Hughes & Riches, 2003:107 and Hutti, 2005:630). Literature on perinatal loss in a South African context is scant and mainly focuses on the psychological perspective, investigating the psychological impact of stillbirth shortly after the incident and not investigating the psychosocial impact on the parents and family.

Research regarding the psychosocial implications of stillbirth not only for the parents but also the impact of the loss on their families and themselves as a "total person" functioning in different systems is scarce. The literature review suggested that there is a need for insight into the implications of stillbirth for the mother and her family, and whether cultural and gender beliefs have an effect on the crisis such a person is experiencing. Do bereaved parents have a need for further support and in what form? As Cacciatore (2009:91) points out, there is an increased awareness of the psychosocial impact of stillbirth loss on the mother, and that a holistic approach from the crisis intervention perspective needs to be done to understand stillbirth as experienced in a South African context where cultural and socio-economic factors are vital in forming an individual.

The overall hypothesis of the study is: "*The loss of a fetus/baby has long-term psychosocial implications for the mother and her family as perceived by the mother and proper social work support is needed to alleviate the grief process during the crisis period as well as the adjustment period thereafter.*"

1.3 AIMS AND OBJECTIVES OF THE STUDY AND THEORETICAL POINTS OF DEPARTURE

The goal of the study is to gain a better understanding of the psychosocial implications of stillbirth for the mother and her family in order to provide guidelines for intervention

by the social worker from the crisis intervention perspective. In order to achieve the goal of the study and to investigate the hypothesis, the individual aims/objectives will be:

- To investigate and gain information regarding the lived experiences of mothers who had experienced a stillbirth and their perceptions of the crisis by means of a questionnaire and semi-structured interview.
- To ascertain the nature and consequences of the loss on marital and/or family relationships as perceived by the mother.
- To investigate the bereaved mother's attitude regarding autopsy, whether she has consented to an autopsy or not and what the significance of autopsy is during the bereavement process.
- To develop pilot data about potential mechanisms for future in-depth analysis concerning how social workers can use a crisis intervention approach to assist mothers who have experienced a stillbirth and to assist the family to adjust constructively.
- To conduct a comprehensive literature review of the medical causes of stillbirth as a foundation for understanding its psychosocial impact in this study.
- To present a comprehensive literature review of the current understanding of the psychosocial implications of stillbirth for a mother and her family. This review will include information from multiple disciplines including social work, theology and psychology.

1.4 CLARIFICATION OF KEY CONCEPTS

For the purpose of this research study the following terms will be defined:

1.4.1 Perinatal

Perinatal means "around the time of birth". Perinatal usually applies to the last months of pregnancy and the first week after delivery (Woods & Theron, 1994). Brummer *et al.* (1990) refer to the perinatal time window as the time from 22 weeks of pregnancy (or 500g fetal weight) up until the first seven days of the neonates' life (Brummer, Cronje, Grobler & Visser, 1990). For the Safe Passage Study, the perinatal period ranges from a gestation period of 20 weeks to the 28 days after birth.

1.4.2 Perinatal loss

Perinatal loss includes early and late fetal death (miscarriage and stillbirth) and the death of a live neonate in the first 28 days after birth (Armstrong, 2002:339).

1.4.3 Stillbirth

A stillbirth (SB), or stillborn infant, is an infant who is potentially viable but is born dead. Potentially viable means that the infant would have had a reasonable chance of surviving had it been born alive. Born dead means that the infant shows no sign of life at delivery. Stillbirths are sometimes referred to as intra-uterine deaths or fetal deaths (Woods, Pattinson, & Greenfield, 2010).

1.4.4 Psychosocial

Psychosocial pertains to a person's psychological development in relation to his social environment. A psychosocial problem is a multiple and complex transaction pertaining to the social functioning of individuals or to the social and organizational functioning of larger social systems which are affected by, among others, personality disorders or mental illnesses, inadequate role performance and life transitions involving developmental changes, crises as well as communication and relationship difficulties (Terminology Committee for Social Work, 1995:50).

1.4.5 Crisis

A crisis can be defined as a functionally debilitating emotional state resulting from the individual's reaction to some event perceived to be so dangerous that it leaves him or her feeling helpless and unable to cope effectively by usual methods (Sheafor, Horejsi & Horejsi,1994:413). Among the events that can precipitate a crisis are the death of a loved one, loss of a job, marital separation, birth of a disabled child serious illness or accident, house fire, rape or other traumatic event.

1.4.6 Crisis intervention

The crisis intervention model is used to address the special needs and concerns of a client in an acute, psychological crisis. Crisis intervention can be defined as follows: "It is a process for actively influencing psychosocial functioning during a period of disequilibrium in order to alleviate the immediate impact of disruptive stressful events

and to help mobilize the psychological capabilities and social resources of persons directly affected by the crisis" (Sheafor, et.al.1994:68-69). Interventive efforts have two principal aims: (1) to cushion the stressful event by immediate or emergency emotional and environmental first aid and (2) to strengthen the person in his or her coping through immediate therapeutic clarification and guidance during the crisis period (Sheafor, et.al.1994:68-69).

1.5 RESEARCH DESIGN AND METHODOLOGY

1.5.1 Research approach

A combination of the qualitative and quantitative approach, with greater emphasis on the qualitative will be used to obtain the aim of the research. De Vos *et al.* (2005:74) explains that the qualitative paradigm stems from an antipositivistic, interpretative approach, is idiographic and thus holistic in nature, and aims mainly to understand social life and the meaning that people attach to everyday life (De Vos, Strydom, Fouché & Delport, 2005).

For the purpose of the study, the qualitative approach will focus on the participants' view of the challenges they faced after losing a baby, and the quantitative approach will present a statistical profile of the respondents' demographic background, whereafter the results will be interpreted.

1.5.2. Research design

Mouton (2001:55) defines a research design as a plan or blueprint of how one intends to conduct the research. For the purpose of this study a combination of the exploratory and descriptive designs will be used. The exploratory design generally refers to the "what" question and the descriptive design refers to the "how" (Mouton, 2001:53).

According to Bless and Higson-Smith as mentioned in De Vos *et al.*(2005:106), exploratory research is conducted to gain insight into a situation, phenomenon, community or individual. The intention of this study is to explore the psychosocial implications of perinatal loss for the mother and her family. An exploratory design will make it possible for the researcher to do this.

Information gained from a survey that will be conducted on identified participants will be described from a social worker perspective with special focus on the crisis intervention theoretical perspective. A descriptive design will be used to describe the findings and will also be used to provide guidelines for bereaved parents and the professionals working with these parents. Deductive reasoning will be used as it moves from the general to the specific. In this research the "general" aspect is the fact that perinatal loss has a psychological effect on the mother and the "specific" aspect would deal with the extent of the implications of the perinatal loss for the psychosocial well-being of the mother and her family, as being perceived from a social work perspective.

1.5.3 Research method

1.5.3.1 Literature study

De Vos *et al.* (2005:123) describe the necessity of a review of literature as a contribution towards a clearer understanding of the nature and meaning of the problem that has been identified. The literature study will thus focus on books, journals, articles and dissertations of both local and international literature, selected from the social and medical sciences as well as from theology.

1.5.3.2 Demarcation of research area

The research will be conducted within the Safe Passage Study – PASS (Prenatal Alcohol SIDS Stillbirth) Network at Tygerberg Hospital. The Safe Passage Study is a research study conducted by the Department of Obstetrics and Gynaecology, University of Stellenbosch in conjunction with the PASS Research Network. The Safe Passage Study investigates the hypothesis that prenatal alcohol and drug exposure increases the risk of negative pregnancy outcomes, like stillbirth or SIDS (sudden infant death syndrome). A sample group of participants who have experienced a stillbirth will be taken from the study where the researcher is currently working. Permission from the Steering Committee of the Safe Passage Study in USA has been granted.

1.5.3.3 Population and sampling

Powers *et al.* (1985:235) define a *population* as a set of entities in which all the measurements of interest to the practitioner or researcher are represented (Powers, Meenaghan & Toomey, 1985). According to Seaberg (1988:240)' a *sample* is a small

portion of the total set of objects, events or persons which together comprise the subject of our study.

For the purpose of this research the *population* refers to all the participants recruited for the Safe Passage Study. These patients come from within the referral area of Tygerberg Hospital, including Belhar, Valhalla Park, Bishop Lavis, Kalksteenfontein, Delft and Netreg. The sample can be representative of any racial group, as long as participants live in the demarcated area and are able to communicate in English or Afrikaans. The *sample* will include a selection or possibly all the participants who have experienced a stillbirth. For this research 30 prospective study-participants who have experienced a stillbirth will be targeted to be part of the study.

Purposive sampling techniques, as part of non-probability sampling methods, will be used for this research. This type of sample is based entirely on the judgment of the researcher, in that a sample is composed of elements that contain the most characteristic, representative or typical attributes of the population (De Vos *et al*. 2005:202). Current data already collected by the researcher in everyday practice indicate the need for ongoing support and not just for support directly after the stillbirth. This was integral in forming the rationale for this study. The criteria for inclusion will be that participants have experienced a stillbirth between six and 18 months ago. This will give the researcher the opportunity to gain insight into the aftercare needs of bereaved parents and their experience of support during the crisis period, as well as looking back a few months later. Another criterion for inclusion is that participants need to be able to speak either English or Afrikaans. Unfortunately the researcher is not able to speak Xhosa and owing to the highly emotional content of the study, it might be difficult to identify themes or feelings through an interpreter.

1.5.3.4 Method of data collection

The main method of data collection will comprise semi-structured one-on-one interviews. The researcher will have a set of prepared questions on an interview schedule, but the interview will be guided by the schedule rather than be dictated by it (De Vos *et al*., 2005:296). Owing to the emotional complexity of the research topic, interviews will provide the best way to collect the most appropriate data and a rich description of the problem would be possible. Prior to these semi-structured interviews, informed consent will be obtained from the participant before the research process will

continue. Obtaining informed consent implies that all possible information on the goal of the investigation, the procedures which will be followed during the investigation, the possible advantages, disadvantages and dangers to which participants may be exposed, as well as the credibility of the researcher, is rendered to potential participants. Consent will be obtained at the beginning of the first interview and after supplying participants with the necessary information; ample opportunity will be given to participants to ask any relevant questions about the consent or study. The participants will also receive a copy of the consent form for future reference.

Holstein and Gubrium (1995:3) stated the following: “Every word that people use in telling their stories is a microcosm of their consciousness. All interviews are interactional events and interviewers are deeply and unavoidably implicated in creating meanings that ostensibly reside within participants.” For this research 25 prospective participants who have experienced a stillbirth will be targeted to be part of the study. Research procedures will include one interview with each participant of between 45 and 75 minutes. During the interview participants will be asked to complete Section A (Particulars of participant) which forms part of the quantitative part of the study. (See Appendix A1 and A2). Rapport and trust will be established during this first part of the interview, which will make it easier to talk about more sensitive/personal issues during the second semi-structured part of the interview. An interview schedule (Section B – G) will be used during the interview. (See Appendix B1 and B2 for the interview schedule). These interviews will take place six months or more after the loss but not more than 18 months after the loss.

In addition to the interviews, questionnaires will be used to obtain specifically the quantitative data needed for the research. Descriptive data will be used because of the qualitative nature of the study. The quantitative part of the study will consist of basic data regarding the profile of the participant (including age, marital status and income) which will be frequency measurements. (See Appendix A1 and A2 for an example of this questionnaire.) Hancke (2009:104) suggested that researchers avoid relying on interview data alone. This remark helps to motivate the use of questionnaires.

1.5.3.5 Pilot study

A pilot study is defined in the New Dictionary of Social Work (1995:45) as the "process whereby the research design for a prospective survey is tested". A pilot study can be regarded as a small-scale trial run of all the aspects planned for use in the main inquiry. A pilot study will be implemented before the main study takes place to clarify uncertainties in the research design and to make modifications where necessary. Two to three respondents qualifying for inclusion in the study will form part of the pilot study.

1.6 DATA MANAGEMENT AND STATISTICAL ANALYSIS

1.6.1 Outcomes

Results relating to the psychosocial experience following the loss of a fetus will be used to determine how the crisis intervention approach can be used for bereavement counselling to parents. The study will be conducted from a social work viewpoint and within a South African context.

Primary outcomes would be measurable reactions of participants indicating that the loss of a fetus/baby is experienced as a crisis. These outcomes will be evaluated on three levels, namely individual, relationship and social levels.

1.6.2 Method of data analysis

Data analysis is the process of bringing order, structure and meaning to the mass of collected data (De Vos *et al*., 2005:333). The following is a summary of the method of data analysis that will be used according to Marshall and Rossman (1995:113):

- Organize the data by reading repeatedly to become familiar with the contents.
- Generate categories, themes and patterns.
- Search for alternatives, explanations and linkages.
- Present the data in a scientific manner. Quantitative data will be presented in tables and figures and qualitative data will be presented by using participants' verbatim responses (De Vos *et al.,* 2005:334*).*

1.6.3 Method of data verification

Lincoln and Guba, (1985:290) suggest using the following constructs to evaluate the trustworthiness of the research:

- *Credibility:* The goal is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described.
- *Transferability:* This guideline refers to the extent to which findings of the study can be applied in other contexts or with other respondents.
- *Dependability:* This is where the researcher attempts to account for changing conditions in the phenomenon chosen for study as well as changes in the design created by increasingly refined understanding for the setting.
- *Conformability:* The concept of objectivity is the focus of this construct. It is important to ask whether the findings of the study could be confirmed by another.

1.7 TIME PLAN AND STUDY LOGISTICS

The investigation was conducted from 8 February 2010 to 1 November 2012. The final proposal was concluded by November 2010. The literature study chapters were completed thereafter and were finalised from January 2011 till June 2012. The data for the research were gathered by means of a questionnaire and semi-structured interviews. This was done from June 2011 until the end of August 2011. The information was presented by means of an empirical study, which was completed by July 2012, after which the conclusions and recommendations were submitted. The final research report was submitted on 1 November 2012.

No logistical impediment was placed on the Safe Passage Study (where the main research is being done) or the clinical coordinators at this site, as interviews with participants took place in the comfort of the social worker's office and did not interfere with the workload of the clinical coordinators.

1.8 ETHICAL ASPECTS

"Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students" (De Vos *et al*., 2005:57). De Vos *et al.* (2005:68) mention that social work research has no specific ethical code in South Africa; however, the general Ethical Code of the South African

Council for Social Service Professions can be seen as binding for social work research as well (SACSSP, 2011). The researcher is registered with the South African Council of Social Service Professions, which means that the researcher adheres to a strict code of ethics that influences the research process and particularly the course of data collection. Because the research was conducted at Tygerberg Hospital and the Safe Passage Study, the proposal had to be reviewed by the Human Research Ethics Committee and the Steering Committee of the study. (See Appendix D for letters of approval.) This is necessary to protect the interests and rights of the participants.

The following ethical considerations will be relevant for the research:

- *Avoidance of harm:* De Vos *et al.* (2005:58) refer to the obligation of the researcher to protect the respondents from any form of physical or emotional harm or discomfort. Every participant must be informed about the potential impact of the investigation.
- *Informed consent:* Obtaining informed consent implies that all possible information on the goal of the investigation, the procedures which will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher, be rendered to potential subjects (Williams, Tutty & Grinnel, 1995: 30). (See Appendix C1 and C2 for example of informed consent form.)
- *Confidentiality:* The researcher has an obligation to handle information in a confidential and respectful manner.
- *Debriefing of respondents:* Debriefing sessions with participants were made available due to the emotional nature of this research. In acute cases, should the participant present with signs of severe emotional distress or indicate that she has suicidal thoughts, an immediate referral would be made to the Registrar of Psychiatry on call at Tygerberg Hospital as was arranged with liaison psychiatrist. In non-acute cases a referral would be made to the Psychiatric Clinic at Tygerberg Hospital at J-lower ground (contact number 021 938 5120) or to the Psychiatric Nurse, at the Community Clinic in Bishop Lavis, (contact number 021 934 6050).

- *Non-discrimination:* Because participants for this research were recruited (or identified) from the main study of the Safe Passage Study, the researcher had to

keep to the guidelines of that study. Because the Safe Passage Study's inclusion criterion regarding language is that only Afrikaans- and English-speaking participants can be recruited for the study, this study had to have the same inclusion criterion. Fortunately participants of all races in South Africa can take part in the study if they live in the demarcated area, as long as they can speak English or Afrikaans.

1.9 RESOURCES AND BUDGET

This study is regarded as ancillary to the main study of the PASS Study Network because of follow-up of participants from the prospective study who had experienced a stillbirth, and additional questionnaires put to these participants. The researcher did not use any information from the main study. The data for this study were obtained during and after counselling sessions by the social worker of the Safe Passage Study, at the Clinical Site, Tygerberg Hospital. Therefore the Safe Passage Study will be the main resource and provider of the sample for this study.

A budget is not needed for this study. The service is already taking place (counselling service). Because a thesis towards a master's degree will present the outcomes of the study, the costs (registration as master's degree student and any other relevant expenditure) will be the responsibility of the researcher, Melanie Human.

1.10 STRENGTHS AND LIMITATIONS

Strengths of study:

- The study will be conducted within the Safe Passage Network.
- The concept sheet/proposal has been approved for the study to move forward.
- The researcher has been involved with bereavement counselling at the Safe Passage Study for three years, which provides the ideal situation to conduct interviews with participants who had experienced a loss more than six months ago.
- Contact details of participants are available therefore simplifying the recruitment of the participants.

Limitations to be considered:

- Shortage of literature regarding the psychosocial implications of perinatal loss from a social work point of view.
- Due to the emotional nature of the research, information gained from interviews might be fragmented or non-chronological. Some participants might not be able to express themselves due to their emotional state.
- Contact details of participants might have changed after a few months. This will complicate the recruitment phase of the study.

Steps to compensate for these limitations:

- Consider literature from other professions such as psychology, theology, nursing and the medical profession. Greater insight will be gained into the research problem.
- Should telephonic contact not provide any results, informative letters will be sent to participants to inform them about the proposed study.
- Enough time will be provided to complete the interview in order to ensure that participants, who might be very emotional, feel comfortable and not rushed to complete the questions.

1.11 REPORTING OF RESULTS

Results will be compiled in a research report (thesis) which will be divided into seven chapters. Chapter 1 serves as an introduction to the study and presents an outline of how the research will be undertaken. Chapter 2 provides an overview of medical information regarding stillbirth. Possible causes of stillbirth will be explained. In chapter 3 a background will be provided regarding grief and the grief process in order to understand the psychosocial implications of stillbirth for a mother and her family better. Chapter 4 will focus on the psychosocial implications for a mother and her family. In chapter 5 the crisis intervention approach is discussed in relation to stillbirth. Chapter 6 l contains a presentation of data collected during the empirical investigation. Based on these findings, chapter 7 provides conclusions and recommendations for social work intervention for mothers and families who have experienced stillbirth.

CHAPTER 2

REVIEW OF THE MEDICAL CAUSES SURROUNDING STILLBIRTH

2.1 INTRODUCTION

Despite more than three million annual stillbirths, more than 8 200 babies dying every day and approximately one million neonatal deaths directly due to preterm birth, these burdens and the associated loss to families and nations are rarely highlighted. The impact of these deaths from stillbirth and preterm birth, plus the morbidity and long-term disability associated with preterm birth, is considerable. Clinical researchers and epidemiologists face formidable barriers in collecting and analyzing data about prevalence and interventions, particularly in South Asia and sub-Saharan Africa where two-thirds of these events occur. The places with the highest risk currently have the least information available (Lawn, Kerber, Enweronu-Laryea & Cousens, 2010: 371). These are shocking statistics taking in account that there are twice as many stillbirths as deaths due to HIV/AIDS. By contrast, stillbirths are almost invisible, unrecognised as a global health issue (Lawn *et al*., 2011:62187). If the prevalence of stillbirth is taken into account, it can be said that stillbirth always was a silent phenomenon with little recognition in the medical, psychological as well as social work fields.

This chapter will meet the first objective of the study, which is to present a comprehensive literature review of the medical causes of stillbirth as a foundation for understanding its psychosocial impact. To achieve this aim this chapter will focus on the definition of stillbirths and other terminology, the causes of stillbirth, what is currently being done regarding stillbirth research and how stillbirth might be prevented. The first part of this chapter will provide some background about the history of perinatal studies and basic information about pregnancy.

2.2 HISTORY OF PERINATAL STUDIES

In an article titled “Regionalization of Perinatal Care” in Child Health, Sawyer (1984:90) wrote that until the latter part of the 19th century, childbirth still took place in the home, whereafter there was an increasing tendency to develop hospital-based maternity centres. While the availability of skilled obstetrics was undoubtedly beneficial in many

cases of dystocia or obstructed labour, infant mortality rates of the order of 100/1,000 live births were not unusual up to the early years of the 20th century.

The first half of this century saw a consolidation of knowledge and practice in obstetric and neonatal medicine as well as further advances in living standards which accelerated the downward trend in morbidity and mortality. Technological advances, particularly in electronics, after the Second World War, provided the means to an entirely new understanding of the pathology-physiology of the newborn. In the early 1950s the thrust for investigation of the mechanisms of normal and abnormal processes in the newborn received a powerful stimulus from the occurrence of the epidemic of neonatal blindness in the Western world, eventually found to be due to the toxic effects of oxygen on the developing retina of the premature.

According to Sawyer (1984:92-93) the decades following have seen extensive advances in knowledge accompanied by the technological means for effective intervention based on this new knowledge.

Systems have been developed for continuous monitoring of vital functions such as heart rate, blood pressure, respiration, oxygen tension in arterial blood, as well as for monitoring and controlling environmental conditions of oxygen administration, temperature and relative humidity. In addition to the monitoring and control of the external environment, recent advances in physics, physical chemistry, ultramicrobiochemistry and electronics have made possible the monitoring of the internal environment of the infant in relation to the acid-base balance, blood gas and electrolyte status, levels of bilirubin, blood sugar and numerous other components which may be important in individual cases. Thus it has become possible to intervene in a rational manner to correct abnormalities disclosed by these means. Infusion pumps enable precisely metered doses of corrective infusion and even intravenous nutrition, ventilators permit support of failing ventilation, and air/oxygen measurement and non-invasive transcutaneous electrodes allow more correct oxygen dosimetry. The development of ultrasonic echography and computerized imaging techniques has greatly improved our diagnostic and prognostic abilities, the essential steps towards more effective prevention and therapy.

Falkner (1984:94) mentioned that the rapid evolution in neonatal medicine and advances in technology, have greatly benefited the science of obstetrics, transforming the practice in this field.

Currently advanced research is being done in most developed and industrialized countries. Due to the fact that the prevalence of stillbirths is the highest in Asia and sub-Saharan Africa extensive research is also taking place there in a quest to obtain answers to the most pertinent questions about stillbirth.

2.3 NORMAL PREGNANCY – IMPORTANT FACTS AND INFORMATION

To understand the literature regarding stillbirth it is important to be familiar with important facts and information about normal pregnancy.

Pregnancy (gestation) is the maternal condition of having a developing fetus in the uterus (womb). The human conceptus from fertilization through the eighth week of pregnancy is termed an **embryo**; from the eighth week until delivery, it is a **fetus.** For obstetric purposes, the duration of pregnancy is based on **gestational age**: the estimated age of the fetus is calculated from the first day of the last (normal) menstrual period (LMP) assuming a 28-day cycle. Gestational age is expressed in completed weeks. This is in contrast to **developmental age (fetal age**), which is the age of the offspring calculated from the time of implantation (DeCherney & Nathan, 2007).

The terms **gravid** and **gravidity** are used to give more information about the number of pregnancies a woman has had. This provides the multi-disciplinary team with information about the obstetric history of the patient. For example it is possible to know immediately whether the patient has had any previous pregnancy losses, and is especially useful to psychologists and social workers in the hospital setting, who need to provide counselling to the patient in the case of a pregnancy loss.

The term **gravid** means pregnant, and **gravidity** denotes the total number of pregnancies (normal or abnormal). **Parity** is the state of having given birth to an infant or infants weighing 500 g or more, alive or dead. In the absence of known weight, an estimated duration of gestation of 20 completed weeks or more (calculated from the first day of the last menstrual period (LMP)) may be used (DeCherney & Nathan, 2007) (24 weeks in South Africa and 28 weeks in many other countries).

DeCherney and Nathan (2007) explain that a fetus is considered viable when it has reached a gestational age of 23 to 24 weeks and a weight of 500 to 600g or more. DeCherney and Nathan (2007) highlight the fact that only very rarely will a fetus of 20 to 23 weeks weighing 500 g or less survive, even with optimal care. With regard to parity, a multiple birth is a single parous experience.

Another important term when discussing normal pregnancy is the definition of a birth. A liveborn infant, according to the Saving Mothers and Babies Manual (Woods *et al*. 2010) is defined as an infant weighing 500 g or more and showing any sign of life at birth (i.e. breathing or movement). All infants born alive and weighing 500 g or more should be included in the definition of a liveborn infant in South Africa.

Falkner (1984:3) recalls the definitions of live birth as being*: "*The complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscle, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered live born".

2.4 DIFFERENT DEFINITIONS OF PERINATAL LOSS

The best way to describe perinatal loss is to define the many concepts associated therewith. It is important to bear in mind that each country has a different definition for "perinatal". In developed countries like Europe and the United Stated of America an infant born with a weight of more than 500 g is included in the definition of perinatal death. This is not the case in developing countries. Normal infants weighing more than 1000 g are included in the perinatal category, because infants weighing less than 1000 g usually do not survive. In many developing countries small infants are not even weighed and are simply seen as miscarriages (DeCherney & Nathan, 2007). Vital perinatal information can be lost in this way.

2.4.1 Perinatal

"The **perinatal period** is strictly defined from the beginning of fetal viability until the end of the sixth day after birth. Defining fetal viability is difficult as it depends on the

gestational age and the special care facilities available. Therefore, it is easier to use birth weight to define viability. In industrialised countries, infants may survive from 22 weeks gestation (500 g) while in developing countries infants are only expected to survive from 28 weeks (1000 g) (Woods *et. al.* 2010).

Perinatal means "around the time of birth". Perinatal usually applies to the last months of pregnancy and the first week after delivery (Woods & Theron, 1994:61). Brummer *et al*. (1990) refer to the perinatal time frame as the time from 22 weeks of pregnancy (or 500 g fetal weight) up until the first seven days of neonatal life.

DeCherney and Nathan, (2007) define the **perinatal period** as the time from 28 weeks of completed gestation to the first seven days of life, spanning the fetal and early neonatal interval. It is clear that different authors disagree about the starting point of the perinatal period and it is debatable whether the starting point of this period is in fact 22 weeks or rather 28 weeks. The Safe Passage Study, where the researcher is conducting this study, has defined the perinatal period as the period from 20 weeks of gestation until the first seven days of life, which will be used as parameters for this study.

2.4.2 Perinatal loss

Perinatal loss includes early and late fetal death (miscarriage and stillbirth) and the death of a live neonate on the first day after birth (Armstrong, 2002:339). The Saving Mothers and Babies Manual which was written as part of the Perinatal Educational Programme, 2010 by Woods *et al.,* (2010) states that perinatal deaths include infants that are born dead plus infants that are born alive but die within the first seven days after delivery, i.e. stillbirths and early neonatal deaths (Woods *et al*., 2010).

2.4.3 What is a stillbirth?

A **stillbirth** (SB), or stillborn infant, is an infant who is potentially viable but is born dead. Potentially viable means that the infant would have had a reasonable chance of surviving if it was born alive. Born dead means that the infant shows no sign of life at delivery. Stillbirths are sometimes referred to as intra-uterine deaths or fetal deaths (Woods *et al*., 2010).

Although stillbirth is a term widely used in the medical field, other definitions can be used when talking about a loss of a fetus. Falkner (1984:3) suggested the use of the term fetal death to imply that the death of the fetus has occurred prior to expulsion from the mother. He explains fetal death as follows: "**Fetal death** is death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy, the death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles (Falkner, 1984:3). The International Classification of Diseases, 10th revision (WHO, 2010) refers to fetal deaths, not stillbirths.

Lewis as quoted in Borg and Lasker, (1981:62) described stillbirth as an "empty tragedy": after a stillbirth there is a double sense of loss for the bereaved mother, who now has a void where there was so evidently fullness. Even with a live birth the mother feels a sense of loss, but the consolation of a surviving "outside" baby helps the mother to overcome her puzzling and bewildering sadness at losing her "inside" baby. With a stillbirth, the mother has to cope with an outer as well as an inner void.

According to the World Health Organization (WHO), stillbirth is the birth of a baby with a birth weight of 500 g or more, 22 or more completed weeks of gestation or a body length of 25 cm or more, who died before or during labour and birth. Frøen (2011:1353) mentioned that for international comparisons, WHO recommends reporting of stillbirths with a birth weight of 1000 g or more, of 28 weeks' gestation or more, or a body length of 35 cm or more. But when does stillbirth most occur? According to Lawn (2011:1454), a practical grouping of stillbirths is by time of death: ante-partum (before the onset of labour) or intra-partum (during labour and birth). Labour and birth are the times of highest risk and most babies who die during labour are term babies who should survive if born alive and their deaths are often associated with suboptimal care.

The perinatal period has now been clarified but two more important terms need to be defined and explained namely **infant** and **neonatal.** Although the terms are mostly used in the medical field, for social work intervention to be effective the social worker needs to be familiar with these terms, especially when crisis intervention takes place.

2.4.4 Defining the term infant: The seven different types of infants

It is clear that during pregnancy, the time period is very important, and this also determines the definition of an infant. The time of birth indicates the term that will be used to identify the infant in medical terms. Below is a classification by weight or duration of gestation of the different types of infants as identified by DeCherney and Nathan (2007):

- **Preterm infant:** A preterm infant is defined as one born before the 37th week of gestation (259 days). In the United States, a sub-classification is increasingly being used, namely, very early preterm, early preterm, mid-preterm and late preterm. This is because the mortality and morbidity numbers are different for these four groups. Also, it used to be thought that it was not a significant problem to be born late preterm (34-36 weeks), but there is mounting evidence that such infants are at risk for respiratory illness, infection and sudden infant death syndrome (Dudley, Goldenberg, Conway, Silver, Saade, Varner, Pinar, Coustan, Bukowski,Stoll, Koch, Parker & Reddy, 2010:258)

- **Immature infant:** An immature infant weighs 500 to 1000 g and has completed 20 or less than 28 weeks of gestation.

- **Premature infant**: This infant is one with a birth weight of 1000 to 2500 g and duration of gestation of between 28 and 37 weeks. The premature infant would be stronger at birth than the immature infant.

- **Low birth weight infant:** A low birth weight infant is any live-born infant weighing 2500 g or less at birth.

- **Undergrown / small-for-gestational-age infant:** This infant is one who is significantly undersized for the period of gestation.

- **Mature infant**: A mature infant is a live-born infant who has completed 37 weeks of gestation (and usually weighs more that 2500g).

- **Post- mature infant:** This infant is one who has completed 42 weeks or more of gestation. The post-maturity syndrome is usually associated with the post-

mature infant and is characterized by prolonged gestation and excessive-size fetus (DeCherney & Nathan, 2007).

2.4.5 What is a "neonate"?

Although in this study the focus is on stillbirths, it is important for the social worker who is going to render the crisis intervention, to be aware of these medical terms. DeCherney and Nathan (2007) describe the neonatal interval as the time from birth until 28 days of life. During this interval, the infant is referred to as a newborn. The interval may be divided into three periods:

- Neonatal period I: birth through 23 hours, 59 minutes.
- Neonatal period II: 24 hours of life through six days, 23 hours, 59 minutes.
- Neonatal period III: seventh day of life through 27 days, 23 hours, 59 minutes.

The following figure provides a clear and identifiable classification of the different stages of the fetus, infant and neonate.

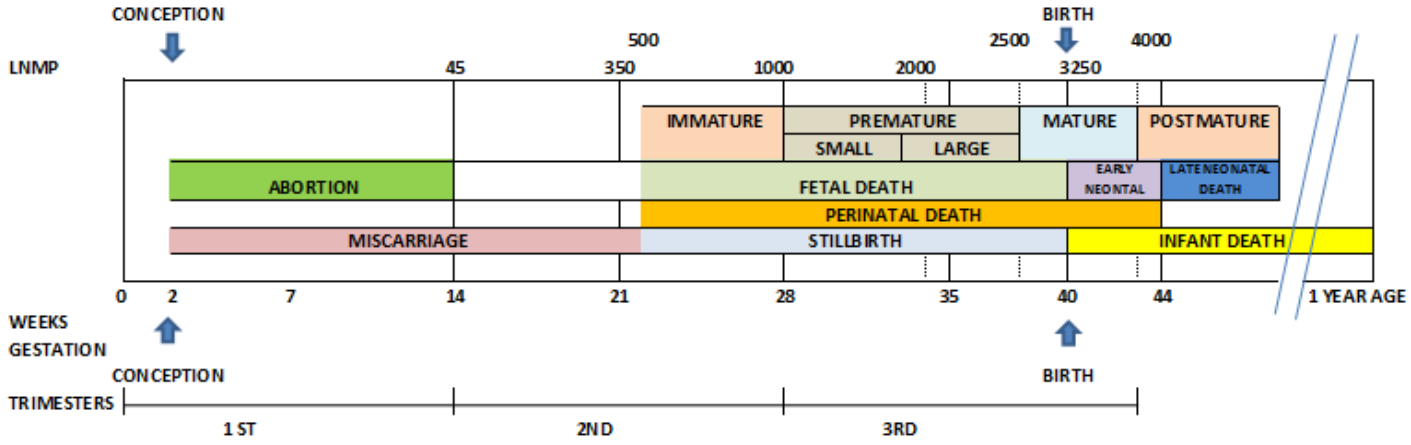

Figure 2.1: Classification of the different stages of the fetus from pregnancy to birth and early neonate. (Adapted from DeCherney & Nathan, (2007), and Lawn, 2011:50.)

2.4.6 Several types of miscarriages

It is important to note that although this study focuses on crisis intervention regarding stillbirth, it is important for the social worker to be familiar with other terms which are also associated with loss. This might be significant when a couple counselled for a stillbirth, have had a previous miscarriage as well. It puts the current loss in greater perspective.

Borg and Lasker, (1981: 35) identified six categories of miscarriages:

- ***Threatened abortion/miscarriage*:** The term is used when a woman bleeds and may have cramps but the cervix is still closed; the process could stop and the pregnancy continues. At least half the women who bleed early in pregnancy will not miscarry and are in fact bleeding for reasons unrelated to the condition of the fetus.

- ***Inevitable abortion**:* Bleeding becomes heavy and continues for several days, and if the cervix opens and severe contractions begin, the miscarriage becomes inevitable. Hospitalization may be necessary, especially if all of the fetus and placenta are not expelled.

- ***Incomplete abortion/miscarriage**:* When some tissue remains the term used is incomplete abortion. A dilation and curettage is performed in these cases to remove the contents that were not expelled. If a dilation and curettage is not performed, the uterus cannot contract and the cervix will not close. This poses a danger of death of the woman from haemorrhage or infection.

- ***Complete miscarriage**:* A complete miscarriage is one in which all the afterbirth is expelled and the cervix closes. The physician will usually determine that a dilation and curettage is not needed in these cases.

- ***Missed miscarriage**:* This occurs when the fetus dies at least four weeks before being expelled. In cases of missed miscarriages the fetus degenerates and emerges in the form of bloody clumps of tissue, in other cases it is a small embryo. Some women expel such embryos at home. Most often the embryo aborts naturally.

- ***Habitual miscarriage/abortion****:* If a woman has three or more consecutive miscarriages, her condition is called habitual abortion. If the miscarriages all occur early (in the first twelve weeks), indicating that the fetus may be abnormal each time, genetic counselling should be considered. If the miscarriages occur after the twelfth week, there may be a defect in the woman's cervix. A cervix that dilates too soon can be corrected 80 per cent of the time by using a stitch to strengthen it until the time of delivery. Other problems such as a double uterus with a partition down the middle can also be the reason for repeated miscarriages. Habitual miscarriage means repeated trauma, physical and mental, and it also signals the possibility that there may never be children.

2.5 WHAT ARE PERINATAL MORTALITY RATES AND HOW ARE THESE CALCULATED

Current data and literature indicate that the number of lives lost during the five-month period from the 20th week of gestation to the seventh day after birth is almost equal to the number lost during the next 40 years of life. DeCherney and Nathan (2007) state that 70% of deaths occurring in the first year of life will occur in the first 28 days of life (the neonatal period). Falkner (1984:3) defines perinatal mortality as the total number of deaths occurring during the late fetal and early neonatal period. But the differences in definitions and methods of calculating rates, the variety of methods used in registration at national levels, and the absence of data for many countries complicate studies of the global rate of perinatal mortality and its components, as well as comparisons in time (for the same region of the same country) or in space (comparisons between or within countries.)

The perinatal mortality rate (PNMR) is the number of stillbirths plus the number of early neonatal deaths per 1000 total viable deliveries. It should be noted that the perinatal mortality rate is expressed per 1000 total births (including stillbirths and livebirths) (Woods *et al*. 2010).

To obtain correct statistics regarding perinatal mortality a universal formula is used to calculate the rate of perinatal losses. A short explanation was obtained from the Saving

Mothers and Babies Manual from the Perinatal Education Programme and can be described as follows:

The perinatal mortality rate is determined over a specific time period and calculated as follows:

$$\frac{\text{Number of stillbirths + number of early neonatal deaths}}{\text{The number of live-born + the number of stillborn infants}} \times 1000$$

For example, in a health care region there were 5000 deliveries in a year. There were 4800 live births, 200 stillbirths and 50 early neonatal deaths (i.e. 250 perinatal deaths). Therefore, the annual perinatal mortality rate for that region is:

$$\frac{250}{(4800 + 200)} \times 1000 = \frac{250\,000}{(5000)} = 50/1000$$

The current perinatal mortality rate in South Africa is approximately 55/1000. This varies widely between different areas from 35/1000 in metropolitan areas, such as Cape Town, to over 100/1000 in some poor, rural areas (Woods *et al*., 2010).

Bachmann, London and Barron (1996:966) also found a significant difference in perinatal mortality rate when comparing South Africa's statistics with the above-mentioned industrialized countries. According to Bachmann *et al.* the infant mortality rate for South Africa is 54 for every 1000 live births and in other countries the Infant Mortality Rate (IMR) was also found to be less than 10/1000 births.

It is clear that the perinatal mortality rate in industrial countries is significantly lower than in poor countries. In developing (poor) countries the rate is seven times higher than in the industrialized countries. This is very important information because it has a direct link to the hypothesis of the studies where support for parents who experienced a loss is investigated. The question is, that if the perinatal mortality rate is so high, is it possible for these parents to get the necessary support for aftercare counseling and support? The perinatal mortality rate is also one of the best indicators of the socio-economic status of a community, region or country. The following table shows the top ten countries with the most stillbirths, maternal deaths and neonatal deaths.

Table 2.1: Top ten countries in the world with the highest number of stillbirths, maternal deaths and neonatal deaths, taken in 2008

Top ten countries for absolute number of stillbirths, maternal deaths, and neonatal deaths in 2008			
Country	Rank for number of stillbirths	Rank for number of maternal deaths	Rank for number of neonatal deaths
India	1	1	1
Nigeria	2	2	2
Pakistan	3	7	3
China	4	12	4
Bangladesh	5	8	7
Democratic Republic of the Congo	6	3	5
Ethiopia	7	5	6
Indonesia	8	9	8
Tanzania	9	6	10
Afghanistan	10	4	9
Total	1-8 million stillbirths; 66% of worldwide total	221 000 maternal deaths; 62% of worldwide total	2-4 million neonatal deaths; 67 % of worldwide total

(Adapted from Lawn, 2011:1453; Cousens, Stanton & Blencowe, 2011; Black & Rubinstein, 2000; World Health Organization, United Nations Children's Fund, United Nations Population Fund, World Bank, 2011)

2.6 CAUSES OF STILLBIRTH

What are the primary causes of stillbirth? The following nine causes were identified by the Saving Mothers and Babies Manual (Woods *et al*., 2010). They are:

- Spontaneous preterm labour
- Intrapartum hypoxia
- Antepartum haemorrhage

- Hypertensive disorders
- Infections
- Fetal abnormalities
- Intra-uterine growth restriction
- Trauma
- Maternal diseases

A few perinatal deaths are due to less common conditions or problems not relating to the pregnancy (e.g. motor-car accident). Of the above-mentioned nine causes, the following causes, namely (1) spontaneous preterm labour, (2) antepartum haemorrhage, and (3) intrapartum hypoxia are the most common. Although not mentioned above, the role of adverse exposure during gestation to smoking, alcohol or illegal substances needs to be emphasized. This is one of the focus areas of the PASS study.

Ndlovu (2009:74) clarifies the causes of stillbirth especially seen from a South African viewpoint. She quotes the following information obtained from the Perinatal Problem Identification Programme (PPIP) which has been collecting data from stillbirths and newborn deaths since 1999. The following data have been collected from 164 maternity sites (2003-2005) in South Africa and 9 943 stillbirths were investigated. The causes identified are: A tiny percentage (1,6% and 2,9% respectively) was because the mother had a pre-existing illness or the fetus failed to grow in the womb (intra-uterine growth restriction.) Three per cent of the stillbirths occurred because the fetus was abnormal in some way. Infection during pregnancy or labour caused 5,1% of the stillbirths. Premature birth accounted for 10,4 % of the stillbirths – the mother had gone into labour much too early, well before nine months, and 11,2% of stillbirths occurred because the baby lacked oxygen during the labour itself (intrapartum hypoxia). Thirteen percent of the stillbirths occurred because the mother had bled from the womb in late pregnancy (placenta abruption). Pre-eclampsia, a condition that causes dangerously raised blood pressure in pregnancy, caused 14.1% of the stillbirths (Ndlovu, 2009:74).

Ndlovu noted that it is worrying that in 37, 7% cases no cause could be found. This can be an indication of limited data collected, lack of resources in South African maternity hospitals or it can also point to limitations in medical knowledge. According to Lawn, (2011:1455), the poor comparability between multiple classification systems is the most substantial barrier to any meta-analysis and estimates for stillbirth causation.

The above-mentioned data can be displayed graphically as follows:

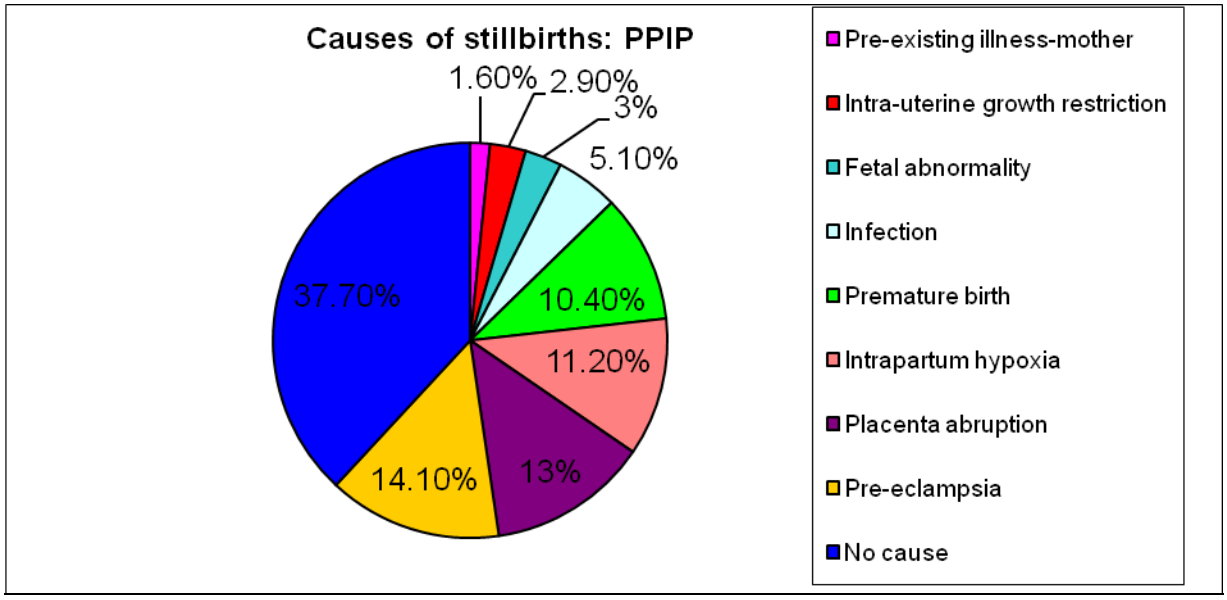

Figure 2.2: PPIP data on causes of stillbirths as discussed by Ndlovu (2009:74)

In a Lancet Journal on Stillbirths, dated April 2011, Flenady wrote an article on major risk factors for stillbirth in high-income countries. The following were identified:

- Maternal overweight and obesity (body-mass index >25kg/m²)
- Advanced maternal age (>35years)
- Maternal smoking
- Primiparity
- Small size for gestational age
- Placental abruption
- Pre-existing diabetes and hypertension

Pregnancy outcomes for mothers and babies are closely linked, yet few data sets present information on all the relevant outcomes. The ICD (International Classification of Disease) (WHO, 2010) recommends that every stillbirth and neonatal death should be given a code for a direct cause and a separate code for maternal cause, enabling better assessment of risk and programmatic implications. For example, fetal growth restriction is common and is possibly linked to maternal hypertension, yet the information is lost if only fetal growth restriction is coded (Lawn, 2011:57). This

highlights the notable role of placental pathology in stillbirth, which is currently receiving more attention than previously, in order to establish a cause for each stillbirth that occurs.

During December 2011, the Stillbirth Collaborative Research Network (SCRN) published two articles in the Journal of the American Medical Association (JAMA) regarding a vast study they conducted on the causes of stillbirth. They were funded by the National Institute of Child Health and Human Development (NICHD) and this is a seminal contribution to the field of stillbirth. Although South Africa lags behind regarding such large-scale studies, current studies, like the Safe Passage Study, seek to address this gap in research in a South African context (Iams & Lynch, 2011:2506).

The rate of unexplained stillbirth varies from 10 to 50%, depending on the rate of autopsy, placental examination and genetic testing. An inability to explain the cause of stillbirth gives rise to a whole set of issues for grief counselling. This is important for the social worker to know, because parents might react differently to grief when they know the cause of death of their baby.

2.7 MATERNAL CONDITIONS ASSOCIATED WITH STILLBIRTH

Lawn, (2011:1458) looked at perinatal audit data for 2008-09, which add up to half the births in South Africa and include almost 20 000 stillbirths. Eighty per cent (80%) of early neonatal deaths, 75% of intrapartum stillbirths and about half of antepartum stillbirths were associated with an identified maternal condition, and the most common conditions were those that also have high morbidity in women. For example, hypertensive disease of pregnancy was associated with about 20% of intrapartum and 10% of antepartum stillbirths and 6% of neonatal deaths. Maternal conditions most often associated with perinatal death in South Africa are, in order, obstructed labour, hypertensive disease of pregnancy, preterm labour, antepartum haemorrhage, and maternal infections and chorioamionitis. The following two figures illustrate the antepartum and intrapartum associated maternal conditions.

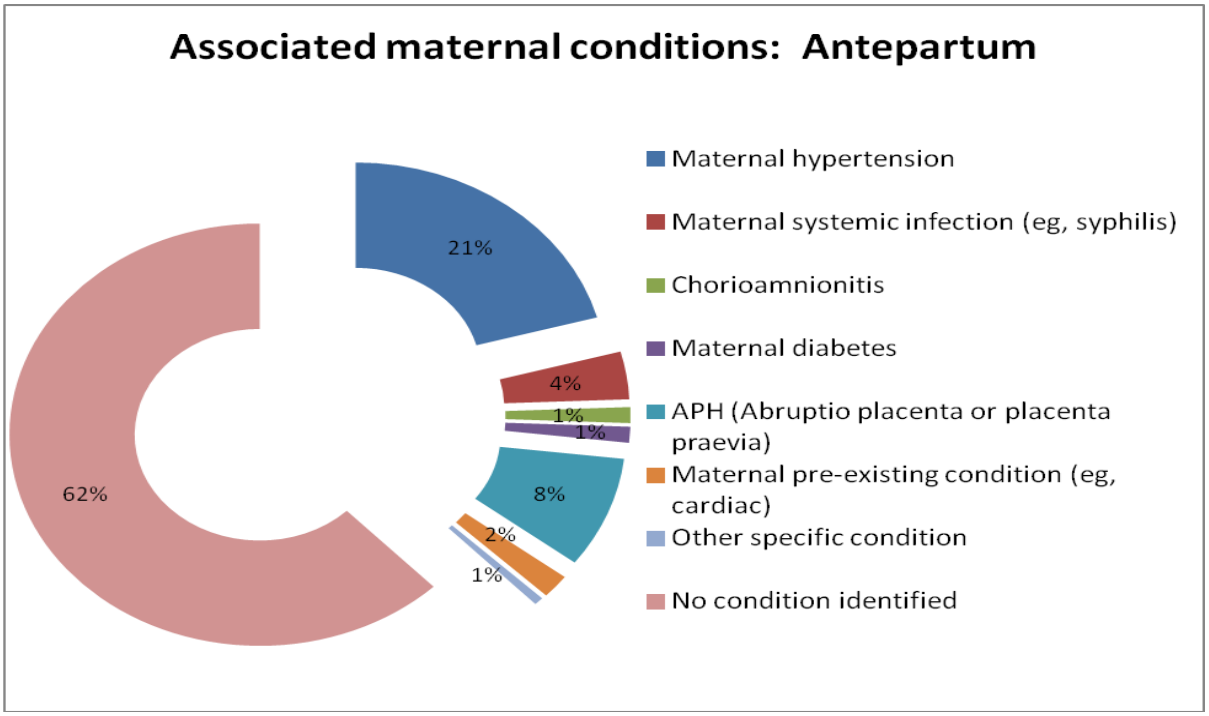

Figure 2.3.1: Associated maternal conditions: Antepartum. (Adapted from Lawn, 2011:1458 & PPIP, 2005)

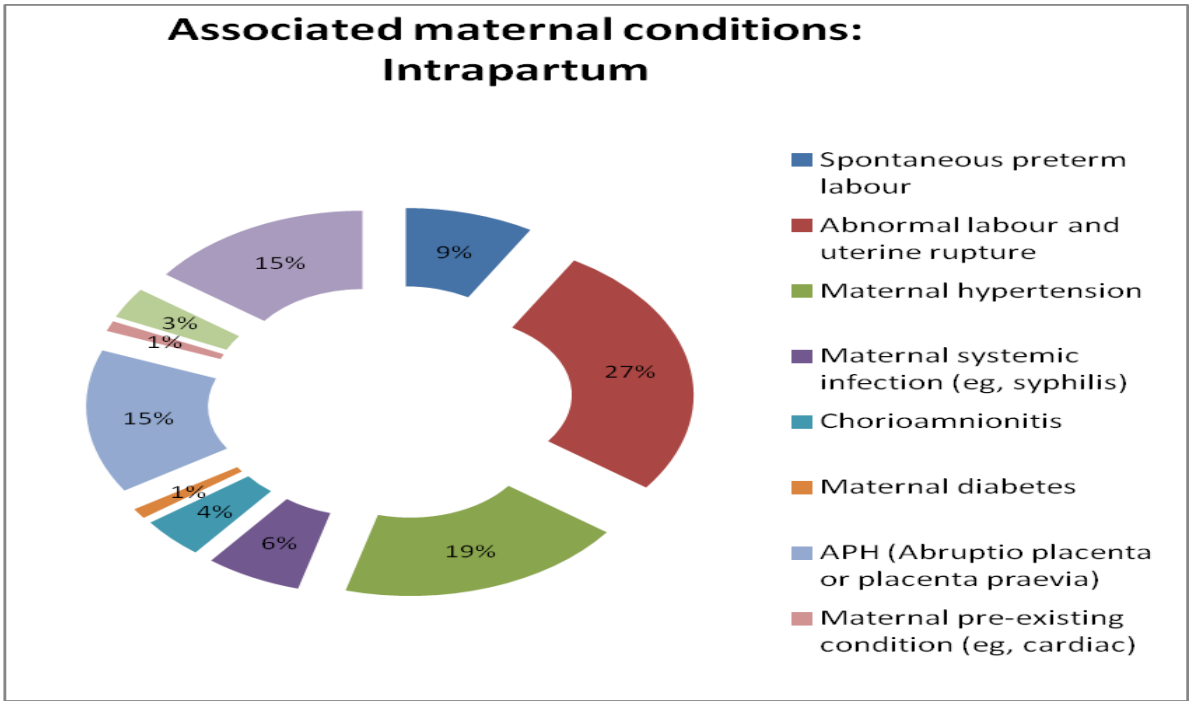

Figure 2.3.2: Associated maternal conditions: Intrapartum. (Adapted from Lawn, 2011:1458 & PPIP, 2005)

Comparing figure 2.3.1 and figure 2.3.2 it becomes clear that it may be easier to determine an associated maternal condition at intrapartum stage than during the

antepartum stage. There are 47% more cases where no condition was identified during antepartum than in intrapartum. Labour-related problems are a common cause of intrapartum condition as by the antepartum stage it is not a possibility yet.

2.8 WORLD-WIDE TRENDS IN PERINATAL CARE/PERINATAL LOSS

This systematic review shows that a large proportion of stillbirths in high-income countries can be attributed to risk factors that are fully or partly avoidable. These findings indicate the possibility for substantial rate reductions. Obesity is one of the leading factors contributing to the overall burden of disease worldwide.

Relevant risk factors not relating to pregnancy or medical disorders are:

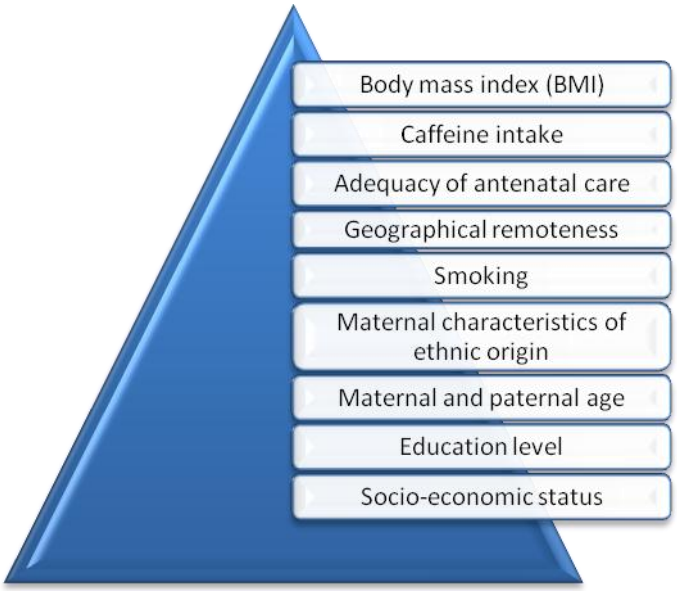

Figure 2.4: Relevant risk factors not related to pregnancy or medical disorders (Adapted from Flenady *et al.* (2011:1332)

The relevant risk factors mentioned in figure 2.4 above, can be addressed if they are prioritised as important enough and if the necessary funding is available. In the first article of the Lancet series, published online during April 2011, the present status of stillbirths in the world was explored. This included a study of the global health policy as well as a survey of community perceptions in 135 countries. Findings were that action needs to be taken and that a mother's expectation of her live-born baby is not recognised on the world's health agenda. Millions of deaths are not counted; stillbirths are listed not in the Global Burden of Disease, and are also not part of the UN Millennium Development Goals (Frøen, 2011:1353).

The International Classification of Diseases does not fully identify the stillborn baby as an individual death. In 90 countries worldwide, stillbirths have not been represented in country data. Because stillbirths have not been counted, and no goals set for prevention, global commitments to preventive efforts are missing. In September 2010, the UN summarised the commitments to improve maternal and child health by seven UN agencies, 36 countries and more than 75 non-governmental organisations and professional organisations; stillbirth is not mentioned in any of them (Frøen, 2011:1353). However, there are some striking exceptions. The National Institute of Child Health and Development (NICHD) has made recognition of stillbirth a priority. It is funding two major stillbirth initiatives – Stillbirth Collaborative Research Network and Prenatal Alcohol Stillbirth and SIDS (PASS study). The Gates Foundation, as well as other non-profit organisations has also targeted preterm birth.

When compared with the leading global causes of death in all age categories, all-cause stillbirths would rank fifth among the global health burdens – before diarrhoea, HIV/AIDS, tuberculosis, traffic accidents, and any form of cancer. Frøen, (2011:1353), also mentioned that inadequate post-mortem investigation protocols and classifications have left most stillbirths unexplained in many settings. Flenady (2011: 1331) states that data for stillbirth are inadequate. A thorough investigation of stillbirth is essential. This includes placental histopathology for all stillbirths and parents being given the option of a high-quality autopsy. Consensus of definition and classification is needed.

Recent studies point to a fall in perinatal (including stillbirth) autopsy rates (Khong & Tanner, 2006:366). The major limiting factor seems to be parental consent (Laing, 2004:248) whilst cultural and religious beliefs resulting from demographic changes in high-income countries might add to the downward pressure on perinatal autopsy rates (Gordijn, Erwich & Khong, 2007:4). Odendaal, Elliott, Kinney, Human, Gasper, Petersen and Dempers, (2011:168), agrees that parental consent and a distrust of the medical establishment by the socio-economically disadvantaged play an important role in decline of autopsy rates. The autopsy is rated useful to establish a cause of death or in counselling after a stillbirth.

Although few babies born alive at 22 weeks survive, most live-born babies in high-income countries survive by 25 weeks. The Nuffield Council on Bioethics recommends

that before 22 weeks of gestation, resuscitation should not be attempted, even if a baby is born with signs of life (Nuffield Foundation, 2012). Stillbirths are not a problem in only low-income countries. Rates in the UK and USA have decreased by only 1% per year for the past 15 years and stillbirths now account for two-thirds of perinatal deaths in the UK.

Lawn (2011:1457) predicts the following trends and progress up to 2020: Although there is a decline in stillbirths in other countries, the slowest decline has been seen in sub-Saharan Africa and South Asia, with almost no change in sub-Saharan Africa since 2000. Assuming that trends from 1995 to 2009 remain constant, the worldwide stillbirth rate in 2020 is projected to be about 16 per 1000 total births, with the smallest change in sub-Saharan Africa. If no new efforts are made to prevent stillbirths or to reduce unwanted pregnancies, particularly for low-income families in rural settings, then it is estimated that by 2020, more that 2 million stillbirths will still occur every year, with potentially 90% in sub-Saharan Africa and South Asia. The poor progress to reduce pregnancy outcomes in low-income countries is not a knowledge gap but an action gap, according to Lawn (2011:1457).

Focus must be on the quantity and quality of pregnancy outcome data that need to be improved, including stillbirth data. According to Lawn (2011:1459) two steps are crucial: First, consensus is needed on a core list of programmatic causes of stillbirth to compare with maternal conditions, which can be distinguished through clinical observations and verbal autopsy. This consensus will need a broad coalition of partners, including the UN, groups who collect and use data in low-income settings, and those who generate estimates, including academics, plus relevant high-income country groups such as the International Stillbirth Alliance. Second, the quantity and quality of input data, especially from low-income and middle-income settings, must be improved to generate enough data to develop national estimates. ICD-10 codes do not capture important categories for stillbirths. The revision of ICD-11 that is underway provides an important opportunity to improve these codes. Stillbirth data are not adequate at present.

Both maternal and child health would benefit substantially from stillbirth prevention initiatives. The focus on stillbirth prevention initiatives during prenatal and intrapartum care is the area in which progress towards the Millennium Development Goals to

prevent infant deaths lags most substantially according to Frøen (2011:1356). According to Pattinson (2011:1610), the cause of stillbirths is inseparable from the causes of maternal and neonatal deaths. Three hundred and fifty thousand (350 000) maternal deaths and 3 to 6 million neonatal deaths occur every year and are counted in the Millennium Development Goals, but no global goals or routine data tracking is in place for the 2 to 65 million stillbirths. To put stillbirths and neonatal and maternal deaths on the policy agenda, global health advocates need to define the problem, communicate the problem and solution, and possibly create institutions, or at least sections within institutions, that are dedicated to this issue (Pattinson, 2011:1611).

Effective strategies to link mothers with skilled care during pregnancy, labour and birth, described by Lee, Lawn, Cousens, Kumar, Osrin, Bhutta, Wall, Nandakumar, Syed and Darmstadt (2009:S68), included increase of community demand for obstetric care through community mobilisation and financing strategies, and use of approaches to bring pregnant women closer to the formal health system, such as community referral systems and transport schemes, antenatal risk screening by health workers, and maternity waiting homes.

Darmstadt, Lee, Cousens, Sibley, Bhutta, Donnay, Osrin, Bang, Kumar, Wall, Baqui and Lawn (2009:S89) systematically reviewed the effect of community-based skilled birth attendants, trained traditional birth attendants, and community-based workers on perinatal and intrapartum outcomes, and recommended skilled birth attendants, and linkage of community strategies with prompt, high-quality emergency obstetric care.

2.9 INTERVENTIONS TO REDUCE STILLBIRTH

With stillbirth rates as high as indicated above, it is necessary to focus on different interventions to reduce stillbirths. Literature studies have shown that various authors have studied interventions and have compiled several interventions that might help in the fight against stillbirth. The table below is a combination and adaptation of the different models of Bhutta's (2011:1523) Lives Saved Tool, Pattinson *et al.* (2011:161087) and Flenady (2011:1703).

Three main categories can be identified: 1) Improvement of health and wellbeing of women before, during and after pregnancy, 2) Detection and management of women at

risk during pregnancy, and 3) Improvement of information and standards of maternity care.

Table 2.2: Interventions to reduce stillbirths

Interventions to reduce stillbirths	
Before pregnancy and basic antenatal care:	Periconceptional folic acid supplementation or fortification
	Prevention of malaria
	Syphilis detection and treatment
	Screening and intervention for alcohol, smoking and illicit drug use
Advanced antenatal care:	Detection and management of hypertensive disease
	Detection and management of diabetes in pregnancy
	Detection and management of fetal growth restriction
	Screening for placental insufficiency
	Identification and induction of mothers with 41 weeks of gestation or more
	Multiple pregnancies: Single embryo transfer for in-vitro fertilisation
Childbirth care:	Skilled care at birth and immediate care for neonates
	Basic emergency obstetric care
	Comprehensive emergency obstetric care
Raising awareness	Parent organisations raising public awareness

(Adaption of the different models of Bhutta (2011:1523), Pattinson (2011:161087) & Flenady, 2011:1703).

Table 2.2 illustrates the four focus areas on which interventions are based. It is important that clinics and hospitals that render antenatal care to pregnant women, need to incorporate such an intervention model as part of their protocol. Regular revision and evaluation of such an intervention model needs to take place.

2.10 WHAT IS CURRENTLY BEING DONE IN SOUTH AFRICA TO IMPROVE PERINATAL CARE?

The population in South Africa is distinguished by different social backgrounds, different traditions and different viewpoints on birth and perinatal care. The stillbirth rates in South Africa are higher because of poor nutrition, poor access to health care, higher burden of risk factors (smoking), and lack of education, particularly about medical issues (the biology of pregnancy and delivery). In South Africa doctors, sisters, other medical staff and significant others recently got together and scheduled an annual conference on Priorities for Perinatal Care in order to discuss and develop new strategies exclusively relating to perinatal care. Together with the Perinatal Education Programme (PEP), they identified certain avoidable factors, missed opportunities and substandard care associated with perinatal death. These can be divided into three categories:

a. *Patient-related*: Most potentially avoidable perinatal deaths in South Africa are due to patient-related factors.

b. *Health worker-related*: Slightly fewer potentially avoidable factors are due to factors relating to health workers.

c. *Administrative*: Administrative factors are less common.

These three categories will be discussed very briefly. According to the Saving Mothers and Babies Manual as compiled by the Perinatal Educational Programme, (Woods *et al.*, 2010) the most common potentially avoidable **patient-related factors** are:

- No attendance, late attendance or irregular attendance for antenatal care.
- Inadequate response to decreased fetal movements.
- Inadequate response to rupture of the membranes.
- Inadequate response to antepartum haemorrhage.

- Delay in seeking medical attention in labour.

To address these patient-related factors it is important to educate pregnant women regarding their pregnancy and what to expect. Education needs to focus on problems experienced during pregnancy, to enable pregnant women to act in a pro-active manner and seek attention early.

The most common factors relating to **health workers** can be divided into three groups:

Table 2.3: Health worker-related factors associated with perinatal death

Antepartum factors (during pregnancy)	Intrapartum factors (during labour)	Neonatal care factors (care of the infant after delivery)
1. No response to a poor past obstetric history. 2. Over- or underestimating fetal size. 3. No response to poor uterine growth. 4. No response to poor fetal movement. 5. No response to hypertension. 6. Multiple pregnancies not diagnosed. 7. No response to syphilis serology. 8. No response to glycosuria. 9. No response to post-term pregnancy.	1. Partogram not used. 2. Fetus not adequately monitored. 3. Signs of fetal distress not interpreted correctly or ignored. 4. No response to poor progress of labour. 5. Prolonged second stage not managed correctly. 6. Delay in calling a doctor or referring the patient.	1. Inadequate resuscitation. 2. Inadequate monitoring or management plan. 3. Delay in calling for assistance or transferring the infant to a level II or III unit.

(Adapted from information obtained from Saving Mothers and Babies Manual (Woods *et al.,*2010))

Table 2.3 illustrates the three different time periods where factors relating to the health workers may contribute to stillbirth (perinatal death). It can be noted that most of the factors occur during the antepartum period (during pregnancy) and that if health workers are better trained and educated and have the necessary resources, negative

pregnancy outcomes can be prevented. The most common **administrative factors** in South Africa relating to perinatal death are:

- Transport delays in getting the patient to the hospital or clinic, or transport delays between health institutions, e.g. getting a patient from a clinic to a hospital.
- Lack of adequate screening for syphilis.
- Too few staff or inadequately trained staff.
- Inadequate facilities, especially theatre and neonatal care facilities.

Although the administrative factors are few, the impact they have is immense. Serious intervention is needed to address these problems. The Department of Health needs to be aware of these factors and needs to change the relevant policies. Application for extra funding needs to be done so that extra staff can be employed.

2.11 CONCLUSION

This chapter gave an extensive overview of the medical causes surrounding stillbirths by exploring the history of stillbirth and giving the most important definitions surrounding stillbirth, miscarriage and infants. This was followed by a description of the medical causes of stillbirths as well as maternal conditions relating to stillbirths. Risk factors of non-medical origin are also mentioned. Finally the chapter looked at interventions that must be implemented to reduce the stillbirth rate.

From the above it can be deduced that stillbirth is a devastating pregnancy outcome and that the causes are not always easy to diagnose. The incidence of stillbirth is currently receiving more interest in the research field and researchers aim to lower the perinatal mortality rate by their contribution and also ultimately to prevent stillbirth. By understanding the medical issue of stillbirth, the social worker working in the medical field will better understand the effect of stillbirth on parents, and crisis intervention can be more effective. The grief process undergone by parents and the different theories on grief will be explored in more detail in the following chapter.

CHAPTER 3

GRIEF, GRIEF RESPONSES AND MODELS OF GRIEF

3.1 INTRODUCTION

"To everything there is a season, and a time to every purpose under the heaven. A time to be born and a time to die."

These well-known words from the Bible affirm the expected order of life. Between birth and death there is a time to live, "a time to sow and a time to reap…a time to weep and a time to laugh". But when the time to be born is also the time to die, when the beginning of life is the same as its end, when the time to love never comes, then this order is violated. The cry of the longed-for baby becomes a sob of bereavement from the family; the anticipated baptism becomes a dreaded funeral. This is a stillbirth (Borg & Lasker, 1981:51).

Statistics do show that the problem of stillbirth is widespread, but they tell nothing about the tears, the regrets, the feelings of guilt, the long process of rebuilding hope. They hide the loneliness of those who feel they are the only ones in the world who have failed to become parents.

To write about the loss of a loved one is such a difficult and personal thing to do. It asks of the writer to try to image what it would be like to lose a loved one, in this case a stillborn baby, and to deal with all the emotions around it. This chapter is designed to provide the reader with an in-depth look at death, grief, bereavement, mourning and then providing an in-depth look at the grieving process. Here the accepted stages of shock, denial and isolation; anger; bargaining, depression and finally acceptance will be discussed. Grief models will be discussed and the chapter will be concluded with an overview of dysfunctional or complicated grief to aid the reader to understand the topic at hand.

3.2 DEFINITIONS OF LOSS, GRIEF, BEREAVEMENT AND MOURNING

Grief, loss, bereavement and mourning are four very closely linked concepts to help define and understand an individual's reaction to the death of a loved one. Although they are closely related, it is important to discuss each term separately as they all have

different meanings and knowledge of each term is necessary to better understand the psychosocial implications of a loss to a mother and her family.

3.2.1 Loss

Schoenberg (1980:9) suggested that loss appears in four forms: loss of a valued person, loss of some aspect of the self, loss of external objects, and developmental loss, which is connected with growth and its accompanying physical, psychological, emotional and social changes. The extent and kind of response to loss are predicated by the personality of the individual undergoing (or having undergone) the loss, the relationship between the bereaved and the lost object, and the values of society.

3.2.2 Bereavement

Bereavement is the state of being deprived after a loved one's death. The first year of bereavement is looked back on as a limbo of meaningless activity (Borg & Lasker., 1981:18). Bereavement is the process of coping with loss (Becvar, 2001:37). Bereavement can also be explained as follows: "In the aftermath of life-altering loss, the bereaved are commonly precipitated into a *search for meaning* at levels that range from the practical (How did my loved one die?), through the relational (Who am I now?), to the spiritual or existential (Why did God allow this to happen?) (Neimeyer & Sands, 2011:9). Averill (1968:721) used the construct of "bereavement behaviour" to encompass the total response pattern, including psychological and physiological signs demonstrated by an individual confronted with loss of a love object and encompassing the components of mourning (following social expectations) and grief (distress of biological origin following loss).

3.2.3 Mourning

Mourning is the externalization of grief. It consists of rituals that take place to mourn the deceased in a physical way. An example of this is having a funeral for the deceased. This helps the bereaved individual to acknowledge the fact that the loved one has indeed passed away. Mourning is a process that must take place little by little over the course of time. According to Badenhorst and Hughes (2007:251) mourning is the process of recovery, with gradual lessening of distress and return to normal patterns of living. Mourning is tremendously painful at the time but it is the ultimate catalyst for

growth. It provides the bereaved individual with a method through which feeling and emotions can be channelled in order to regain equilibrium. Mourning may be characterized by paradoxes that are not easily resolvable, rather than an orderly linear progression through the stages of grief (Callister, 2006:228).

3.2.4 Grief and grief responses

Grief stands in contrast with mourning as it is an internal state and cannot be externalized. Averill (1968:748) conceptualized four main features of grief:

- It is a complex but stereotyped response pattern which includes such psychological and physiological symptoms as withdrawal, fatigue, sleep disturbances and loss of appetite;
- It is elicited by a rather well-defined stimulus situation, namely, the real or imagined loss of a significant object (or role), and it is resolved when new object relations are established;
- It is an ubiquitous phenomenon among human beings and appears in other social species as well, especially in higher primates;
- It is an extremely stressful emotion, both psychologically and physiologically, and yet behaviour during grief is often antithetical to the establishment of new relations, and hence the alleviation of the stress.

Bowlby (1980) conceptualized grief as a form of separation anxiety resulting from the disruption of an attachment bond: in this study, brought about by the death of an unborn baby or stillbirth. Moody and Arcangel (2002:211) defined grief as a process that carries a number of feelings and behaviours, and an underlying sense of sorrow and longing. Grief is an instinctive response to loss; it is a process harbouring a host of feelings. It consumes the body, mind and soul around the clock, for many days or weeks. Grief illuminates our humanity (Moody & Arcangel, 2002:146,211). Parkes (1972) described grief as a process of realization whereby internal awareness is brought in line with external events. Sigmund Freud (1957) saw the grief reaction as a hurtful dejection, withdrawal of the capacity to love, inhibition of all activity, a loss of interest in external events, and a loss of self-esteem. All the authors thus agree on the

fact that grief is a *process* consisting of *feelings and reactions,* that consumes a person's mind and soul.

3.3 GRIEF PROCESS

In literature regarding loss and bereavement, various authors mention that grief is a process and that an individual needs to move through this process to be able to accept the loss. Parkes (1972) explained that the modification of a person's internal world takes time and is aided by the repeated discrepancies encountered when remembering the deceased in an environment where the deceased no longer exists. The awareness of this discrepancy between the outside world and internal awareness leads to frustration. Since being continually frustrated is an aversive state, the behaviours (such as dwelling on the loss) producing frustration are eventually extinguished and the grieving process gradually comes to an end. Although this explanation of Parkes (1972) helps to understand the process, it fails to mention that each individual grieves differently because his/her circumstances are unique and constantly changing. To understand the distinctiveness of each person's grief, Moody and Arcangel (2002:58) identified a few variables that can have a serious impact on the length and depth of an individual's grief process:

- *Age of the loved one*: When an elderly person dies, although we grieve, there is a sense of understanding that nature is following its normal time line; that of elders dying first. The universe seems in confusion, however, when a child or baby dies. Bereaved parents struggle with this devastating loss, because their sense of future died as well.

- *Age of the survivor:* Most children up to the age of 12 do not comprehend that death is permanent and can happen to them, but they grieve by playing at mourning. If they are supported in their resilience, they adjust to loss over time.

- *Grief history:* Every loss which an individual experiences has an effect on the next loss. Current bereavement is preparatory to the next. It may be that a mother experiencing a stillbirth for a second time, may understand her feelings and emotions better, although because it's her second devastating loss she may

be even more distraught than the first time. Her fears of ever going to have a live-born baby will be real and undeniable.

- *Mental, emotional, physical and spiritual health:* These four aspects play a major part in the way we cope with loss. People already in an emotional crisis like major depression or people facing major surgery may intentionally or unintentionally postpone their deepest mourning until later. If this mourning doesn't take place later, it may be detrimental to the individual's total well-being.

- *Cultural influences:* Different cultures have different ways in which mourning is conducted, and if these rituals are not respected it may lead to confusion. Different religious denominations have different rituals that need to be respected. A violation of these rituals will have a negative effect on the bereaved person, in this study the bereaved parents.

- *Family dynamics:* Each person in a family has a specific role and when death occurs in a family, it is easy to conceal our grief by the roles we play. A death of a family member leaves a hole in the system and this is true for a family who have lost a baby as a result of stillbirth. Although the unborn baby was not yet physically part of the family, the family might have made future plans for the baby already, with the siblings already excited about a new brother/sister.

- *Relationships:* The stronger and deeper the relationship with the deceased, the more profound the loss.

- *Gender:* Research findings (Moody & Arcangel, 2002:58) indicate that women and men respond differently to loss. Women will be emotional, cry and start mourning for the lost one whereas men will try to delay their grief and immerse themselves in work or other distractions. This can lead to strain in marriages, especially after a stillbirth.

- *Manner of death:* Death can be anticipated – time is given to say good-bye but the bereaved is left emotionally and physically tired. This may be the case with an intra-uterine death of a baby. Parents are notified of their baby's death before the birth. Although it is still a shock to the parents, they have a few hours/day to prepare them for not having a live baby. Death can be sudden – no time is given

to say good-bye and mourning is more intense. When a baby's heart is still beating just before labour and death occurs during active labour, death is sudden and parents have no time to prepare themselves.

- *Personality:* Having an extroverted or introverted personality type may influence the way an individual responds to loss. Introverts may share with few close friends their feelings of sorrow and grief, extroverts will share with many more.

- *Religion:* Survivors rely on religion and their religious community to bring reason in the chaos of grief.

- *Spirituality:* Spirituality is remembering that something greater than the self exists. When bereaved, those who are spiritually enlightened, experience death at a different level. This can be positive, or negative if denial is part of this experience.

- *Social support:* Survivors need to reminisce over what has happened and this is where social support from friends and family is helpful.

- *Professional support:* Bereaved individuals struggling to go through the grief process sometimes need some help. Grief facilitators help survivors sort through their thoughts and feelings.

Stages, as well as components of grief have been described by various authors. Compare the works of Elizabeth Kübler-Ross (1969), Ramsay and Happée (1977), Worden (1991), Degner (1976), Schulz (1978) and Schoenberg (1970) on stages of grief. The views of these authors helped many therapists in bereavement counselling, but it was interpreted incorrectly by some who saw the stages as a linear process with bereaved individuals/parents literally moving from one staged to a next. Critics also complained that the stages of grief were too passive. Kübler-Ross suggested that grief is a continuously evolving process and that growth is the end product of it. Unfortunately she did not indicate how this growth could be achieved. Some therapists even tried to put a time limit to each stage. However when used as a tool in therapy and not as a given, it can be very helpful in working with bereaved parents.

The following table explains the stages of grief as identified by Ramsay and Happée (1977:55) and Borg and Lasker (1981:18) which coincide. Although these stages apply to any type of loss, they have been adapted and applied to parents losing a baby. The grieving process can take from six to 24 months. The stages may overlap, and their ordering and degree of intensity may vary for different people (Borg & Lasker, 1981:18).

Table 3.1: Stages of grief

Stages of grief	
1. Shock	Natural response; it is beneficial in that it gives the individual time to absorb the gravity of the tragedy by delaying the impact. Feelings of numbness are common during the first minutes and days. Shock enables parents to get through the tragic situation initially without losing control.
2. Denial	Some degree of denial is a normal part of grieving. It is a form of self-protection, a way of not having to face up to the pain. Although these are normal reactions, the parents must ultimately distinguish between fantasy and reality and confront the very real tragedy that has occurred.
3. Depression	Overwhelming sadness after the tragedy. Parents feel sad for the baby and that it is unfair that the baby had to die. Feel as if baby never had any chance.Parents are sad for themselves as well, sad because of the emptiness and the disappointment.The parents mourn not only for the dead infant, but also for all the future possible children, a kind of mourning that is even less recognized and supported.
4. Guilt	One of the strongest emotions of bereaved parents. Many parents blame themselves for the tragedy and wonder what they had done to cause it, perhaps a deficiency in their physical make-up, their “bad genes” or bad blood. They wonder what they might have done to prevent the tragedy. Parents scrutinize every activity, looking for a clue. What some parents feel most guilty about is the ambivalence they had experienced in response to the idea of becoming parents, and this memory is one of the sources for the strong feelings of guilt and depression that assail parents whose infants die. It is important for the social worker to recognized this and to be able to identify these feelings experienced by the mother.

5. Anxiety	This anxiety, sometimes leading to panic reactions, occurs as the full realization of the loss begins to come through – anxiety for the changes that will have to take place, for the loneliness looming ahead, possibly suicidal thoughts, for increased responsibilities that the loss entails, for the thoughts of aggression that begin to break through, and for the violence of the emotions as necessary expression of a grief reaction.
6. Aggression	Feelings of guilt turn into anger toward others. They blame God, the doctor and even the baby for causing them so much heartache. They are angry that they have suffered through a pregnancy and then have nothing. It might seem surprising to feel anger toward a baby, especially one so longed for, so innocent. Expressing this hostility overtly may be impossible, but the feeling is still there – how could you have left us and made us so miserable? Why couldn't you have been stronger? The husband and wife may blame each other. Some parents are angry at their friends because they don't know how to be supportive, or perhaps they say foolish and thoughtless things in an effort to be kind.
7. Intellectualization	Parents start to intellectualize the loss in order to understand it better and in a way try to accept it. Many parents and family members mention ideas for research, with the hope that it may indicate the cause of death of their baby.
8. Reintegration	Once the subject of loss has been relinquished and laid to rest, and the emotional reactions have been extinguished, the person is capable of starting a new way of life. During this phase there are usually some relapses, such as on the anniversary of the loss, at birthdays, Christmas and so forth; these relapses are usually of short duration.

(Adapted from Ramsay & Happée, 1977:55, and Borg and Lasker,1981:18)

Parents grieve for the person whom they feel they already knew well and for the dream of what that person would become. It is especially important for professionals to assist parents in beginning to grieve. They can do this by helping to create concrete memories for the parents to hold on to. The social worker needs to be aware of the causes of the loss and needs to support the mother and family accordingly. Most of the literature found on the grieving process dated several years, but the researcher learned from recent literature that the process stayed the same. This was confirmed by Sue

Hale, a bereaved mother, who presented a course on bereavement (Hale, 2009). She identified the grieving process as follows:

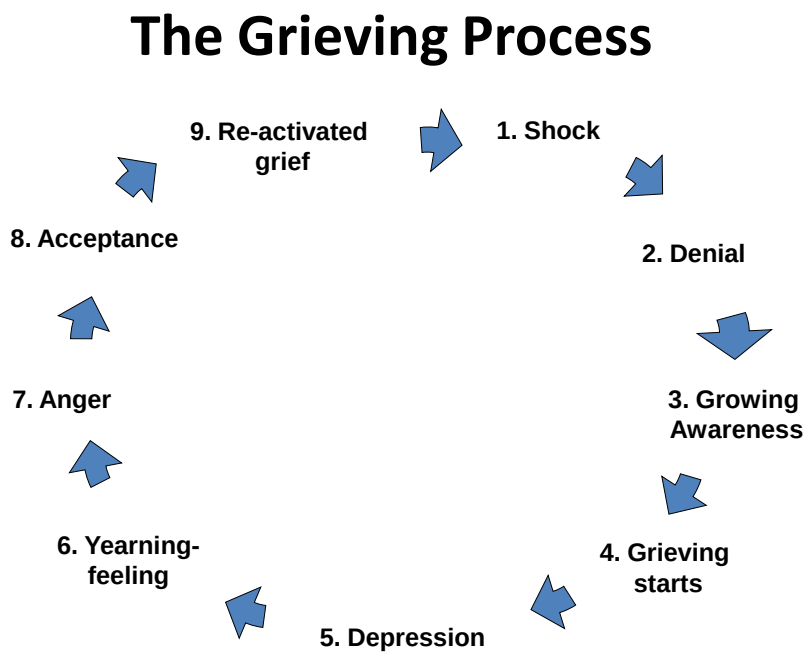

Figure 3.1: Circular grief process as described by Sue Hale (2009) (Adapted from a personal conversation with Sue Hale)

Figure 3.1 shows that the only difference now evident is the fact that it's not necessarily a step-by-step event, but that it can be seen as a circle, repeating itself when necessary. Again it coincides with feelings of yearning that parents experience through this process. Leon (1990, 1996) agrees with the above-mentioned grief circle, but argues that numerous events following discharge from the hospital have also been reported as relatively unique stress points for bereaved parents. Given that each event can precipitate a grief reaction, there would seem to be a need for models specific to perinatal grief, which reflect these physical and temporal characteristics.

3.4 MODELS OF GRIEF

When comparing models of grief with the "stages" of grief it is significant to note that grief models are a more modern approach to understanding grief than grief processes. This is clear if one looks at more recent literature (Worden, 1991; Stroebe, Schutt & Stroebe, 2005) available on grief models. Below the most recent grief models will be compared.

3.4.1 Task model

William Worden (1991) developed a task model which is seen as a goal-oriented model where certain steps are to be followed to enable the individual to rebuild life after loss. The task-centred model of Worden (1991) was based on a cognitive approach where bereaved individuals need to complete the task at hand, before moving on to the next task. See figure 3.2 below for an illustration of these four tasks.

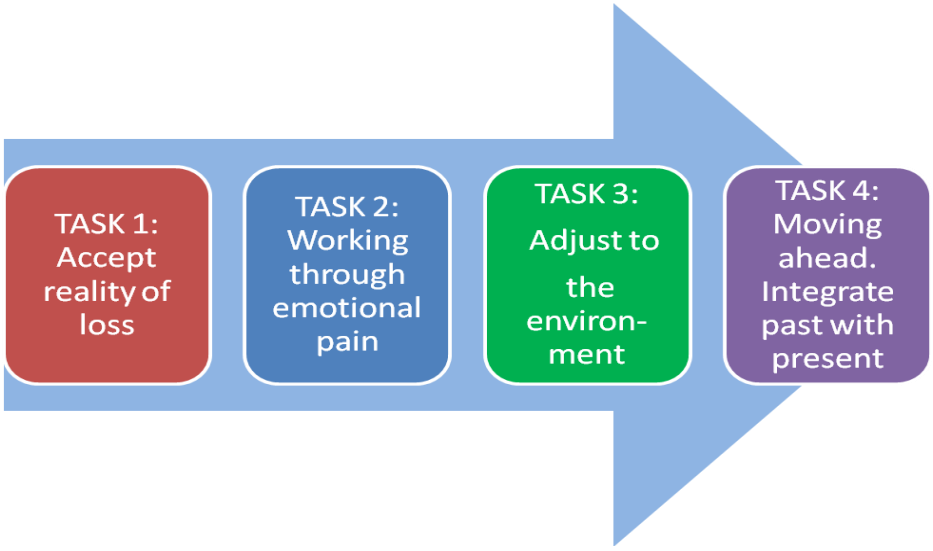

Figure 3.2: Coping with grief: Task-centred model (Adapted from Worden, 1991)

Figure 3.2 above illustrates that to be able to *work through the emotional pain* of grieving, bereaved parents need to *accept* that their baby has really passed away. *Adjustment* to the environment is the next step which may involve packing away unused, new baby clothes and adjust to the fact that they might need to be within a group of friends where everybody has children. The final and most difficult task is *integration* of the past with the present. Bereaved parents and individuals need to focus on being here and now, and not longing for the baby all the time. When assisting bereaved parents or individuals in the grief process, it is important that the social worker know the four tasks because some people will benefit from these sequential steps while others mayeed a different approach, as the model below explicates.

3.4.2 Dual-process model

Stroebe and Schutt, (1999) developed the “dual-process model” of coping with bereavement with the aim to set a theoretical framework in which the phenomenon of

effective coping skills regarding bereavement can be understood. According to Stroebe *et al*. (2005) the purpose in developing such a model was to try to represent the process of coming to terms with a death accurately and to identify patterns among the diverse reactions that are part of grieving. The model specifies the relationship between coping and outcome variables.

To address the definitional problem and to take better account of the diversity of stressful experiences in bereavement, the DPM (Dual-Process Model) specifies two categories, so-called *loss-oriented* and *restoration-oriented stressors.* In contrast to cognitive stress theory, it postulates that a person experiencing the global stressor of bereavement needs to deal with two types of specific stressors concurrently: *Loss- and restoration-oriented stressors* (Stroebe *et al*., 2005). Figure 3.3 below illustrates loss- and restoration-oriented stressors.

Figure 3.3: The dual-process model of coping with bereavement (Adapted from Stroebe *et al*., 2005)

The dual-process model illustrates that the bereaved person alternates between what theorists (Stroebe & Schutt, 1999; Bowlby, 1980) call loss orientation and restoration orientation. Coping with loss-orientation stressors has to do with processing the loss of the person him/herself. According to Stroebe *et al*. (2005) this involves grief work, positive and negative reappraisal of the meaning of loss, and the effort to "relocate" the deceased in a world without his or her presence. Separation distress, identified by Bowlby (1980) is a major component of grief. By contrast, restoration orientation has to do with the secondary stressors that come about as an indirect consequence of the bereavement, for example changing identity and role from "expectant woman", to not having a baby. Restoration incorporates the rebuilding of shattered assumptions about the world and one's own place in it, just as loss orientation incorporates rebuilding of assumptions about the presence of the lost person in one's life (Janoff-Bulman & Berg, 1998). Restoration is part of the coping process, in that it involves dealing with the situational changes that have come about as a result of loss. Stroebe *et al*.,(2005:52) explained that this conceptualization differs from the stage or phase theory assumption that there is a reorganization "phase" later on in bereavement. In the Dual-Process Model "restoration" is integral throughout the coping process itself.

Stroebe *et al*. (2005:52) propose that confrontation-avoidance alternation is the single central process in adaptive grieving. At any particular time (during coping), there is confrontation with some aspect and avoidance of another. According to Stroebe *et al.* (2005:52) there are two types of stressors, loss-oriented and restoration-oriented and because it is not possible to attend to both dimensions at the same time, oscillation takes place between them, which is successfully illustrated by the Dual-Process Model. Further empirical research done by Schutt, Stroebe, de Keijser and Van den Bout (1997) suggests the need for confrontation of neglected aspects of loss and avoidance of aspects that may have been dwelt on too relentlessly (see also Hogan & Schmidt, 2002).

The effectiveness of this model is furthermore in not only showing the impact of grief on the person's immediate adjustment, but also on her/his future restoration. This is a central concept in the crisis-intervention approach within the social work theory. Thus this model will aid the social worker in immediate crisis intervention and long-term adjustment, which is also the focal point of this study. In chapter 5 a complete overview

will be given of the crisis intervention approach and how it can be applied in a situation where a stillbirth has occurred. The model however fails to recognize dysfunctional grief.

3.4.3 Transcendence model

Most survivors of grief will eventually rebuild their lives, but Moody and Arcangel (2002:140) elucidates that some survivors experience more than just rebuilding their lives, they experience transcendence. Transcendence is a spiritual rebirth where one feels elevated above one's former self. The figures below illustrate this within the context of a mother who had a stillborn baby.

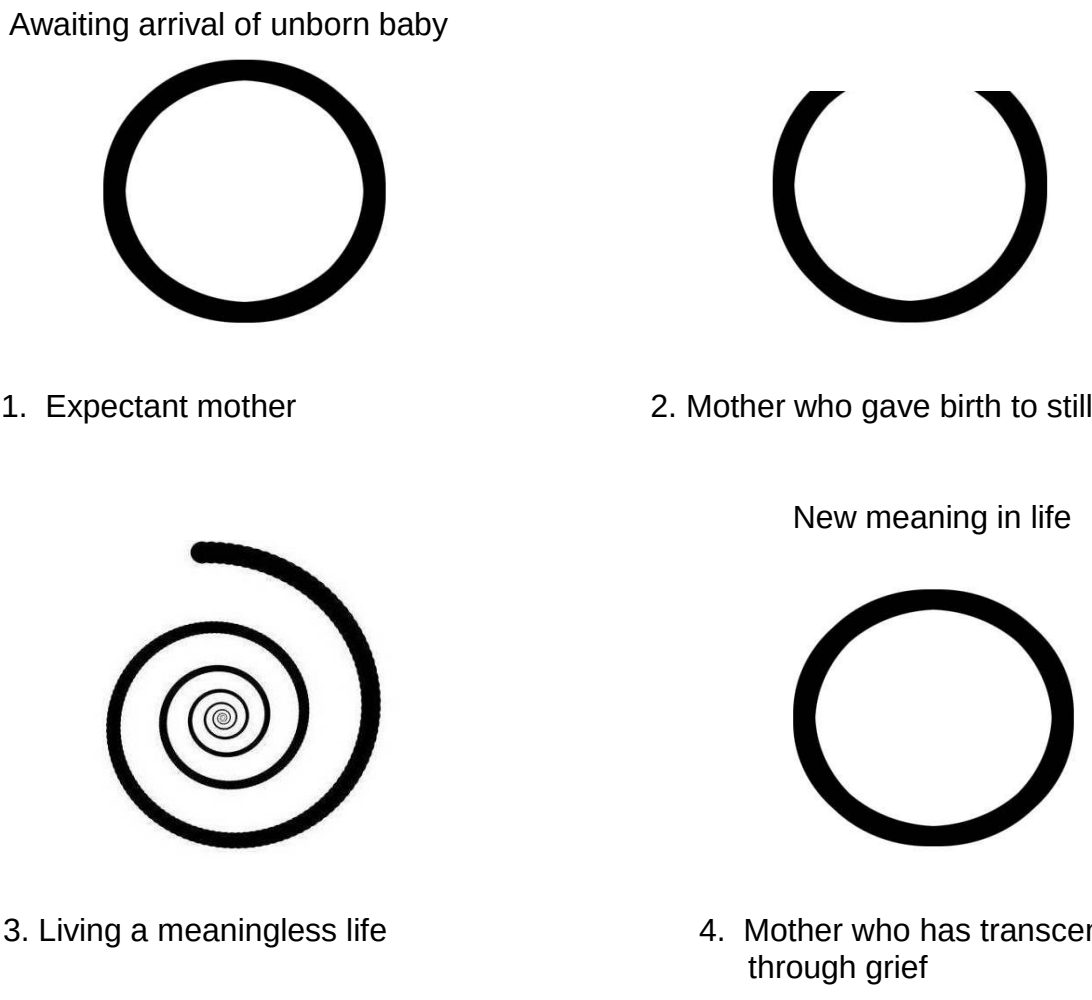

Figure 3.4: Transcendence model of grief. (Adapted from Moody & Arcangel, 2002:141)

The four circles above present the journey to transcendence. The first circle illustrates a strong, healthy relationship. Although the baby has not been born, it is normal to have formed a bond with the unborn baby. Every time the mother feels her baby kicking, she is aware of her baby and dreams are being created of a possible name, baby's room, etc. In the next circle the birth of the stillborn baby leaves a hole in the circle. The bereaved mother's body, mind and spirit still create energy, but without focus. There is no baby on the other side of the circle to receive and reciprocate. The third circle illustrates that without a target for the bereaved mother's time, love, and focus, her energy swirls within and around her with no meaning. The fourth circle demonstrates a mother who has found new meaning in life which has now become the recipient of her time, energy and love. The circle is complete again, although there will still be waves of sorrow, but they will become fewer and fewer according to Moody and Arcangel (2002:143). This new meaning can take the form of many things, and need not be another baby.

3.5 TYPES OF COMPLICATED GRIEF

Grief is a very complex process and it may happen that the individual, who is grieving, is not grieving in a healthy way. Then complicated grief occurs and it is important for the social worker rendering crisis intervention to be aware of these complicated grief forms.

3.5.1 Chronic grief

This is a complicated form of grief characterized by the long-lasting presence of symptoms associated with intense grief (rumination, preoccupation with thoughts of the deceased, depressed mood) and the absence of apparent progress in coming to terms with the loss of a loved one (Stroebe, *et al*., 2005:55; Cacciatore, 2010:145). Individuals experiencing chronic grief will be preoccupied with loss orientation and no/little oscillation toward restoration orientation. In terms of social work intervention, crisis intervention would be helpful throughout intervention although a shift needs to be made towards a more task-centred approach of intervention.

3.5.2 Delayed grief

Delayed grief is characterized by a shallow grief response, often described as" business as usual". The individual shows little or no sign of grieving early on in bereavement, and keeps on suppressing it, although he/she may do so at a later point (Stroebe, *et al.,* 2005:55). The bereaved person is barely slowed by the loss, and only at another time, weeks or even years later, is the true grief experienced.

3.5.3 Absent grief

Absent grief is difficult to distinguish from delayed grief (Stroebe, *et al.,* 2005:55).The individual continues with life as though nothing had happened. (This does not always indicate pathology.) In both absent and delayed grief, individuals tend to focus on the tasks of restoration exclusively and avoiding loss orientation. With these individuals it is complex to initiate any crisis-approach intervention because the individual does not see her/himself as being bereaved and experiencing a crisis. When looking at the psychosocial implications of stillbirth, the general assumption is that men especially present more with delayed or absent grief. Fraley and Shaver (1999) mentioned that although suppression of grief may be harmful for some, the extent may have been overestimated.

3.5.4 Posttraumatic stress disorder (PTSD)

This disorder occurs consequent to the experience of a trauma such as stillbirth. Individuals who have suffered extreme trauma have difficulty in controlling their anxiety and stress arousal and in keeping these emotions at a functional level. Persistent highly distressing re-experiencing is combined with persistent efforts to avoid recollections. According to Stroebe *et al*. (2005:55) posttraumatic stress disorder causes a disturbance of the natural oscillation process.

3.5.5 Fixated grief

Moody and Arcangel (2002:97) explain that healthy grief is a natural continuing process, although an individual can stop to rest. Fixated grief causes survivors to remain stuck at one point. They slide into an unhealthy, prolonged withdrawal.

3.5.6 Denial

The function of denial is to protect the psyche from a crisis initially too intense to absorb. Denial is seen as functional during early stages of mourning, but becomes dysfunctional if prolonged (Moody & Arcangel, 2002:98).

3.5.7 Reversibility of the loss

Most bereaved adults, according to Moody and Arcangel, (2002:103) experience moments of expectation that their loved one will return. If this continues, the grieving process becomes dysfunctional.

3.5.8 Mementos

Different authors (Callister, 2006:232; Pauw, 1991:293 & Capitulo, 2005:394) have different opinions regarding “memory making” and keeping mementos of the deceased. Moody and Archangel (2002:104) identified four types of mementos:

- Transitional objects: These objects are kept for a while. This could be flowers parents received after having a stillbirth.
- Keepsakes: These objects are preserved permanently, and could include sonar photos, hand- and footprints of the baby and a photo.
- Lifeline objects: The bereaved parents hold on to their mementos to the extent that these articles become lifeline objects and the process becomes dysfunctional.
- Rejected objects: Discarding all objects that could serve as reminders. When bereaved parents are in denial, they sometimes pack up all the baby’s clothes and will give it away or sell it. Because this is being done on impulse, the bereaved parents are filled with regret later on by doing that and long for something to show that their baby was indeed real.

3.5.9 Emotions in disguise

Moody and Arcangel (2002:111) explained that emotions can be disguised after the death of a loved one. When a stillbirth happens, the father may for instance blame the

mother for the death, because he feels guilty for not being there for her during the pregnancy.

3.5.10 Anniversary reactions

The anniversary of certain events can bring different reactions to bereaved individuals/parents, such as feelings of sadness or depression. Moody and Arcangel (2002:112) identified events like original birth date of a stillborn baby, certain milestones which were due to take place such as sitting, walking as well as following birthdays. Such anniversaries bring painful reminders even when the process of grieving is almost completed. Reactions to anniversary events can become dysfunctional if bereaved parents are in denial regarding these events or their feelings of grief are so overwhelming that they cannot function during this period.

3.5.11 Replicated loss

Previous losses are revisited with every new loss which occurs or losses are replicated. The same fears and feelings of grief are experienced again. Replicated loss is especially troublesome if the original loss was not mourned (Moody & Arcangel, 2002: 116).

3.6 CONCLUSION

This chapter presented an in-depth review of the current understanding of grief by exploring the notion that grief, loss, mourning and bereavement are terms closely related to one another. Focus was placed on factors that influence different grief reactions. The chapter then described the grief process and a description of the three different grief models, namely task-model, dual-process model and the transcendence model was given. This serves as a foundation naturally flowing to the next chapter which focuses on the psychological implications of a stillbirth on the mother, father, couple, single mother/teenager, children and grandparents/family.

CHAPTER 4

REVIEW OF THE CURRENT UNDERSTANDING OF PSYCHOSOCIAL IMPLICATIONS OF STILLBIRTH FOR A MOTHER AND HER FAMILY

4.1 INTRODUCTION

The following chapter presents a literature overview of current understandings of psychosocial implications of stillbirth for a mother and her family. This review will include information from multiple disciplines including social work, theology and psychology. The chapter will help to equip the researcher towards implementing the empirical study, where participants will be interviewed regarding their personal experience of a stillbirth.

The focus will shift to the specific grief of a mother and her family who lost a baby. Finally the different perspectives on loss will be discussed from a social work, psychological and theological viewpoint. Through this comprehensive literature review of current understanding of the psychosocial implications of stillbirth for a mother and her family, an important objective of the study is being addressed. Included will be information from the multiple disciplines cited above.

4.2 PSYCHOSOCIAL IMPLICATIONS OF A STILLBIRTH

The realization that the death of a baby or fetus prompted a response similar to the grief reactions listed above did not dawn quite as quickly (Mahan & Calica, 1997:142). Expectations of mourning associated with perinatal loss are noticeably absent in society according to Callister (2006:227) and Borg and Lasker, (1981:14*)*. A stillborn baby is a baby born into silence – often the silence continues long after the birth (Stringham, Riley & Ross, 1982:322).

The following section of this chapter will focus on the psychosocial implications of a stillbirth for the mother and her family.

4.2.1 Implications for the mother

The word for “pregnancy” in Spanish also means full of life, light and promise for expectant parents. When such dreams are lost there may be a deep sense of sorrow.

The death of a baby immediately before or during the birth process is not only a shock, but truly a tragedy (Mahan & Calica, 1997:143). Because a stillbirth happens during an advanced stage of pregnancy, preparations for the baby may have been started or even been completed. These include readying the nursery, selecting names and arranging maternity leave. To realise that all the arrangements are not necessary any more, can be devastating to the mother.

Psychologically, mothers can question their own ability to be a good mother, for not being attentive to their own body signals, such as decreased fetal movement that could have warned them and possibly prevented the tragedy. According to Mahan and Calica (1997:72) there are usually little warning signs and no reason to anticipate such a turn of events. Callister (2006:228) agrees with Mahan and Calica (1997:3) that stillbirth represents a significant loss of the mother's perception of her body's functional adequacy, associated with body image and feelings of selfworth. Being in hospital can have a negative impact on the bereaved mother's emotional state who has to face the anxiety and loneliness of remaining in a hospital near new mothers and their babies. According to Borg and Lasker (1981:62) mothers experience the sadness and pain of feeling their breasts swell with useless milk.

Stringham *et al*. (1982:322) conducted a study on 20 women, investigating the experience of giving birth to and mourning a stillborn baby and their findings correspond with those of Borg and Lasker (1981:62) and Callister (2006). Stringham *et al.* (1982:322) mentioned that knowing that your baby is dead before delivery, may prepare you for the birth and anticipatory grief work can be done. This can also be perceived as negative as one woman described herself as a "walking coffin". Other emotional reactions that mothers may experience include disappointment, grief, anger, self-pity, feelings of inadequacy, failure, social isolation and helplessness. It is important for the social worker to be aware of this when giving supportive feedback during crisis-support intervention.

Women who have lost a child experience varying levels of grief based on individual circumstances. Reactions, as identified by Brownlee and Oikonen (2004:519), can be influenced by indicators as illustrated in figure 4.1.

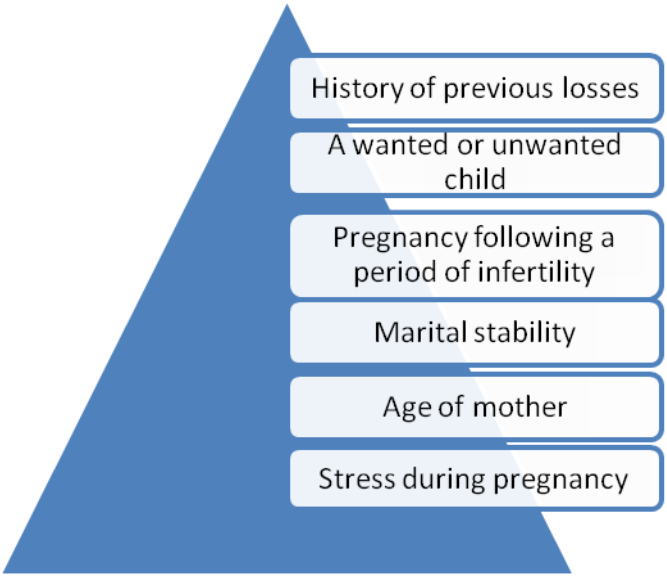

Figure 4.1: Important indicators that can influence reactions afer a stillbirth (Adapted from Brownlee & Oikonen, 2004:520)

Figure 4.1 depicts important indicators that can influence reactions after a stillbirth. Each bereaved mother is individual and so are her circumstances. For example, if a bereaved mother is still very young, she might feel guilty because she had not wanted the baby at first. She may also feel relief, but not showing this, that she does not need to face the responsibility of motherhood yet. Figure 4.1 above also illustrates that if, for example, pregnancy followed a long period of infertility and a stillbirth occurs, this loss will probably cause extreme grief to the mother for she is not sure if she would be able to conceive again.

There is a tendency on the part of the general public to underestimate the impact of stillbirth. Mahan and Calica (1997:72), Brier (2008:456) and Callister (2006:228) all mentioned that especially the expectant mother and in most cases her partner/husband as well, already bonds with the unborn baby from the day they learn about the pregnancy. Modern technology makes it possible to hear the heartbeat of the baby at 12 weeks and see the child via ultrasound. This allows the parents to integrate the unborn child into the family at a very young gestational age (Brownlee & Oikonen, 2004:519). This is why one of the most difficult tasks facing parents experiencing a stillbirth is coping with the loss of someone they never really got to know. In many hospitals, all reminders of the baby are removed quickly, and rarely are parents

encouraged to consider a funeral or other formal mourning practices. Mahan and Calica (1997:145) and Borg and Lasker (1981:8) suggest the following ways the social worker can suggest to the mother/parents to help make the baby as real as possible and to start the grieving process:

- *Naming the baby*: A name helps to acknowledge the fact that the baby was an individual and therefore a grief response is normal. Encourage the mother/parents to name the baby.

- *Seeing, touching and holding the baby*: This is a highly debatable topic due to the extremely sensitive nature thereof. According to Mahan and Calica (1997:145) social workers/perinatal caregivers need to offer the mother the opportunity to see, touch, or hold the baby that has died. Literature (Stringham *et al.*, 1982:324; Wretmark, 1993:59) indicates that spending time with your stillborn baby, promotes a healthy grief process because the baby was a reality for the mother. In cases where the baby/fetus is disfigured or is macerated the mother/parents may take their cue from the social worker about what is appropriate. It is recommended that the family (grandparents and siblings) of the parents see the stillborn baby as well so that the loss is a reality to them as well and not as disenfranchised as it normally is. Badenhorst and Hughes (2007:249) disagree with Stringham *et al.* (1982:323) and believe that contact with a stillborn may have adverse effects including inducing symptoms of posttraumatic stress disorder.

- *Photographs*: One of the most important and lasting mementos is the bereavement photograph. It is believed that photographs of the infant who has died are important in assisting parents and families to work through their grief (Mahan & Calica, 1997; Primeau & Recht, 1994). It confirms the existence of the baby. Primeau and Recht (1994:22) mention that a hospital in Massachusetts has offered bereavement photographs to families for about 15 years as part of a bereavement programme. They found that the response of parents to these photographs has been overwhelmingly positive. A photograph is appropriate to offer as a memento of the baby, but is a very individualistic decision (Mahan & Calica, 1997:145). Because of the lack of staff and equipment in some South

African hospitals, having a photo taken of your stillborn baby was not a priority. Fortunately with access to better technology than a few decades ago, more patients take photos on cellular phones than before. A non-profit organisation in America called "*Now you lay me down to sleep",* was formed and is now operating in South Africa as well where professional photographers take photos of the stillborn baby at no cost. These photos serve as beautiful mementos but again, this is an individual decision (Now I Lay Me Down to Sleep, 2011).

- *Tangible remembrances:* Parents should be offered all tangible remembrances of the infant's brief life, including hand-and-foot prints, name tags, hair and blankets.

- *Autopsy:* Discussing the issue of autopsy with bereaved parents needs to be done with sensitivity and careful consideration should be paid to parents' questions and concerns. Mahan and Calica (1981:72) mentioned that parents normally wonder what type of incisions are made, how much they show, and whether the autopsy will delay the funeral. Whenever death is unexpected or sudden, results from an autopsy take on heightened importance. When the medical explanation is given, the mother understands more about the death. The knowledge of having produced a "normal baby" affected parents differently. Some were reassured to know that their infants had developed normally and that the stillbirth was an isolated occurrence that would not necessarily affect subsequent pregnancies. Others felt angry that a normal baby could not have been saved but were gratified to know that they had been able to produce a normal infant. A study conducted by Stringham *et al*. (1982:324), found that parents often feel that they need to persevere to get the results from the hospitals or pathologists. Parents become frustrated and feel that no one cares about their babies. Mahan and Calica (1981:72) highlight the importance of the social worker needing to support the family in their decision to not have an autopsy done and to advocate their right to decide, even though this is counter to standard medical practice.

Mahan and Calica (1997:16) identified that in addition to the factors present in any grief process, families who experienced a stillbirth are faced with additional issues. During

the crisis-support session the social worker needs to advise the mothers/parents of these issues including:

1. Awakening at night hearing their baby cry.
2. Women whose baby died during pregnancy may still “feel” pregnant.
3. Some women report a sensation of feeling the baby still kicking.
4. Mothers, parents and families are preoccupied with fantasies of what might have been.
5. Causality is another issue. Most parents are desperate for as much information as possible as to “what went wrong”.
6. Mother blames herself and feels guilty that she might be the cause of the stillbirth. She might have irrational thoughts such as she was too stressed, working too hard, eating unhealthy food, using illicit substances, smoking and having feelings of not wanting the pregnancy at the beginning.
7. Mothers and father’s feelings of pregnancy after stillbirth. There may be a pervasive sense of anxiety and insecurity, ambivalence and doubt, with concern that the loss of another child will occur. The “vulnerable child” syndrome, where parents are overprotective of a subsequent child, needs to be discussed.

Cacciatore (2009:92) discusses the issue of giving a birth certificate to parents of a stillbirth baby. It was only in 2001 that the law in some states in America was altered and the issuing of a birth certificate was approved. According to Cacciatore (2009:93) there are tangible psychological and genealogical benefits to issuing of a certificate recognizing the birth. It is said that it will help women actualize their losses and may help them to cope with their losses.

4.2.2 Implications for the father

The father of the baby may envy his wife’s closeness to the baby and ability to feel his or her presence from inside; he is eager to see and hold his baby for himself. Not having carried that baby, the father may not feel quite as intense an attachment as the mother (Borg & Lasker, 1981:15).

Literature (Armstrong, 2001; Puddifoot & Johnson, 1997; Wagner, Higgins & Wallerstedt, 1997; Borg & Lasker, 1981; Cacciatore, 2009:91; Worth, 1997) has indicated that there is a growing investigation of the paternal experience of stillbirth. Intense feelings of loneliness, isolation, and pain have been described by fathers. O'Neill (1998:33) quoted the following words of a bereaved father: "I feel like I'm on a rollercoaster. It was clear my role needed to be one of strength and support…My grief was not a priority." According to Wallerstedt and Higgins, (1996:389) society's expectations that the father remain stoic and strong may affect his grief; because he responds in a manner he feels the culture demands. Fathers may return to work sooner and immerse themselves in their work. A father's grief response often is dictated by the responsibilities that he is expected to fulfil. He may be expected to support the mother physically and emotionally in her weakened state. It is usually the father who has the task of informing family and friends of the infant's death and making funeral arrangements. Funeral arrangements tend to confirm the finality of the infant's death and may facilitate the grieving process for the father (Stierman, 1987:352).

Feeley and Gottlieb (1988–89:51) and Theut, Pedersen, Zaslow, Cain and Morihisha (1989:635) found in their studies that the gender of the dead infant was significant in predicting coping mechanisms of the father. When an infant son dies, fathers are "more likely to have emotional self-control, accepting responsibility, problemsolving and replacement", than fathers whose daughters had died. When supporting the bereaved parents during crisis intervention and further counselling, it is important that the social worker explain to the parents that it is easy to understand how different styles of coping with grief can complicate a relationship. They need to be encouraged to talk about their needs to each other or to a professional.

4.2.3 Couple/parents

"*Matthew was stillborn January 17, 2006. Even though he never took a breath of air, he has eternally touched our lives, Richard and Kimberley."*

The abovementioned obituary illustrates the need for recognition of the death and that the bereavement surrounding stillbirth is a unique mourning situation, as the parents' expectations and joy at the prospect of a new life change into despair and grief (Radestad, Nordon, Steineck & Sjogren, 1996:209; Cacciatore, 2009:91). Callister

(2006:228) summarizes stillbirth as follows: “Stillbirth includes the loss of the creation of a new life; the loss of the hoped for, planned for, anticipated and loved child; the loss of dreams and hopes; and the loss of an extension of both parents. The death of a child is not part of the natural order of life, since children are not expected to predecease their parents. When one loses a parent through death, the past is lost. In contrast, when a child dies, one has lost the future. Since parenthood is a developmental task, perinatal loss represents the loss of the role of motherhood and the symbolic loss of fatherhood.”

Mahan and Schreiner (1981:70) advise that it is best to tell both parents together about the possible death of a baby while in utero and that if possible a member of the hospital staff who has a positive relationship with the parents, like a social worker, needs to be there. The news should be shared in a room in which privacy and seating are assured. It is important to stay with the family to answer questions but also to allow them time alone with each other.

Whatever a couple’s relationship is like before the loss of a child, afterward it is likely to undergo change. “Grieving is a lonely process. Sometimes even the closest of couples find that they can provide each other with only limited support when they lose a baby. As much as they might wish to, a man and woman cannot ‘make it go away’ for each other.” (Borg and Lasker, 1981:79)

The grief process after a stillbirth is normally more complicated owing to the different needs and coping mechanisms of each partner. “Incongruent grief” is used to refer to gender differences in how stillbirth is experienced by each parent, since those differences have been identified in a small but impressive body of literature (Callister, 2006:228; Robinson, 2011:572; Cacciatore, 2010:692). Mahan and Calica (1997:148) explain that one parent might wish to talk often and at length about the baby and his/her resulting grief, while the other does not want to discuss it at all. The father may view the mother as being overly emotional whereas the mother may view the father as cold and distant (Stierman, 1987:352). Parkes (1987-1988:365), Zeanah (1989:467) and Rubin (1975:143) explain that women are more vulnerable to the death of an infant than are men due to maternal prenatal attachment. The unborn child is incorporated into the mother’s entire physical and emotional self. Because the father has not embodied the fetus as has the mother, the infant is perceived as part of his intellectual rather than

emotional self.

Proper communication is vital for couples during the bereavement process. Failure to communicate can lead to serious obstacles to resolving the tensions that frequently arise from the loss of an infant. When the couple start talking about the loss of their baby, they share something unique and they might understand each other's feelings better. If underlying problems already exist in the marriage/relationship this might create the potential for especially troubling problems.

Borg and Lasker (1981:15) mentioned that parents experience a strong sense of failure. The parents have failed to accomplish what every "normal" couple presumably do with ease, what some do without effort or even without desire. The loss of self-esteem is a recurring theme with mothers. Stillbirth is complicated further when the mother or the father believes his or her whole life and future depend on the child. Parents may have difficulty letting go because this would mean giving up their only source of self-esteem. Social workers assisting the couple need to be attentive to this and help to facilitate the grief process. With the loss of the child so intricately intertwined with a loss of self and self-esteem, both parents must re-adjust or redefine their self-image (Wallerstedt and Higgins, 1996:291).

Wheeler (2001) suggested that the process of "finding meaning" for bereaved parents can be separated into two categories, namely, cognitive mastery and a search for purpose. The implication is that practical considerations, including stress-induced reactions, require action and mastery and are separate from existential questions such as "Why did this happen to my child?" During counselling and crisis support, the social worker will focus on the client's unique strengths.

Because the mother and father grieve differently, sexual problems may develop and their sexuality might be challenged. Wallerstedt and Higgins (1996:391) mentioned that the father normally wanted coitus earlier than did the mother. In some cases, parents reported that fathers desired coitus on the day of the child's funeral. The researcher has experienced this during her clinical practise. Fathers tended to view sexual activity as comforting and sharing, but often the mothers, because their grief was so intense, perceived the father to be uncaring and insensitive. This can lead to the sexual

relationship changing and inhibited sexual intimacy may occur. Partners may feel that their sexuality is challenged. Wallerstedt and Higgins (1996:391) state that it is not uncommon for sexual intimacy between bereaved parents to be compromised by disinterest, depression, or avoidance for two years after the death of child.

Borg and Lasker (1981:15) identified that parents might have the fear of not ever being able to have children and being jealous of others having children. Parents often experience their identity as being threatened because having a child is seen as part of being an adult. They may also feel disoriented, depressed and bitter. Blame and anger towards each other are two main reactions that often occur in couples. The man might think that perhaps she was not careful enough during her pregnancy and should not have worked; she blames him for urging her to make love or for arguing and upsetting her. Anger, guilt and blaming are unavoidable responses to the tragic loss.

Financial problems can be another potential source of troubles especially in cases where the baby or the mother received specialized medical care, for example resuscitation of the baby. The parents might feel they just went through such a loss and now they have trouble paying the bills.

Fortunately many bereaved parents grow closer and develop an even stronger relationship. Bereaved parents often experience an intense level of personal growth and maturity that allows them to develop more effective communication skills, which strengthen their relationship. Although it is clear that couples go through a tough time during and after a stillbirth, Borg and Lasker (1981:85) mentioned the following: “Although many couples experience tensions, these usually fade eventually. The positive effects on their relationship stand out most sharply for some people. Often they gain increased respect and admiration for each other. They realize that at least they have each other.”

4.2.4 Single women or teenage mothers

Literature (Borg & Lasker, 1981:89) indicates that the younger the girl, the higher the risk of danger to the baby as well as for the mother. Adolescents have a four to five times higher rate of serious complications than do women in their twenties owing to a greater likelihood of poor prenatal care and nutrition, venereal disease, and drug

problems. These factors contribute to prematurity and low birth weight. Thus the stillbirth rate is high for adolescents.

Borg and Lasker (1981:89) stated that adolescent girls may consciously or unconsciously want to become pregnant as a way of resolving emotional and family tensions. Many times a young girl who feels unloved and unwanted may wish for a baby so that she will have someone to love her and someone to rid her of isolation. But if after all of this, the pregnancy ends in tragedy, her isolation usually becomes even more intense. Since no one seems to understand her loss, she is more alone than ever – her failure is complete.

When a pregnancy ends in tragedy, the love and support of others are especially needed. But, if the teenager is already alienated from her family and if the boyfriend is uncaring, she has no one to turn to. She may suffer from severe guilt feelings if it was an unplanned pregnancy and she had not wanted it at the beginning. The guilt may be particularly acute if she considered having an abortion or tried to get one but was unable to.

“Adolescence is a time of separation from parents, which often creates a great sense of loss. The pregnancy may have been a way to compensate, and if the baby dies the emptiness that results can lead to severe depression” (Borg & Lasker, 1981:90).

Adolescents may become extremely worried about the failure of their bodies to function properly and may feel a need to become pregnant again to prove they are normal. If they do become pregnant right away without working through the grief for the first baby, it will be difficult for them to complete the mourning process and reach a state of resolution.

Some single pregnant mothers need to organise everything alone during the pregnancy and do not have anybody to lean on. They are proving there independence and responsibility, but when tragedy occurs, their confidence is often shattered.

4.2.5 Children

Every member of the family, including the children, is affected by a birth tragedy. Birth and death together? It is confusing and frightening enough for adults, but how are young children to understand it? For them the baby never really existed. Too often,

children's feelings about these issues are ignored or misunderstood. When parents are struggling to deal with their own feelings, they find it even harder to respond to the emotional needs of their other children. For some parents, the dual task of trying to make sense of what has happened to them and also helping their other children may be so overwhelming that they decide to tackle only one aspect. They either ignore the children or send them to stay with others until they themselves feel better, or they attend to the children's needs so completely that their own feelings are repressed. This is why involving children and explaining to them what is happening is crucial for the parents as well as for the children.

Most parents struggle with questions like "what, when and how to tell the children". Siblings experiencing grief at the death of a younger sibling have also been termed "forgotten mourners" (Callister, 2006:229). Siblings may feel left out, neglected, guilty and sad. Mahan and Calica (1997:148) suggest that the perinatal social worker needs to give some guidance and encourage parents to be honest but simple in discussions with their children. The amount and specificity of information shared with children must be appropriate to the developmental stage of the child. Many parents will want to incorporate their personal religious beliefs into the explanations that are offered children (e.g., the baby has gone to heaven). Quite often parents make mistakes as illustrated below.

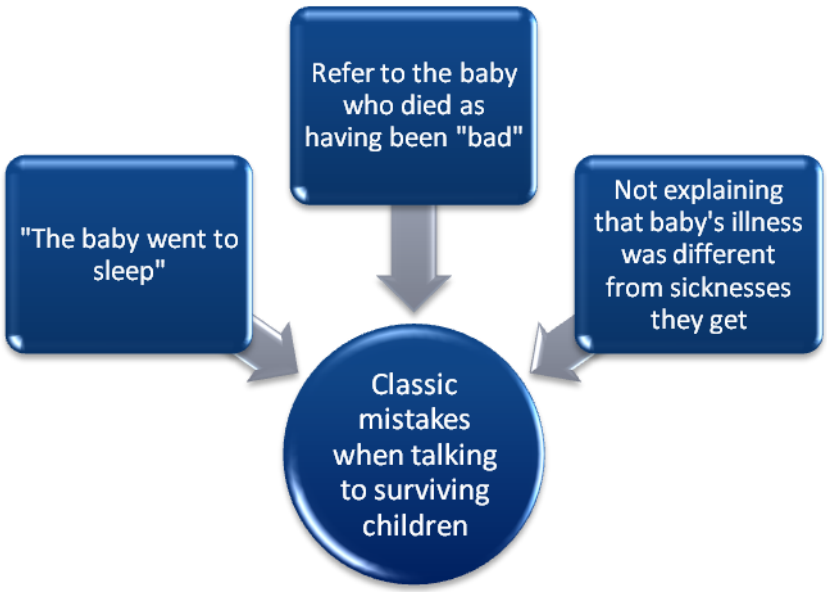

Figure 4.2: Classic mistakes parents make when talking to surviving children (Figure designed from data reported in Mahan& Calica, 1997:149)

As seen in the figure above parents sometimes tell stories to children regarding the baby's death in order to prevent them from hurting. By wanting to protect their child parents will often "soften" the death by saying that the person is asleep or that the baby was sick and died, without specifying how seriously sick the baby was. This has the opposite effect in the long run because siblings cannot find closure on what has happened. It is important to explain to children that the baby's illness was unique and different from normal childhood illnesses they get, to prevent children from developing fears that they, too, might die. The child can become petrified of sleep and cannot distinguish a life-threatening disorder from ordinary disease. This leads to tremendous anxiety when minor illness occurs. Some parents underestimate their child's awareness of this family crisis. Various authors (Wolfenstein, 1966; McConville, 1974; Borg & Lasker, 1981) agree that the psychosocial impact of the stillbirth on children/siblings depends on the developmental stage of the child. The following table, a combination of findings by various authors, illustrates the different developmental age and the cognitive and affective impact on the child.

Table 4.1: Impact of stillbirth on children/siblings according to their developmental stage

Impact of death on a child depending on her/his developmental stage	
Age 0 - 4 years	Death has little or no meaning up until the age of four. Most children under the age of five are unlikely to comprehend the finality of death; they are apt to think that it is like sleep. Very young children will fear that they will not be taken care of and that their routine will be disturbed.
Age 5 - 7 years	Death is a reversible process. "When will Daddy come back from his trip?" Younger children displayed relatively more egocentricity, aggression, denial, preoccupation with the dead and restitutive dreams. Children aged five to nine usually understand when a person dies, but they do not think of death as something that happens to everyone. A very common reaction in somewhat older children is a change in behaviour, such as increased aggressiveness, playing dead, or breaking toys.
Age 8 - 9 years	After seven, death is perceived as irreversible and caused by "bad things". Schoolage children have thought about death a great deal and, although they may not mention it, it is a part of their fantasies and play.
Age 9 - 13 years	Around age nine, death is accepted as a biological event. Older children display more concern for others. However, it is possible that combined cognitive and emotional aspects of death are not developmentally apprehended until adolescence. The ages at which new understanding develops are far from being fixed and depends to some extent on the particular child's experience with death.

(Table compiled from data reported in Wolfenstein, 1966; McConville, 1974; Borg & Lasker, 1981)

During pregnancy and birth when everything goes well, children experience feelings like confusion about birth and hospitals, the shift of everyone else's attention to a new child and separation for their mothers. These are "normal" problems. When the new baby dies there are many additional problems those children may experience:

- Confusion about what happened
- The guilt of believing they might have caused the baby's death
- Isolation from their grieving parents

- Fears for their own lives and security
- Disappointment on not having the brother/sister they wanted

Children, as their parents do, look to their own thoughts and behaviour to find a cause, feeling guilty even though there is no way they could have been responsible. According to Borg and Lasker (1981:98) many children view the world in a very self-centred way, so they naturally see everything as somehow related to themselves. They feel alternately extremely powerful and totally helpless, and it is the feeling of powerfulness that allows and encourages the child to feel responsible.

Young children might feel guilty because during the pregnancy they unconsciously wished that the baby would not arrive. Every young child watches Mother's growing abdomen with ambivalence. On one hand the new baby will be a playmate but the baby will also be the centre of attention, a rival for the parents' affection and time.

Children also remember bumping into Mummy's tummy, demanding to be picked up or making too much noise. This also leads to guilt and children cannot yet make the distinctions between rational or irrational thought. Along with guilt, children can also blame their parents for what has happened. "Mother and Father had promised a sister/brother and nothing happened."

Borg and Lasker, (1981:98) mentioned that fear of abandonment by the mother appears to be a predominant feeling in children less than five years old when confronted by death. "Scared, remorseful and confused by the unexpected tragedy, a child can easily wonder if he or she is still loved." In their minds, the parents must have been dissatisfied with the children they already have. It is essential during this time that parents give the child the necessary reassurance, parental support and love.

Some children will hide their feelings and emotions. When this happens, professionals advise parents to raise the subject and to reassure the child that they are there for their child and that the death of the baby doesn't mean that mother and father will also die. Literature (Cacciatore, 2010:142; Brier, 2008:462) suggests that it is important to remind children how normal it is for them to wonder whether they are responsible for what happened, but that in no way are they to blame. The best grieving parents can be expected to do is present the facts simply and clearly, taking into account the child's

age and experience. It is important to know that children cannot be deceived easily nor can they be protected from tragedy for ever. If the parents are not honest about this sad event, the children might wonder if the parents are honest about other matters.

4.2.6 Grandparents, extended family and friends

As the baby grows, a personality and characteristics also develop in the minds of the parents and their friends. They speculate at length about the sex and seize upon a variety of signs for evidence. Tests to detect possible birth defects actually make the sex known. Parents identify limbs – a foot pushing out here, a head felt there.

This creation of a person, with an identity and life of his or her own, is a typical part of pregnancy and is encouraged by society. The expectant parents are being treated like members of a special club. But suddenly, instead of being members of the club, they stand outside it, pitied and isolated (Borg & Lasker, 1981:14).

Despite the progress and the growing awareness surrounding stillbirth and neonatal death, many people still underestimate the impact of the loss of a baby (Mahan & Calica, 1997:147). (Also see Stringham *et al.*, 1982:326; Brownlee & Oikonen, 2004:519.) Callister (2006:228) mentions that as a result, the reactions and remarks that parents receive to minimize the loss like “you can always have another baby”, “at least you didn’t get to know her”, and “she probably wouldn’t be normal”, may be very insensitive. Some people avoid the situation by saying nothing. Sometimes family members and friends do not respond because they feel they are being helpful by doing nothing. Perhaps they are told by someone, or they tell others, to refrain from calling the bereaved parents so as not to upset them. They avoid the mother or grow impatient with her continued sadness (Stringham *et al*., 1982). But the parents may wonder why no one seems to care. No appropriate language seems fitting to communicate this pain. For parents of a stillborn child, for example, to speak about “the day our baby died” is terribly difficult when it was also “the day our baby was born”.

Borg and Lasker (1981) explained that sometimes in mourning situations, the bereaved often help their friends who are uncomfortable by directing the conversation. Parents who are mourning for their infant receive a strong message from society that their loss is not significant. During crisis-support sessions the social worker needs to prepare the parents for this reaction from others.

Grandparents on the other hand also experience pain as they feel double pain. Pain for seeing the hurt of their own children and pain for not being able to become a grandparent and holding a grandchild. One grandmother expressed it as follows: *"I sit with her and I cry with her. She cries for her daughter and I cry for mine*" (Callister, 2006:229).

Friends and relatives who listen and react with understanding, who console and distract, are cherished by bereaved parents. Existing relationships may be strengthened when there is a deepened appreciation of others' affection and helpfulness. New friendships may develop with people who were not previously close but who provided a special word or action at the right moment and those that continue with their support.

4.3 PERSPECTIVES ON LOSS

4.3.1 Social work perspectives on loss

Brownlee and Oikonen, (2004:518) and Mahan and Calica, (1997) found that crisis support to families following a stillbirth has typically been provided by medical *professionals whose primary concern involves the medical and practical* management of mother and baby. However, social workers are in a unique and important position to intervene in the event of a stillbirth, given their training and expertise in attending to the emotional needs of individuals and families and assessing the crisis in relation to the family's social environment.

Social work requires an integrative worldview. Cacciatore (2009:93) states that stillbirth is an emotion-based, social problem; there are rational imperatives for social work's response. Indeed there is an obligation for a larger shift in the macro culture; a shift that will likely sway attitudes, beliefs, and values about women experiencing stillbirth. This implies that the shift needs to begin with subtle changes to deconstruct the way that stillbirth is perceived and to allow women who have undergone stillbirth to construct their own realities about their losses. This corresponds with social work values such as advocacy, social change and self-determination. To this effect, the recommendation by Cacciatore (2009:93) is significant: "Social workers can put stillbirth on their agenda, and break the silence, acknowledging these women as mothers and providing dignity and recognition for their loved-and-longed-for babies."

Frøen (2011:1354) explained that under the most extreme conditions, in which a family cannot meet basic needs for food and shelter, the time and resources to grieve might not be available. Poverty can also contribute to highly complex situations for women having a stillbirth in a setting of domestic violence, unwanted pregnancy, and induced abortions. But stigma seems to be a much more prevalent barrier to grief than poverty. Social workers can intervene in these problems mentioned above and if the means are there and the silence of stillbirth can be broken, bereaved parents will be able to mourn publicly.

4.3.2 Psychological perspective

Badenhorst and Hughes (2007:251) mentioned that from a psychological perspective it is important that health professionals not pathologize a normal response to bereavement and treat it as though it were an illness. Bereavement is part of life, and the vast majority of people recover with time, not without continuing sadness, but able to live happy and productive lives.

Badenhorst and Hughes (2007:251) also mentioned that the severity of disabling symptoms diminishes over the first year, but are normal for up to 1 to 2 years, with about 20% of women having symptoms at case level a year after the loss. More intense or prolonged grief has been associated with poor levels of social support, history of mental health problems, and more “neurotic” pre-loss personality. In addition to depressed feelings, 20% of mothers were found to have posttraumatic stress disorder (PTSD) in the pregnancy subsequent to stillbirth, and symptoms were enduring.

Psychologists consider pregnancy – especially the first - an important life crisis, a turning point in the individual’s development as significant as puberty. Ordinarily this crisis is resolved by the birth of a healthy child. When this does not happen, the crisis deepens. Parents may feel they have suffered a major setback in their lives. (Borg & Lasker, 1981:7)

Organized support groups can put parents in touch with one another. Professionals such as physicians, social workers and clergy are being instrumental in organizing

these groups, where individuals meet with others who understand their troubles from personal experience. Often it is only by sharing their emotions with those in the same situation that they can believe their own reactions are normal, that they are not going crazy. These support groups are usually most helpful for parents going through the normal grief process. They do not offer intensive therapy but rather provide a setting where feelings can be expressed and will be understood. Groups may differ, but in all groups the atmosphere is one of acceptance, of allowing people to speak or simply to observe as they wish. Many families/parents find that they are not yet ready to become involved, they are reluctant to expose their open wounds so quickly to others. Fathers especially are less likely to participate in groups, perhaps because many of them prefer to keep their feelings to themselves. For some parents this is an important part of the recovery process. It is one way in which they can begin to overcome the terrible isolation of their personal grief.

4.3.3 Theological perspective

The area of stillbirth seems to have been neglected in pastoral theological literature before the 1970s and the beginning of the 1980s (Wretmark, 1993:45). If rites of passage are seen as appropriate in pastoral care when it concerns birth and death, there is a life situation when both occur at the same time, namely when a child is born dead. This is a pastoral challenge in itself.

The funeral is, in some traditions or cultures, a rite of purification to ensure the deceased's return to God. (Compare Chichester, 2005 and Clements, Vigil & Manno, 2003.) Some chaplains will conduct baptism at the request by the parents, whilst others and most probably most of them would refuse. Those who refuse would probably do so referring to church doctrine that the sacraments are for the living. Those who would baptize a stillborn child would probably do so because they think that pastoral considerations override church doctrine in a crisis situation, even if they fundamentally agree that baptism is for the living and not for the dead. If a pastoral caregiver were to deny the parental request to baptize a stillborn infant, it may be tantamount to a denial of the life and significance of their child (Cacciatore, 2010:691). Reasons parents might ask for baptism, are the following:

- Feel need for ritual to mark the event and that baptism is the only rite they know.
- Desire to place the child in God's hands.
- Naming and the baptism represent a way of doing the utmost in an extreme situation of loss and grief, as well as a bestowing of personhood (Wretmark:1993:36)

Some religious groups do not forbid nor require funerals for infants, but they leave the choice to the parents. Participants in this study are mainly from Muslim and Christian religions and are divided into mainly two different ethnic groups: black and coloured South African.

Frøen (2011:37) found that in West Africa, the traditional view is that the spirits of a dead infant will seek a vulnerable new pregnancy. Therefore the tradition in western Ghana to not have a burial of the stillborn baby is seen as a preventative measure to discourage the stillborn baby from coming back to the same mother. In sub-Saharan Africa, for example, respondents to our survey reported that stillbirth is as frequently attributed to the mother's own sins and fault, bad luck, or witchcraft as to medical disorders.

When death occurrs in the Muslim culture, naming is essential, because in Paradise the baby and mother will eventually be bound together. The deceased Muslim stillborn baby should be bathed and wrapped in a seamless white sheet and buried within 24 hours. It is usual, on hearing of a death of a fellow Muslim, to recite the following brief prayer: *Innaa lillayhi Wa Innaa llayhi Raaji'oon* (verily we belong to Allah and will return to Allah). Islam does not permit postmortems if they are not required by the law. If not required by law, a doctor will possibly ask for an autopsy for research purposes. This is also not allowed. If the death was unexpected, an autopsy will be done whether or not it is against the rules of Islam. The preparation of a Muslim's body for burial is very important in their religion and can have an impact on the bereaved parents' grieving process. The parents are still in shock but must immediately bury their baby. The social worker needs to address this during crisis intervention.

4.4 CONCLUSION

In this chapter an in-depth review was given of the current understanding of psychosocial implications of stillbirth for a mother and her family by exploring the notion that grief, loss, mourning and bereavement are terms closely related to one another. This afforded the reader a foundation to better identify with the next section the chapter focused on which was the psychological implications of a stillbirth on the mother, father, couple, single mother/teenager, children and grandparents/family. The chapter concluded with a short overview from a social work, psychological and theological perspective.

According to the above discussion it is clear that any type of loss affects a person and that such a person will go through a grief process. Grief is a very individualistic process and no two people grieve the same. The review indicated clearly that stillbirth is perceived as a “silent grief”. It is seen as disenfranchised because people don’t seem to understand that bereaved parents can grieve so intensely about a baby that never even breathed. Society also expects mothers to not think about it and continue living as before. The development of a lifelong grief response filled with comfort and creativity, coupled with sorrow, may be more realistic and fulfilling than the myth that parents should just “get over it”. Certainly, the effects of this type of tragedy appear to be timeless in nature, a lifelong experience of grieving and re-grieving, understanding and re-understanding, as new associated meanings of the baby’s death emerge and evolve.

In the next chapter support for mothers who have experienced a stillbirth will be explored in terms of the crisis intervention approach in social work. A theoretical discussion will be conducted and will be applied to the crisis of stillbirth.

CHAPTER 5

THE USE OF THE CRISIS INTERVENTION APPROACH IN SOCIAL WORK TO ASSIST PATIENTS WHO HAVE EXPERIENCED A STILLBIRTH

5.1 INTRODUCTION

In the previous chapter an in-depth look at death, grief, bereavement, mourning and the grieving process was presented. The stages of grief were discussed as well as grief models. Finally the focus fell on the specific grief of a mother and her family who had lost a baby to stillbirth. There is little doubt that the stresses and uncertainties of life in today's highly complex and technical world are crisis provoking. Therefore an understanding of the concepts of stress, coping and crisis is an important part of the knowledge base of social work practice.

Gilloland and James (1993:v) believe that practically all counseling is initiated as crisis intervention. People tend either to avoid presenting their problems to a helper until those problems have grown to crisis proportions, or allow them to become ensconced in situational dilemmas that wind up in unforeseen crises. With its broad range of theoretical frameworks in social work, the crisis intervention model is frequently used. In this chapter support for mothers who have experienced a stillbirth will be explored in terms of the crisis intervention approach in social work. A discussion of models will be conducted and will be explained by applying it to the crisis of stillbirth. This chapter also aims to address the research aim of developing pilot data about potential mechanisms for future in-depth analysis, dealing with how social work intervention from a crisis intervention approach can be used to assist mothers who have experienced a stillbirth and to assist the family to adjust constructively.

5.2 ORIGINS OF CRISIS INTERVENTION

As far back as 400 B.C., physicians have stressed the significance of a crisis as a hazardous life event. Hippocrates himself defined a crisis as a sudden state that gravely endangers life (Roberts, 2005:15). The movement to help people in crisis began in 1906 with the establishment of the first suicide prevention centre, the National Save-a-

Life League in New York City. But it was only in the 1940s that crisis intervention theory was formally elaborated on, primarily by Erich Lindemann and Gerald Caplan.

O'Hagan (1991:139) mentioned that these American psychiatrists were the principal contributors to the emergence of crisis intervention as a new, identifiable professional intervention approach. The crisis pioneers, such as Caplan (1964); Langsley, Pittman, Machotka & Flomenhaft (1968) and Pittman (1966) became aware of the benefits of brief, intensive, and action orientated therapy in dealing with crises, as opposed to the then well-established long-term psychotherapy programmes.

There are however, some aspects of this crisis heritage which have limited its relevance to social work practice. The subject matter at the centre of the pioneers' study was the mental illness of individual psychiatric patients – more often than not American, middle class, articulate, professional and managerial people. The location of study and intervention was often the psychiatric ward or clinic. Such a clientele and locations are far removed from the vast majority of social work clients in Britain living in conditions of poverty, deprivation and family fragmentation, and from generic social workers working in understaffed area offices, responsible for far too many cases. In these living conditions and environments, the dominant feature of the crises which social workers encounter is conflict (Gilliland & James, 1993:10). In South Africa today the same situation applies where the crisis can come in different forms, for example violence against children/women, rape, suicide, hijacking, assault, murder and death. This implies that crisis can apply to bereaved persons as well, as will be explained later.

5.3 DEFINITIONS

5.3.1 Crisis

Gerald Caplan depicts a crisis as being the following:

"A crisis is an upset of a steady state in which the individual encounters an obstacle (usually an obstacle to significant life goals) that cannot be overcome through traditional problem solving activities. For each individual, a reasonably constant balance or steady state exists between affective and cognitive experience. When this homeostatic balance or stability in psychological functioning is threatened by physiological, psychological, or social forces, the individual engages in problem-solving methods designed to restore

the balance. However, in a crisis situation, the person in distress faces a problem that seems to have no solution. Thus homeostatic balance is disrupted, or an upset of a steady state ensues" (Caplan, 1961:15).

Brammer (1985:94) reported "*a crisis as a state of disorganization in which people face frustration of important life goals or profound disruption of their life cycles and methods of coping with stressors. The term crisis refers usually to a person's feelings of fear, shock, and distress about the disruption, not the disruption itself*."

France (1990:4) identified *"a crisis as being a brief period of transition during which the person has the potential for heightened maturity and growth or for deterioration and greater vulnerability to future stress*".

There are many more definitions of *crisis.* The three presented above are believed to collectively represent and define *crisis* and to provide a foundation for further discussions. It can be interpreted that the collective core elements of a crisis are "balance is disrupted", "state of disorganization" and "opportunity for growth or deterioration".

5.3.2 Crisis intervention

The *crisis intervention* model is used to address the special needs and concerns of a client in an acute, psychological crisis. Crisis intervention can be defined as follows: "It is a process for actively influencing psychosocial functioning during a period of disequilibrium in order to alleviate the immediate impact of disruptive stressful events and to help mobilize the psychological capabilities and social resources of persons directly affected by the crisis. Interventive efforts have two principal aims: (1) to cushion the stressful event by immediate or emergency emotional and environmental first aid, and (2) to strengthen the person in his or her coping through immediate therapeutic clarification and guidance during the crisis period" (Sheafor, *et.al*. (1994:69).

Parad and Caplan (1960) and Sheafor *et al*. (1994:69) are of the opinion that *crisis intervention* refers to a therapist entering into the life situation of an individual or family to alleviate the impact of a crisis, and help mobilize the resources of those directly affected. They urge timely intervention to individuals so that a "relatively minor force, acting for a relatively short time, can switch the balance to one side or another, to the

side of mental health or the side of mental ill-health". Kfir (1989:4) holds that crisis intervention focuses on the present alone. It relates primarily to the person in the situation and not on the personality or personal history. The intervention is direct and the interventionist controls the session. The goals of the intervention must be immediate, concrete and feasible. These three authors' opinions correlate as all of them are focusing on helping the persons in crisis regain stability and using their own strength in doing this through a minimum number of contacts.

5.4 CHARACTERISTICS OF A CRISIS

It is important to differentiate between a stressful period versus a crisis. Innumerable situations have the potential to provoke a crisis. Most people experience what it is like to be in crisis at least once in their lives. Kfir (1989:4) explains that a "stressful period" poses a challenge, an opportunity to grow, to develop more of our potential. We accomplish more, function on less sleep, work efficiently under pressure, and survive without support. We often accomplish things we never believed we could do. In comparison with this, crisis situations are totally new, unpredictable, psychologically paralyzing and posing a shock to the emotional system.

5.4.1 Possible crisis reactions

People can react in any one of three ways to a crisis, as illustrated below:

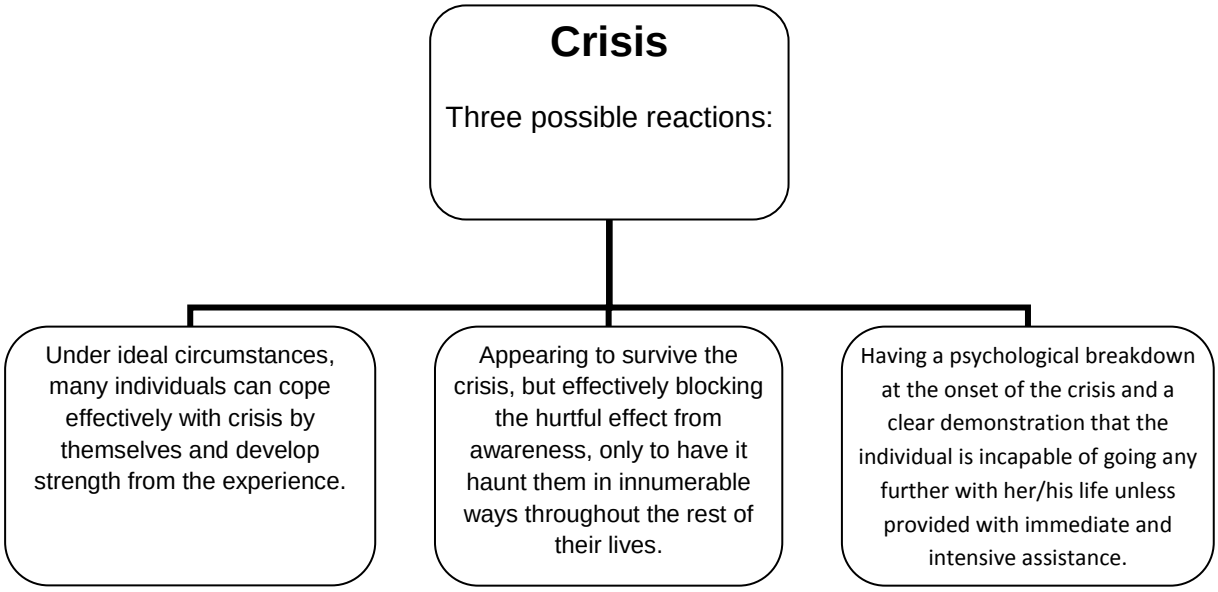

Figure 5.1: Crisis: Three possible reactions (Adapted from Gilliland & James, 1993:4)

According to figure 5.1 individuals will under ideal circumstances be able to cope effectively with a crisis by themselves and they will develop strength and be more compassionate after the crisis. Compton and Galaway (1994:141) agree with Gilliland and James (1993) by reporting that every individual has generalized coping resources, but the ability or inability to use these resources must be assessed. The second possible reaction, as shown in figure 5.1, is that of appearing to survive the crisis, but effectively blocking out any feelings or thoughts from the event, but with these thoughts haunting them throughout their lives on different levels. This is sometimes a common reaction after a stillbirth, due to the community and family not acknowledging the loss and not providing the bereaved mother with a chance to start with her grief process. She feels obliged to hide her feelings from the people around her and so protects herself from unwanted remarks, for example, "*you are still young, you can have another child*".

Figure 5.1 records the third reaction as having a psychological breakdown at the onset of the crisis. And the individual then clearly demonstrates an incapability of going any further with her/his live unless provided with immediate and intensive assistance. A bereaved mother, who had just lost her baby during birth without any warning signs, will

be very vulnerable to suffering a psychological breakdown due to the trauma of the loss.

5.4.2 Characteristics of a crisis

On the basis of this background regarding the possible reactions to a crisis, the following section will attempt to examine the different opinions of various authors on the characteristics of a crisis. Below, table 5.1 illustrates a comparison between the conceptualisation of Gilliland and James (1993:4) and France (1990:4-5).

Table 5.1: Characteristics of a crisis: A comparison

CHARACTERISTICS OF A CRISIS	
Gilliland and James (1993:4)	**France (1990:4-5)**
(i) Presence of both danger and opportunity	(i)The resolution can be adaptive or maladaptive
(ii) Universality and idiosyncrasy	(ii) Crises are normal and universal
(ii) Complicated symptomology	(iii) Precipated by specific identifiable events
	(iv) Crises are personal
	(v) Crises are resolved in brief period of time
(iv) Necessity of choice	
(v) Seeds of growth and change	
(vi) The absence of panaceas or quick fixes	

Table 5.1 illustrates the opinion of both Gilliland and James (1993.4) and France (1990:4) that a crisis can present both danger and opportunity to the individual. A crisis can be dangerous because it can be overwhelming and result in maladaptive behavioral patterns such as psychological problems. The authors argue that it can give the individual the opportunity to learn new problemsolving skills, which will ensure positive adaptation to the crisis.

France (1990:4-5) used very simple terminology describing a crisis as being normal and universal. Gilliland and James (1993:4) shared this perception but added the word "idiosyncrasy" as well to illustrate that not only is no individual safeguarded against a crisis but no two individuals will react the same. What one person may successfully overcome, another may not. France (1990:4-5) called this crisis "personal". This characteristic of a crisis is especially important when working with bereaved mothers after a stillbirth. The context of the crisis needs to be evaluated, i.e., was it this couple's first baby after several infertility treatment or have this couple already had three successful pregnancies. Idiosyncrasy may play an important role and these two couples may handle their crisis completely differently. The social worker rendering crisis intervention needs to carefully assess this situation.

Table 5.1 also indicates that Gilliland and James (1993:4) are of the opinion that a crisis has complicated symptomology. They believe that a crisis is complex and difficult and when an event reaches crisis point, there may be so many compounding probes that the social worker has to intervene directly in a variety of areas. France (1990:5) also mentions that a crisis is precipated by specific identifiable events which also need recognition by the crisis intervention worker.

On the next three points, Gilliland and James (1993:4) differ slightly from France, because they provide more details. Gilliland and James (1993:5) explain that any crisis situation contains seeds of growth and change. In the disequilibrium that accompanies crisis, anxiety is always present, and the discomfort of anxiety provides an impetus for change (Janosik, 1984:39). On the second last point, Gilliland and James (1993:4) mention that people in crisis are generally amenable to help through a variety of forms of intervention, some of which are brief/short therapy. For problems of long duration, quick fixes are rarely available. France (1990:5) does agree with the brief/short therapy and mentions that some crises are resolved in a brief period of time. They are too intense to be long-standing or chronic. When the crisis is not resolved, the crisis will become a disease reservoir that will be transformed into a chronic and long-term state.

The comparison that was made in table 5.1 and the discussion which followed clearly indicate that a crisis has definite characteristics which aid the social worker to intervene with the individual. The characteristics identified by Gilliland and James (1993:4) are

more comprehensive than those by France (1990:5) and these will be highlighted in the discussion in the rest of this chapter.

5.5 CRISIS INTERVENTION MODELS AND STRATEGIES

Stillbirth is a crisis situation and special focus must be given to the crisis-intervention theory, suggesting that the individual needs to have the capability to use generalized coping mechanisms in a way that will resolve the crisis situation. Several systematic practice models and techniques have been developed for crisis intervention work. It is important that the crisis interventionist uses the intervention model which he/she feels comfortable with and skilled enough to implement. Competence when engaging in crisis intervention needs to be highlighted, as this is crucial for progress during the crisis. The first model which will be discussed is Roberts's (2005) Seven-Stage Crisis Intervention Model.

5.5.1 Roberts's Seven-Stage Crisis Intervention Model

It is important to gauge the stages and completeness of the intervention to be able to evaluate whether crisis intervention was successful. According to Roberts (2005:20) his seven-stage model is a guide to the interventionist and not a rigid process; stages may overlap.

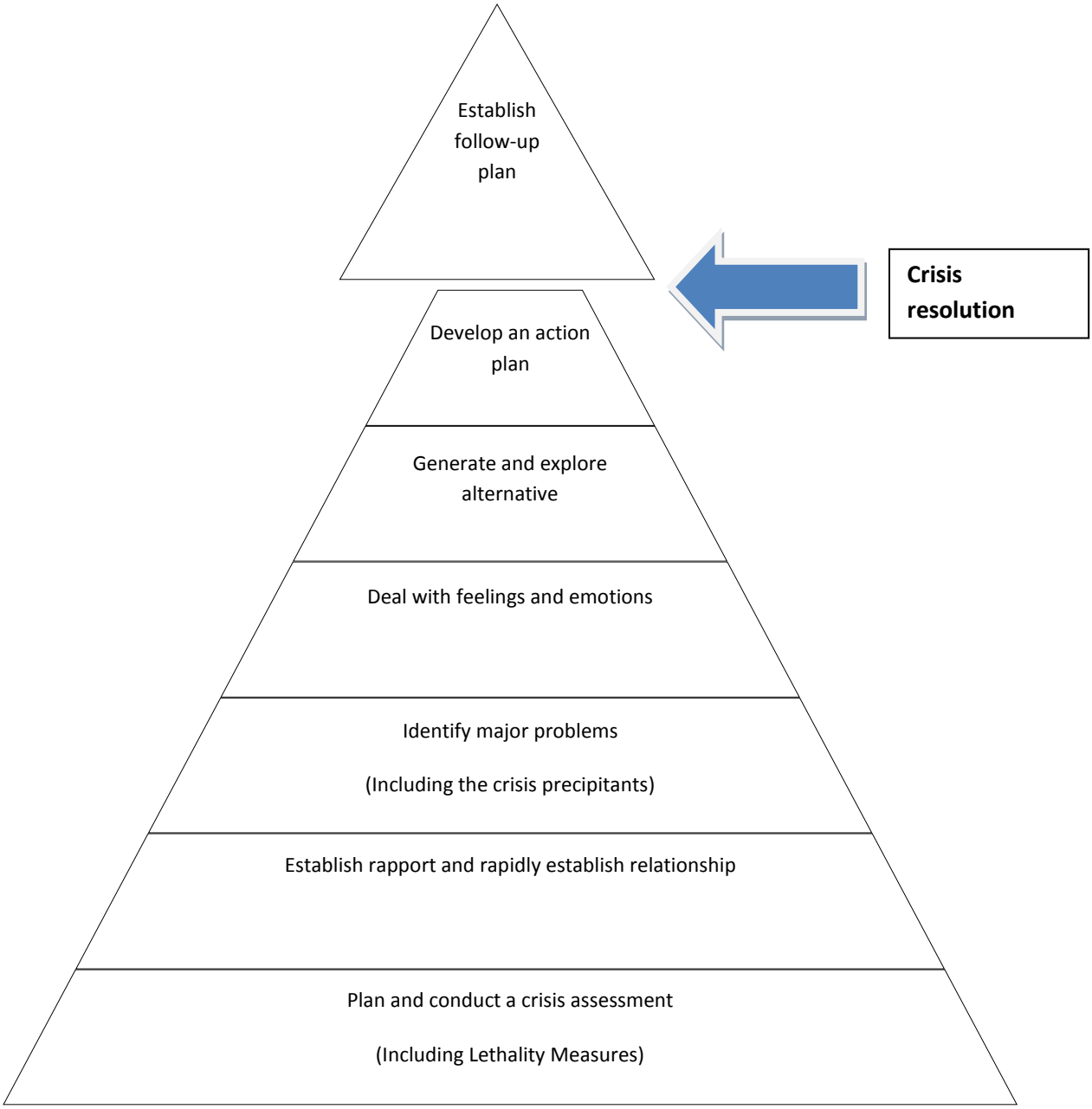

Figure 5.2: Roberts's Seven–Stage Crisis Intervention Model (Adapted from Roberts, 2005:20)

5.5.1.1 Plan and conduct a crisis assessment

According to Roberts (2005:20), basic information needs to be obtained in order to

determine whether the person in crisis is safe or needs any medical attention. Any possible suicidal thoughts or previous attempts at suicide need to be evaluated to ensure that the client is safe and open to any intervention. This is important when working with bereaved mothers as well. If the mother has a previous history of major depression or suicidal thoughts, this needs to be taken into consideration when starting with crisis intervention. A stillbirth is such a sudden, overwhelming tragedy that it may trigger previous depression or suicidal ideations.

5.5.1.2 Establish rapport and rapidly establish a relationship

During initial contact it is important to establish rapport by conveying genuine *respect* for and *acceptance* of the client. The social worker needs to let the client feel that this is the place that she/he can get help. The social worker furthermore needs to indicate that he/she is trustworthy and willing to listen.

5.5.1.3 Examine the dimensions of the problem in order to define it

Roberts (2005:23) suggests that it is useful to identify the following: (i) the precipitating event that led the client to seek help; (ii) previous coping methods; and (iii) danger or lethality. The use of open-ended questions as a technique of counselling can be very effectively applied here. The focus must be on *now* and *how*, rather than *then* and *why.* A good example would be: “What situation or event led you to seek help at this time?”

5.5.1.4 Encourage an exploration of feelings and emotions

This is particularly important because some therapists overlook it in their attempt to make a rapid assessment and find the precipitating event. According to Roberts (2005:23) and Mahan and Calica (1997: 144) it is extremely therapeutic for a client to express feelings and emotions in an accepting, supportive, private and nonjudgmental setting. The primary technique for identifying a client’s feelings and emotions is through *active listening.* This involves the crisis worker/social worker listening in an empathic and supportive way to both the client’s reflection of what has happened and how the client feels about the crisis event. Redman (2003:731) is also of the opinion that support received by professionals is critical in the long-term adjustment of childbearing families coping with a stillbirth. Listening could prove to be more important that talking, and being there may be more important than doing. Hammersley and Drinkwater’s

(1997:584) views about stillbirth correlate with this viewpoint, that when the crisis worker listens to the bereaved mother, she feels that her feelings are acknowledged and that she is allowed to grieve about her stillbirth baby.

5.5.1.5 Explore and assess past coping attempts

As explained by Caplan (1964:39) one of the major focus points of crisis intervention involves identifying and modifying the client's coping behaviours at both the preconscious and the conscious level. It is useful to ask the client how certain situations are handled, such as feelings of intense anger, loss of a loved one, disappointment or failure. Roberts (2005:23) suggests that *solution-based therapy* should be integrated into crisis intervention at this stage. This method emphasizes working with client strengths. It is important to help the client to generate and explore alternatives and previously untried coping mechanisms or partial solutions. If possible, this involves collaboration between the client and the social worker to generate alternatives. Most clients have some notion of what should be done to cope with the crisis situation, but they may well need assistance from the social worker in order to define and conceptualize more adaptive coping responses. A good example of this is the social worker working with the bereaved mother and helping her with ways in which to cope with her own feelings and how to react towards her other children and partner/husband. The social worker needs to identify what positive coping mechanisms she is already using and help her to expand on this.

5.5.1.6 Restore cognitive functioning through implementation of an action plan

Roberts (2005:24) explains that the crisis worker using a *cognitive approach* helps the client focus on why a specific event leads to a crisis state and what the client can do to effectively master the experience. When applied to stillbirth, the loss of the baby may leave a mother/couple to feel that their expectations have been violated. They were looking forward to become parents and have been dreaming of this for some time. In order to help the client understand why she is in a crisis and how to handle it from a cognitive approach, the worker needs to explain the three phases of cognitive mastery as mentioned below.

Cognitive mastery involves three phases:

- The client needs to obtain a realistic understanding of what happened, why it happened, who was involved and the final outcome.
- The client needs to understand the event's specific meaning: how it conflicts with his or her expectations, life goals and belief system.
- The final part of cognitive mastery involves restructuring, rebuilding, or replacing irrational beliefs and erroneous cognitions with rational beliefs and new cognitions.

When these phases are to be put in practice after a stillbirth, the first phase normally takes place when the social worker listens to the bereaved mother/couple telling their story of what exactly happened, who was involved (family and medical personnel) and how they were treated. This is essential so that the couple can understand the full implications of the stillbirth. Next, the conversation must focus on the impact of the stillbirth and what it means for the couple not being able to reach a certain life goal of parenthood, for example. The skilled social worker should take note of any cognitive errors or distortions, like catastrophizing and irrational beliefs. Then the third phase needs to be implemented and the social worker needs to help the bereaved couple to restore rational beliefs and new cognitions. This correlates with the grief process where acceptance occurs.

5.5.1.7 Follow-up

The client should be told that if at any time she or he needs to come back for another session, the social worker will be available. It often happens that the clients cancel their second or third appointment before the crisis has been resolved. Clients often go into crisis at the anniversary of the trauma and then need help again.

5.5.2 Crisis-in-Context Theory Model

The Crisis-in-Context Theory model (CCT) is grounded in an ecological model and provides a theoretical underpinning for understanding the impact of a crisis on individuals and organizations. Gilliland and James (2005) and Stuhlmiller and Dunning (2000) state that the concept of an ecological perspective is based on the idea that crises do not happen in a vacuum but are shaped by the cultural and social contexts in which they occur. Recognizing that a crisis occurs in a context that includes individuals

and the systems in which the individuals reside is essential in expanding the field of crisis intervention.

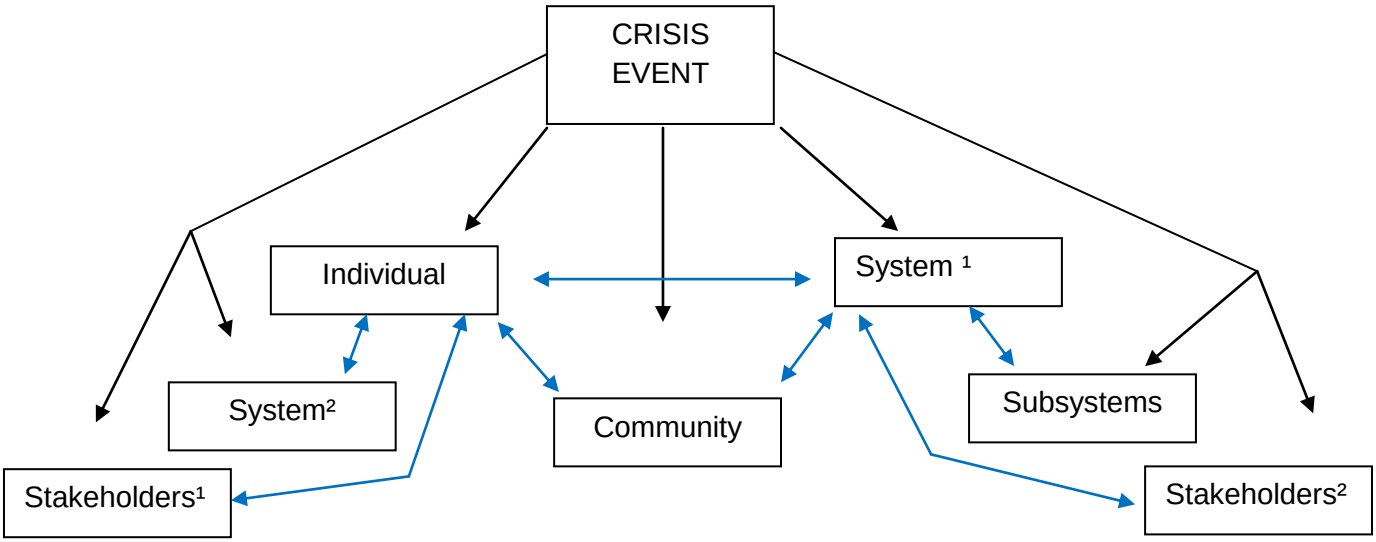

Figure 5.3: Layers and interactions of crises (Adapted from Myer & Moore, 2006:140)

Figure 5.3 consists of several components. Each component represents a person or a group affected by a crisis event. The effect extends to several layers that are interrelated. The initial layer of the model is depicted in figure 5.3 as i**ndividual** and s**ystem**[1]. An example of this layer would be the bereaved mother as the individual and the hospital as **system**[1]. Another component is the c**ommunity.** The notion of community may be viewed as broadly or as narrowly as the situation warrants. Generally the narrow perspective is more useful and realistic. An example of a community would be the community from which the bereaved mother comes and to whom she must return with empty arms. s**ystem²** would be the family of an individual who had a stillbirth. The crisis almost always has an impact on the family because their dreams of becoming grandparents, uncle and aunt have been violated. They also might find it difficult to support their loved one in her loss (Individual). s**takeholders**[1] symbolize those systems that are further connected to the i**ndividual.** Examples include friends, organizations, and places of worship or the workplace. According to

figure 5.3 **stakeholders**, just like s**ystem²**, can be directly affected by the crisis, but **stakeholders** will normally be less affected than s**ystem²**. **Subsystems** represent groups within a s**ystem¹**. Because this study focuses on stillbirth, **system¹** would be the hospital and s**ubsystems** would be different departments like the pre-natal department, day-clinic and the labour ward. Finally, s**takeholders²** represents those systems that are also connected to s**ystem¹** but are outside the system itself. For an institute like a hospital, s**takeholders²** can be patients, suppliers, public utilities and medical service providers.

Myer and Moore (2006:140) suggest that the potential exists for overlap or dual roles among the components in the diagram. Therefore, components can appear in more than one place in the model. Three premises constitute "Crisis-in-Context Theory" (CCT) providing a powerful tool for conceptualizing the impact of crises. Bronfenbrenner (1995) points out that the usefulness of these premises is not in the ability to predict, rather in the capacity to isolate factors that influence the overall impact of the crisis. The following section will provide a brief description of these important premises.

(i) Premise 1: Layers of a crisis

Individuals and systems experience the impact of crises in layers. The layers are dependent on two elements: (a) physical proximity to the trauma with respect to physical distance, and (b) reactions that are moderated by perception and the meaning attributed to the crisis event. Literature (Mitroff & Anagnos, 2001 & Veal 2003) supports this idea of layers in relation to the impact of a crisis and states that effective crisis management must take into account the divergent effects of a crisis of various subsystems within the organization. The black lines in figure 5.3 represent Premise 1 of the Crisis-in-Context theory model. These lines depict the connection of the crisis event to the people or systems that have been affected. Although the experience is unique for each person and system, understanding the impact of a crisis involves consideration of all layers. Failure to recognize the uniqueness of reactions is the primary source of ineffective and potentially harmful interventions.

Proximity is one of the elements integral to understanding the impact of a crisis within the context of layers. The closer an individual or system is to an event, the more

forceful the impact (Granot, 1995). An example within the stillbirth context is that of a bereaved father being present at the labour and a father being absent. The impact of the crisis would probably be more severe and forceful for the first father than for the one who didn't actually experience the "*silent birth*". Lastly when reacting to a crisis, an individual or system has a perception of the crisis situation that not only affects the reactions to the crisis but also assigns meaning to the crisis. Myer (2001) identified four life dimensions which might be affected in a crisis: physical, psychological, social relationships and moral/spiritual dimension. These dimensions help individuals to establish the meaning of the crisis.

(ii) Premise 2: Reciprocal effect

Understanding the reciprocal effect involves recognition of two elements: (a) the interactions among the primary and secondary relationships and (b) the degree of change triggered by an event. The second premise critical to understanding the impact of a crisis is the recognition of primary and secondary relationships among individuals and systems affected by the event (Dyregrov, 2001). Primary and secondary relationships may be understood in respect of the directness or indirectness of the interaction. Direct interactions in which no intervening component (i.e., individual or system) mediates that connection are primary relationships. Relationships mediated by at least one component are secondary or indirect interactions.

The dashed lines in figure 5.3 represent the reciprocal interactions, both direct and indirect in the Crisis-in-Context Theory. Figure 5.3 shows that **system¹** and the Individual have a direct relationship. The connecting line shows that no other component mediates the interaction, making this a primary interaction. An example would be a couple who had just experienced a stillbirth in a hospital. Their reaction directly affects s**ystem¹.** They might try to investigate the cause of the baby's death and start asking questions about the level of properly skilled medical staff present during the birth process.

In contrast, Myer and Moore (2006:84) suggest that a secondary relationship occurs when the connection is mediated by at least one of the components. An example would be the individual mediating **system¹** and **system²** (figure 5.3). Using the same stillbirth scenario, the individual might be influenced by her family to report a case of possible

negligence against the medical staff. The interaction in this situation was indirect and obstructive because the individual working for **system¹** acted as a go-between with **system²**. Indirect interactions can also be supportive. For example, some organizations (like the hospital) provided support for families of their patients beyond what was obligatory. Premise 2 finally states that the degree of change in the typical level of and ability of individuals and systems to function must also be considered in order to understand the impact. Degree of change concerns the amount of disruption caused in both short- and long-term functioning (Brewin, 2001). All disruptions experienced by individuals or the system's operation are considered in this component. Using the stillbirth scenario again, several changes might occur; for example, the grandmother was supposed to care for the baby during the day when the mother returns to work. Now all of a sudden this is not necessary any more. Or the husband or partner wanted to change his work shift to be able to spend more time with his wife and the newborn baby. Now that the baby is stillborn, this is also not necessary any more. This can be heartbreaking.

(iii) Premise 3: Time factor

Myer and Moore (2006:143) state that time directly influences the impact of crises. Two elements of time are (a) the amount of time that has passed since the event and (b) special occasions such as anniversary dates. The third premise for the Crisis-in-Context theory model concerns time. Bronfenbrenner (1995) and Brewin (2001) confirm the need to include the element of time in crisis theory. Early beliefs were that an event has varying degrees of impact on an individual's development and this impact decreases with the passage of time. Caplan (1961) was of the opinion that time played an important role in recovery from a crisis. According to him, most people recover from a crisis in 6 – 8 weeks, but it is now believed that the recovery process may extend beyond that time. Callahan (1998) and Salzer and Bickman (1999) disagreed with Caplan (1961) stating that 6 – 8 weeks were needed for individuals to reestablish a sense of equilibrium, not to fully recover from the impact of a crisis. The following chapter, chapter 6, will include findings regarding participants' opinions on crisis intervention and whether it was beneficial to them. Considering the above, it is irrefutable that time has a moderating effect on crisis. In the first few weeks after a crisis, individuals and systems vary in the ability to function. Issues such as an inability

to concentrate, disruption in behaviour and problem-solving skills and shifts in the roles and dynamics within the individual and systems are present (Collins & Collins, 2005; Myer 2001).

The second significant element of time concerns anniversary dates. As time passes, the impact of the crisis changes as people assimilate the experience into their lives and anniversary dates become either a positive experience, focusing on the precious memories a baby, coming into this world stillborn, made or it can be a negative experience, with a possible problematic outcome, where further intervention is necessary.

To conclude the discussion of the Crisis-in-Context theory model, it is important to notice that a critical issue in the development of this model involves maintaining focus on the individual while balancing this focus with a consideration of the system. This concept is different for systems theories. In the latter, the system is the point of intervention, not the individual (Gladding, 1995). Fortunately, having a variety of data collection and assessment tools available, for example genograms and ecomapping, the social worker has the opportunity to gain information from both individual and system during further sessions conducted with the client.

5.5.3 Comparison between the two models

Both models have a well-defined theoretical background and will be of assistance when working with a client in crisis. Although the two models both focus on the dimension of the problem, it can be said that the Crisis-in-Context theory model's special focus on the individual and the effect of the crisis on different levels and systems, will be more functional when working with bereaved parents after a stillbirth. Stillbirth has an effect on the individual, the couple, and family, community and health institutions and by using the Crisis-in-Context theory model, the reciprocal effect between these can be ideally observed and can provide information for better intervention.

5.6 FOUNDATIONS FOR CRISIS INTERVENTION IN SOCIAL WORK

To be able to incorporate crisis intervention into an unstable, always changing social environment, four foundations for crisis work in social work have been identified and

need to be implemented during crisis intervention. These foundations are presented in figure 5.4 below.

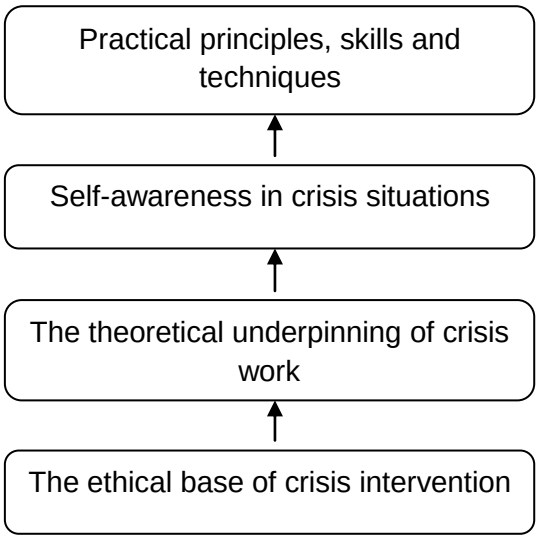

Figure 5.4: Flow-chart indicating the foundation in crisis intervention in social work (Adapted from O'Hagan (1991:140-155))

5.6.1 The ethical base of crisis intervention

As stated by O'Hagan (1991:141) ethical principles need to involve depth and complexity and need to be specific and realistic. Crisis work evolves around three main necessities: (i) knowledge and experience, (ii) the use of power and control, and (iii) resources. A short description of these necessities will be given in order to provide theoretically-based knowledge about crisis work.

(i) Knowledge and experience

Social workers in the front line of crisis work must be experienced, knowledgeable practitioners and experienced in the types of crises they are attempting to resolve. It is important to be enlightened about the social and political contexts of crises, and how gender culture and ethnicity may influence and dominate crisis processes. When working with bereaved parents who are experiencing an acute crisis due to losing their baby, knowledge about stillbirth is essential. The social worker or counselor needs to be

aware of the medical facts surrounding stillbirth as well as the psychosocial implications of such a loss.

(ii) The use of power and control

Although the use of power and control does not directly apply to crisis work with bereaved parents who just had a stillbirth, it is worthy to take note of this. Social workers counselling a bereaved couple might need to use their authority to help the couple gain access to the deceased baby before they leave the hospital. Normally a crisis situation cannot merely be managed or minimized by listening to the clients; it often demands action (O'Hagan, 1991:142). Facilitating another change to view their baby might be the correct action needed in such a crisis.

According to Cacciatore (2009:93) a shift needs to begin with subtle changes to deconstruct the way that stillbirth is perceived and to allow women who have undergone stillbirth to construct their own realities about their losses. This position is congruent with social work values such as advocacy, self-determination and service. Cacciatore (2009:93) is of the opinion that social workers can break the silence around stillbirth, acknowledging these women as mothers and providing dignity and recognition for their loved-and-longed-for babies, using the power and control given to them.

(iii) Resources

Resources are very much a matter of ethics, and it is crucially important for social workers to determine the quality and type of resources which are necessary for an effective and professional crisis intervention service. Resources which may play a role when working with bereaved mothers especially, is an adequate amount of support groups. (Cacciatore, 2009:94).

5.6.2 The theoretical underpinning of crisis work

It is unwise for social workers or any counselor to approach crises without a firm grasp of theory. Theory creates an understanding that a crisis is a painful, chaotic, potentially destructive experience, demanding an intellectual ability to theorize on how the crisis has come about, on the processes and people who sustain and exacerbate it, and on the likely strategies for first imposing order upon it, and then attempting to resolve it.

O'Hagan (1991) suggests using the systems theory when working with crisis intervention.

The systems theory in social work has the following perspective: the client, upon whom all attention is focused, is merely a component of a larger social system, usually the family. The family is merely a component of the larger system embracing friends, relatives, neighbours and professionals. This, in turn, is part of the even larger living system which we refer to as the community. All of these systems and their components are likely to be interrelated and interdependent to varying degrees and this interrelationship and interdependence is likely to have contributed significantly to events leading to the crisis. Sheafor *et al*. (1994:52) agree with O'Hagan (1991) on the subject of systems theory and the use of it during crisis intervention. They clarify this "interrelationship and interdependence" as a *"symbiotic relationship*".

The systems theory can be positively employed in crisis intervention with bereaved mothers after a stillbirth. When assessing the client (bereaved mother), the social worker needs to anticipate how any intervention will affect other people in the client's immediate environment. The most important subsystem will probably be the relationship between the bereaved mother and her husband or partner. The social worker will need to know what level of support there is between the couple and how the partner/husband felt about the unborn baby. Another important subsystem to explore is the relationship between the bereaved mother and her family. They will be the ones supporting her when she returns home with empty arms. The social worker needs to assess whether the client has a positive or negative relationship with her family and if the subsystem is striving to preserve an equilibrium or steady state. Nash (2005:33) agrees that from a systems perspective any change in a family has a direct effect on the whole family. The systems theory helps to gain better understanding about the situation the individual finds him/herself in. By examining the interactions between different systems it might be possible to support and counsel the bereaved parent in a more appropriate way.

5.6.3 Self-awareness in crisis situations

According to O'Hagan (1991:146), self awareness is the most important component in crisis training. It has three main tasks:

- It seeks to enable social workers to explore rigorously their own vulnerabilities in crisis situations.
- It seeks to identify the precise cause of that vulnerability.
- It seeks to enlighten the worker as to how particular vulnerabilities can seriously limit the quality of their intervention and lead them to making unprofessional and damaging decisions.

When working with any crisis, the social worker needs to look at: (1) The environmental context of a crisis, (2) Different categories of crisis, and (3) Different types of clients at the centre of each crisis. When applying these three steps to the crisis of "*stillbirth*", the following outline can be given. When a client had a stillbirth, it is important to understand the environmental context of the crisis. Does the client have the opportunity to have a grief process or is the socio-economic situation such that instead of seeing the stillbirth as a crisis, the client just moves on to the next crisis, that is perhaps not having food to feed her other children.

To identify with the different categories of crisis, the social worker needs to assess the bereaved client and recognize that a stillbirth leads to an intense feeling of loss and isolation. This is regarded as the main category of the crisis. When considering the different types of clients at the centre of each crisis, again an assessment must be made to identify the main individuals or groups (subsystems) who have an influence on the bereaved client. O'Hagan (1991:148) mentioned that he has used these frameworks often during crisis intervention training with social workers and the crisis he constantly found to be the most challenging and the most revealing of social workers' vulnerabilities is that generated by cot deaths and stillbirth. O'Hagan (1991:148) asked himself why cot death and stillbirth crises are so challenging. Is it because the worker is overwhelmed by the enormity of the loss, and feels that any reaching out, any offer of help and support, is futile, even insulting? Or is it the unbearable thoughts about the apparent cruelty of this event, and the professional ignorance as to its real cause and consequences?

5.6.4 Practical principles, skills and technique

Literature (Sheafor *et al.*1994:69 and O'Hagan, 1991:150) recognizes that when using crisis intervention, certain principles are important.

5.6.4.1 Principles

The following is a combination of the principles presented by these two authors:

- Quick access to the client and rapid response by the helper
- Use of time limits is important (for example, five sessions over a four-week period)
- Focused attention on the crisis configuration (on the nature of the precipitating event and its subjective meaning to the client)
- Emphasis on helping the client make decisions and take action
- Mobilization of resources within the client's social network
- Choice of the right kind of minimal intervention during a crisis to achieve a maximum and optimum effect.

Stillbirth as a crisis will be used to illustrate the implementation of these principles. It is important to see the bereaved mother as soon as possible after the loss. In scenarios where the mother is informed about the absence of a fetal heartbeat shortly before birth, the crisis begins, and not only after the birth. It would be recommended that contact with the mother should be made even before delivery to create trust and a rapport. The social worker then needs to assess the emotions and feelings that were invested in the expected baby to establish the subjective meaning the baby had to the client. The client can further be assisted to make important decisions such as what to do with the baby clothes and baby equipment. Then the bereaved mother needs to be linked to possible resources should she wish.

5.6.4.2 Techniques and skills

Kfir (1989:32) stated that crisis intervention is direct and the interventionist leads the session. The interventionist/social worker must be trustworthy, authoritative, and knowledgeable and must regard the intervention as a short encounter, possibly a one-

time occurrence. The goals of the intervention must be immediate, concrete and feasible.

Gilliland and James (1993:9) differentiated between professional skills and personal skills. They explained that professional skills are based on the training of the social worker in the field of crisis intervention, whereas personal skills are those inherent skills that make one more suited to crises intervention. Table 5.2 below illustrates the difference between personal and professional skills:

Table 5.2: Techniques and skills used in crisis intervention

TECHNIQUES AND SKILLS USED IN CRISIS INTERVENTION	
(A) Professional Skills	**(B) Personal Skills**
(i) Attentiveness	(i) Poise
(ii) Accurate listening and responding	(ii) Creativity and flexibility
(iii) Congruence between thinking, feeling and acting therapeutically	(iii) Energy
(iv) Reassuring and supporting skills	(iv) Quick mental reflexes
(v) Basic assessment and referral skills	(v) Tenacity
(vi) Ability to explore alternatives and solve problems	(vi) Courage

Table 5.2 illustrates the different skills needed in crisis intervention. When focusing on the professional skills, it is important to remember that these skills can be used by any worker in the human services work. The difference in crisis intervention is that these skills must be used when problem onset is sudden and dramatic, emotions are highly volatile, and background information may be vague. The skills mentioned in table 5.2 can be explained as follows:

(a) Professional skills

The seven professional skills are not an all-inclusive list, but provide the social worker with a background of skills needed for crisis intervention.

(i) Attentiveness

Words associated with attentiveness are “special treatment”, “care”, “consideration” and “courtesy**”.** When a social worker or crisis interventionist shows attentiveness towards a client, the client needs to feel that he/she is special and important to the worker. This is extremely important when working with bereaved mothers after a stillbirth, because already some of their family or the nursing staff may be avoiding her. She needs to feel that she is important and that she can connect with somebody. (See Pauw, 1991:291 and Aquilera & Messick, 1982:45).

(ii) Accurate listening and responding

Accurate listening can be described as “precise” listening and taking mental note of everything that is said. Sometimes it becomes a habit just to listen, but it is important to note that no two bereaved parents feel exactly the same. It is also important to respond at the right time, to not avoid the participant from not verbalizing feelings (Compton & Galaway, 1994:307).

(iii) Congruence between thinking, feeling and acting therapeutically

Table 5.2 shows that there must be a congruence between thinking, feeling and acting therapeutically. This is important because as a social worker or crisis interventionist, you need to be sincere in the way you think and communicate. You will win the respect of your clients and also be able to create a rapport for the session and those to follow. Your words and actions need to echo your sincerity to a bereaved couple.

(iv) Reassuring and supporting skills

Gilliland and James (1993:9) highlighted reassuring and supporting skills as being very important in crisis intervention. Although it might feel totally inane to be reassuring at a time of death in a family, especially a stillbirth with all the feelings and emotions surrounding this type of death, the social worker can be reassuring simply by being there for the mother and father and supporting them with practical issues. Mahan and Calica (1997:144) agree with this statement and mention that services provided to the family may include crisis intervention, concrete services, information and referrals.

(v) Basic assessment and referral skills

In table 5.2 basic assessment and referral skills are also identified as being very important in crisis intervention. Meyer (1983:30) suggests using an ecosystemic approach when doing initial or basic assessment. This involves understanding the "interrelated, complex reality in people's lives". A social worker, who does an ecosystemic assessment, will examine as many of the forces as possible that affect the client system. It starts where the client is, and it is based on the principle that how a person thinks, feels, and behaves is based on the person's perceptions.

(vi) Ability to explore alternatives and solve problems

When exploring alternatives in a crisis situation, the social worker/crisis worker needs to be skilled to take on different intervention roles in order to assist clients the best. An interventionist role refers to the behaviour by means of which both client and social worker will help each other to accomplish goals specified at the beginning of an intervention session (Compton & Galaway, 1994:428*)*. Literature (Tobias, 1990; Mahaffey,1972) includes several different roles, but the five roles mostly used in crisis intervention are those of social broker, enabler, teacher, mediator and advocate. These five roles can be demonstrated within a stillbirth setting as follows:

- *Social broker*: The social worker serves as a link between the client and other community resources. Activities of the worker are directed toward making connections between the client and the community to accomplish the objectives specified in the service contract. Working with a bereaved family after having a stillbirth, the social worker can help them to link with funeral services or support groups. While still in hospital, the worker can be a link between the mother and the nursing staff when the mother wants to view her baby but needs assistance and emotional support. The social worker can be present if the client needs support.

- *Enabler:* The worker assumes an enabler role when intervention activities are directed toward assisting clients to find the coping strengths and resources within themselves to produce changes necessary for accomplishing objectives of the service contract (Compton & Galaway, 1994:430). When a couple, having experienced the trauma of stillbirth, are struggling to communicate with each

other due to their different grief reactions, the social worker will act as enabler by assisting the couple to understand that it is normal to feel differently about the loss of their baby. The social worker needs to explain that the couple need to find coping strengths within themselves to improve communication and better understanding of each other's feelings.

- *Teacher:* Teaching is an important aspect of social work practice. Frequently the social worker will provide clients with information necessary for decision making. A practical example of the social worker practicing the teacher role as interventive role, is when information is given about the positive and negative aspects of seeing and holding the baby. Important information can also be given to the bereaved couple regarding what to do with the baby clothes at home. It is seen as part of the grief process for the couple to put away the clothes in their own time, when they are ready. Sometimes the family believe that it will be sad for the bereaved mother when she returns from hospital to see all the baby accessories and clothes. When the social worker acts as a teacher, she/he will explain the different options to the couple so that they can make an informed decision.

- *Mediator:* Mediation involves efforts to resolve disputes between the client system and other persons or organizations (Compton & Galaway, 1994:433). Mediation is often necessary between a couple when the partner blames the mother for the loss of the baby by saying she was too active or was drinking or smoking too much.

- *Advocate:* Advocacy involves arguing, debating, bargaining, negotiating and manipulating the environment on behalf of the client. An example to best explains this interventionist role is when a bereaved mother is put in the same post-natal room as mothers with healthy, living babies. The social worker will then act as advocate and emphasise the importance for the bereaved to be alone and not in the same room with healthy babies.

(b) Personal skills

Although the therapeutic skills necessary to intervene in crisis situations can be modelled and processed, inculcating the personal skills necessary to do effective crisis intervention work is another matter. Gilliland and James (1993:10) identified six personal skills they believe are necessary to be an effective crisis worker. These skills can be described as follows:

(i) Poise

The nature of crisis intervention is such that the worker is often confronted with shocking and threatening material from clients who are completely out of control. Belkin (1984:427) suggests that probably the most significant help the interventionist can provide at this juncture is to remain calm, poised and in control. Creating a stable and rational atmosphere provides a model for the client that is conducive to restoring equilibrium to the situation.

(ii) Creativity and flexibility

Creativity and flexibility are major assets to those confronted with perplexing and seemingly unsolvable problems (Aguilera & Messick, 1982:24). It is one thing to teach a person a repertoire of skills. It is quite something else to teach the use of those skills in ways that are adaptable to clients' needs. The social worker needs to use this skill in the best interest of the client, this being the bereaved mother.

(iii) Energy

Functioning in the unknown areas that are characteristic of crisis intervention requires energy, organization, direction and systematic action (Carkhuff & Berenson, 1977:194). Professional training can provide organizational guidelines and principles for systematic acting. What it cannot do is provide the energy required to perform this work. Feeling good enough about oneself to tackle perplexing problems day after day calls for not only an initial desire to do the work but also the ability to take care of one's physical and psychological needs so that energy levels remain high. The social worker confronted with stillbirth cases daily, needs to have self-help strategies in place.

(iv) Quick mental reflexes

Crisis work is different from typical therapeutic intervention in that time is a critical factor. Time to reflect over problems is a rare commodity in crisis intervention. When the crisis worker is seeing a bereaved couple who are highly emotional, intervention needs to be quick and direct. Because of the great sensitivity of the situation the social worker needs to be ready to say the right things at the right time.

(v) Tenacity

Gilliland and James (1993:11) are of the opinion that although tenacity can be explained as being obstinate and stubborn it could also be considered persistent and determined. The social worker or crisis worker needs to be persistent and determined when working with bereaved parents for they need guidance and someone with determination to help them and acknowledge their loss. They might not experience this in the community because of the lack of recognition of the impact of a stillbirth.

(vi) Courage

Courage to work with a person in crisis is important as some people rather want to avoid it. The crisis worker needs to be brave enough to work with the sadness, frustration and bitterness after a stillbirth and to cope with the overwhelming feeling that any intervention might be insignificant, but is needed.

The four foundations for crisis intervention in social work have been explained and discussed and the next section will focus on implementing crisis intervention as method in social work, specifically focusing on a stillbirth scenario.

5.7 IMPLEMENTING CRISIS INTERVENTION AS METHOD IN SOCIAL WORK TO ASSIST PATIENTS WHO HAVE EXPERIENCED A STILLBIRTH

Several authors agree that social work professionals are well prepared to work with clients experiencing both acute and chronic stress, and they have been trained to intervene during an immediate crisis and to implement post intervention services. Bell (1995:32) mentions that social workers have the knowledge and skills to educate, empower and assist victims of trauma. Cacciatore, Carlson, Michaelis, Klimek and

Steffan (2011:82) points out that crisis intervention is strongly person-centred and emphasizes communication, collaboration, and caring, ideals consistent with the social work value of caring for others. Gray (1996:4) states that human beings need to be recognized as a whole, integrating moral sensitivity, moral awareness, moral reflection and moral commitment. Professional social workers have a history of advocating social support for those in need, often using creative intervention strategies such as “nonfamilial sources of support from within the community”. It is clear that social workers are in a unique position to assist families with important tasks of grieving and may be most able to assist the family with the difficult emotional issues they are facing. Services provided to the family may include crisis intervention, concrete services, information and referrals (Mahan & Calica, 1997: 144). Some practical examples will be discussed next.

5.7.1 Important tasks during crisis intervention by social workers

Stringham *et al.* (1982:326) identified eight tasks that are important when assisting parents to cope with grief over stillbirth. Table 5.3 below highlights these tasks.

Table 5.3: HOW SOCIAL WORKERS CAN ASSIST PARENTS TO COPE WITH GRIEF OVER STILLBIRTH

HOW SOCIAL WORKERS CAN ASSIST PARENTS TO COPE WITH GRIEF OVER STILLBIRTH
1. Help the mother and father to make memories. Offer opportunities to look, hold and say good-bye to the baby. Take a picture. Provide information about the cause of death, burial, naming and other rituals that parents have used.
2. Talk to the parents and listen to them. Help them, especially the mother, to fight feelings of failure, guilt, and helplessness that complicate this grief. Tolerate their anger.
3. Help parents to find a trusted friend, clergyman, or undertaker to assist them with their planning. Give people time to weigh their options. Give families and friends cues about ways in which they can support and share in the parents' mourning.
4. Refer parents to a self-help group or put them in contact with others who have had a stillbirth. Consider starting a self-help group if none exists.
5. Help parents to obtain results from an autopsy and provide them with the opportunity for questions and discussion.
6. In medical or mental health practice, be alert, in taking a history, to the presence of a stillbirth or other perinatal loss, which may result in grief that has been delayed or is reactivated by a recent loss.
7. Recognize that the birth of a stillborn baby, as in any loss, requires a process of mourning that may last a year or longer and that can be made more difficult by attempts to short circuit it.
8. Advocate for changes in hospital policies and procedures that would make carrying out the above recommendations possible.

Table 5.3 identifies the eight essential tasks that need to be done by the social worker during crisis intervention with the bereaved mother and father after a stillbirth. Stringham *et al.,* (1982:326) are supported by other authors working in this field, as will be described below.

5.7.1.1 Making memories

Kobler, Limbo, Kavanaugh (2007:294), Mahan and Calica (1997:145) and Pauw (1991:293) all agree with Stringham *et al.*(1982:326) that it is very important to provide

the bereaved parents with as much tangible memories as possible. When in crisis, the parents are so overwhelmed by a mixture of feelings that they do not think of creating memories. It must be taken into account that some parents might decline any form of memorabilia. The social worker might then keep it on file, in case they express a need for the memorabilia later.

5.7.1.2. Talk to the parents and listen to them

Brownlee and Oikonen (2004:524) agree with Stringham *et al.* (1982:326) that by telling their story, bereaved parents get a chance to express their grief and loss. Brownlee and Oikonen (2004:524) suggest that the narrative model emphasizes that people form meaning through the construction of stories about their lives. The value of the narrative model is that stories are open to change. They allow for the incorporation of parental wishes, hopes and dreams and allow for variations in the timing of expressions of grief, differences in the significance of the loss and shifting positions of meaning. Borg and Lasker (1981:36) agree and state that talking about the experience helps make it seem more real. Mahan and Calica *(*1981:71, 73) recommend that parents need to be prepared for reactions they will experience after their baby's death, for example grief stages and normal reactions. Ultimately is not specifically what is said or done, but the presence of concerned and caring individuals that is remembered.

5.7.1.3 Help parents to find a trusted friend, clergyman, or undertaker to assist them with their planning

Families are usually immobilized by the shock of their loss and often are unable to make many decisions. Much of what is told them will be forgotten, reinforcing the need for other family members or somebody they trust to guide them when making decisions shortly after the stillbirth (Mahan & Calica, 1981:70). Social support of the bereaved couple is necessary, but because many women feel that their grief was not socially sanctioned, care must be taken that the support is positive and motivating. Family members often do not know how to respond appropriately to the bereaved couple, and lack of response or inappropriate response may result in a rupture in family communication.

5.7.1.4 Refer parents to a self-help group or put them in contact with others who have had a stillbirth

Support is often viewed as most credible when it comes from someone who has previously experienced and successfully managed a similar crisis (Dakof & Taylor, 1990:633). When referring parents to a self-help group, it is essential to first explore whether the parents are ready to be part of such a group. Saflund, Sjögnen and Wredling (2004:135) are of the opinion that parents may not be ready to consider a support group until several weeks after the loss. This information should not be provided until after the birth. The great benefit of self-help groups is that women are given an opportunity to share their feelings in an atmosphere of acceptance and understanding and to realise that their grief was not unusual or abnormal.

5.7.1.5 Help parents to obtain results from an autopsy and provide them with the opportunity for questions and discussion

Holste, Pilo, Petterson, Radestad & Papadogiannakis (2011:1289) and Odendaal *et al.,* (2011:168) agrees that obtaining consent for autopsy is a very sensitive issue and needs to be approached with care. The social worker plays a very important role here, because of emotionally being the closest to the bereaved couple. In the study by Holste *et al*.,(2011:1289), it was found that a quarter of the respondents would have appreciated the opportunity to talk to the pathologist who performed the autopsy. The social worker must keep this in mind during crisis intervention and during further intervention.

5.7.1.6 Be alert, in taking a history, to the presence of delayed grief or reactivated grief

While intervening with the bereaved couple, the social worker needs to assess the possibility of pathological grief. Pathological grief differs from normal grief in its duration and in the degree to which day-to-day behaviour and emotional states are affected (Bowlby, 1980). If pathological grief is present the social worker needs to consider a referral for further psychotherapy.

5.7.1.7 Recognize that the birth of a stillborn baby, as in any loss, requires a process of mourning

Although people grieve for differing periods, it is generally felt that most people take at least six months to a year. Social workers need to take this into consideration after crisis intervention is completed and further therapeutic sessions may be needed. In some instances the social worker needs to assist the parents to start with their mourning process, because they may feel overwhelmed by feelings of loss and sadness.

5.7.1.8. Advocate for changes in hospital policies and procedures that would make carrying out the above recommendations possible

Although it may seem that stillbirth is an emotion-based, social problem, there are rational imperatives for social work's response. Indeed, there is an obligation for a larger shift in the macro culture; a shift that will likely sway attitudes, beliefs, and values about women experiencing stillbirth. Social workers, particularly in hospitals, have an opportunity to become involved in helping women find their voices after the death of a baby. This position is congruent with social work values such as advocacy and social change, self-determination and service (Cacciatore, 2009:94). Brownlee and Oikonen, (2004:523) added that the implication of poverty as a critical variable in the grief process reinforces the contribution and role that social work could play in identifying women at risk, reducing social isolation and addressing the complete well-being of families who have lost a child in the stillbirth period.

5.8 CONCLUSION

This chapter provided an overview of crisis intervention and how it can be implemented by social workers. First the origin of crisis intervention was discussed, where-after definitions of crisis intervention and characteristics of a crisis were discussed. This laid the foundation for the rest of the chapter. The importance of using a crisis intervention model was also discussed. Two models, the Roberts's Seven-Stage Intervention model and the Crisis-in-Context theory model were discussed and compared with each other.

The focus then shifted to the foundations for crisis intervention in social work. It is of critical importance to examine these four foundations, as they provide the basis for the

implementation of crisis intervention within any crisis situation but specifically when experiencing a stillbirth (O'Hagan, 1991:146). The chapter ended with a discussion of eight practical tasks a social worker can do in order to provide the most appropriate crisis intervention possible for the bereaved mother and her family. This chapter concludes the literature review for this research. In the next chapter the results of the empirical study will be presented and discussed.

CHAPTER 6

AN EMPIRICAL STUDY OF THE LIVED EXPERIENCES OF MOTHERS WHO HAD A STILLBIRTH AND THEIR PERCEPTION OF THE CRISIS

6.1 INTRODUCTION

The previous chapters explored the medical causes surrounding stillbirth, the current understanding of psychosocial implications of stillbirth for a mother and her family, as well as an explanation of the crisis-support approach/intervention in social work and how it can be beneficial in stillbirth support. This literature study formed a base underpinning an understanding of mothers' and their families' experiences during a stillbirth and how crisis intervention can be beneficial during this time.

Research confirms that it is important to know and to understand the possible causes and other medical information regarding stillbirth in order to provide the necessary support during a crisis support session and to be able to validate a bereaved mothers' feeling of loss. (Stringham *et al.,* 1982:322; Cacciatore, 2010:141; Mahan & Calica,1997:144; Brier, 2008:451 and Callister, 2006:228).

When considering the complex psychosocial implications presented by a stillbirth, it is necessary to explore the grief process and different grief reactions, as well as the impact of the loss on the mother, father, their relationships and possible siblings. This helps to create an understanding of what exactly the psychosocial implications are.

Research confirms that support from social workers, counsellors and chaplains during a stillbirth could assist families with important tasks of grieving (Mahan & Calica, 1997:144; Friedman & Bloom, 2012:274; Baddeley & Singer, 2009:202). When this support/intervention is provided through the crisis support approach in social work, it can have a greater impact on the bereaved mothers' crisis and trauma during the loss.

In the light of the above-mentioned facts, the literature review provided a basis for the empirical study. The findings of the empirical study can be verified against the literature review and hence be explored in terms of its validity and applicability to mothers who have experienced a stillbirth.

In this chapter the results of the empirical study will be presented and discussed. Where relevant, the data will be presented in tabular, figure or narrative form in order to best capture the findings of the study. The aim of this chapter is to verify the findings of the literature review and to explore the lived experiences of mothers who had experienced a stillbirth and their perceptions of the crisis by means of a questionnaire and semi-structured interview (see Appendix A1, A2, B1 & B2).

6.2 Delimitation of the study

The research was conducted within the Safe Passage Study – PASS (Prenatal Alcohol SIDS Stillbirth) Network at Tygerberg Hospital. The Safe Passage Study is a research study conducted by the Department of Obstetrics and Gynaecology, University of Stellenbosch in conjunction with the PASS Research Network. The participants came from within the referral area of Tygerberg Hospital, which include Belhar, Valhalla Park, Bishop Lavis, Kalksteenfontein, Delft and Netreg. The population refers to all the participants recruited for the Safe Passage Study. The sample can consist of any racial group, as long as participants live in the demarcated area and are able to communicate in English or Afrikaans. Current data already collected by the researcher in everyday practice indicate the need for ongoing support and not just for support directly after the loss. This was integral in forming a rationale for this study. The criteria for inclusion were thus that participants have experienced a stillbirth more than six months ago but less than 18 months ago. This will give the researcher the opportunity to gain insight into the aftercare needs of bereaved parents, and their experience of support during the crisis period when looking back a few months later. The sample consisted of 25 prospectively recruited study participants who have experienced a stillbirth.

Purposive sampling techniques, as part of non-probability sampling methods, were used for this research. This type of sample is based entirely on the judgment of the researcher, in that a sample is composed of elements that contain the most characteristic, representative or typical attributes of the population (De Vos *et al.*, 2005:59,202). This ensured that participants were selected who met the criteria for inclusion and hence could fulfil the purpose of the study.

6.3 The empirical study

The investigation can be classified as a combination of both the exploratory and descriptive design as described by De Vos *et al*.,(2005:106) and Mouton (2001:53). A combination of the qualitative and quantitative approach, with greater emphasis on the qualitative was used to obtain the aims of the research. For the purpose of the study, the qualitative approach focused on the participants view of the challenges they faced after losing a baby and the quantitative approach provided a statistical profile of the respondents' demographic background.

Data were collected by means of a questionnaire and a semi-structured interview (see Appendix A1, A2, B1 & B2), which consisted of both open and closed questions. This ensured that the data collected were both measurable and rich in description (De Vos *et al.*, 2005:106).The interviews were conducted by the researcher individually with each participant and despite the planned avoidance of discussing deep-seated emotional concerns of each mother, these inevitably arose in many of the interviews and frequently required that the researcher give opportunity for debriefing. Fortunately it was not necessary to do a referral for further immediate debriefing.

The data which were collected through the questionnaire and interview were then coded and represented by means of graphs and figures. This allowed the researcher to identify consistent and relevant patterns within the data.

6.4 Results of the empirical investigation

The findings of the empirical study and the interpretation of the data in comparison to the literature review will be presented below according to Section A of the administered schedule. Section A forms part of the quantitative part of the study. (See Appendix A1 & A2.)

6.4.1 Identifying particulars (quantitative study)

The participants were asked to supply information about their age, language, marital or relationship status, educational status and housing circumstances. These identifying details, along with the criteria of inclusion allow for a profile of the participants to be created. Each aspect will be discussed separately below.

6.4.1.1 Age of participants

The 25 mothers who were interviewed ranged from the ages of 16 years old to 39 years. Their ages are represented in figure 6.1 below.

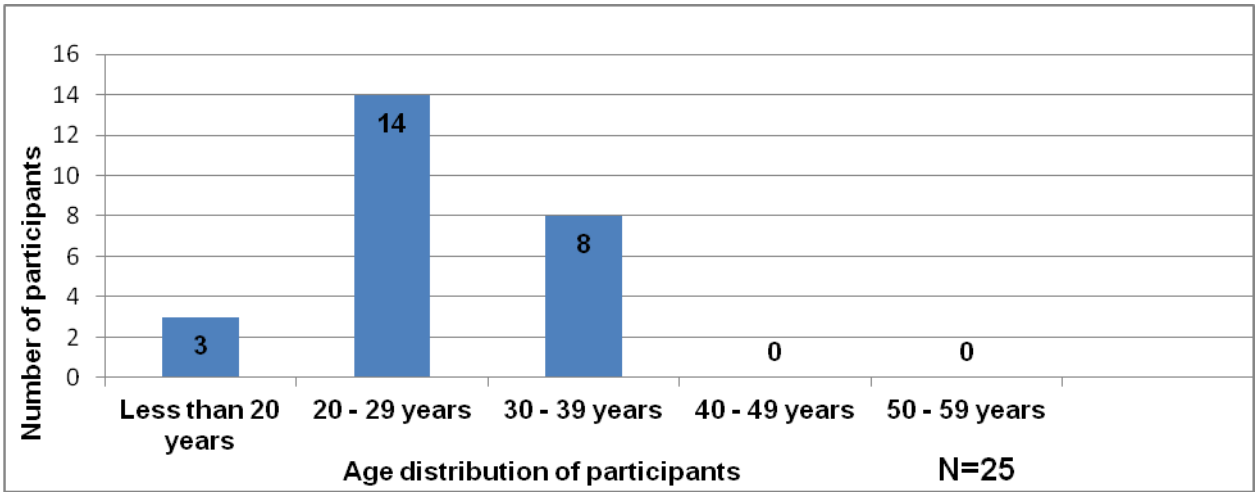

Figure 6.1: Age of participants

As depicted in figure 6.1, three (12%) of the mothers interviewed were less than 20 years of age, 14 (56%) of the mothers were between 20 and 29 and eight (32%) of the mothers were between 30 and 39 years of age. No mothers were represented in the last three categories, ranging from 40 to 69 years of age. This correlates with the fact that a woman's childbearing age declines from 40 years of age.

The findings show that a majority of the participants (14 or 56%) were within the age bracket of 20 to 29 years. This indicates that pregnancy occurse more when young women have completed their adolescent life phase and are now in the young adult life phase. According to Weiten (1995:458) this is the time that individuals' energy is focused on intimate relationships, learning to live with a marriage partner, starting a family and managing a home. A stillbirth during this time can thus have a significant bearing on the mother's emotional well-being. Erik Erikson's stages of psychosocial development identified "*Intimacy versus isolation*" as the psychosocial crisis during early adulthood (Weiten, 1995:433). When a stillbirth occurs it often leaves the mother feeling isolated from society because of the tendency of the public to underestimate the impact of such a loss.

Three (12%) of the participants were under the age of 20 years, which indicates that they were in the adolescent life stage where *"Identity versus confusion"* is the psychosocial crisis during this stage, as identified by Erikson (Weiten, 1995:458). Losing a baby during this life stage can be extremely stressful as the mother is still searching for her own identity and probably not mature enough to deal with the impact of such a grave loss.

6.4.1.2 Home language

Participants were asked to identify their home language, and the information is displayed as follows in figure 6.2.

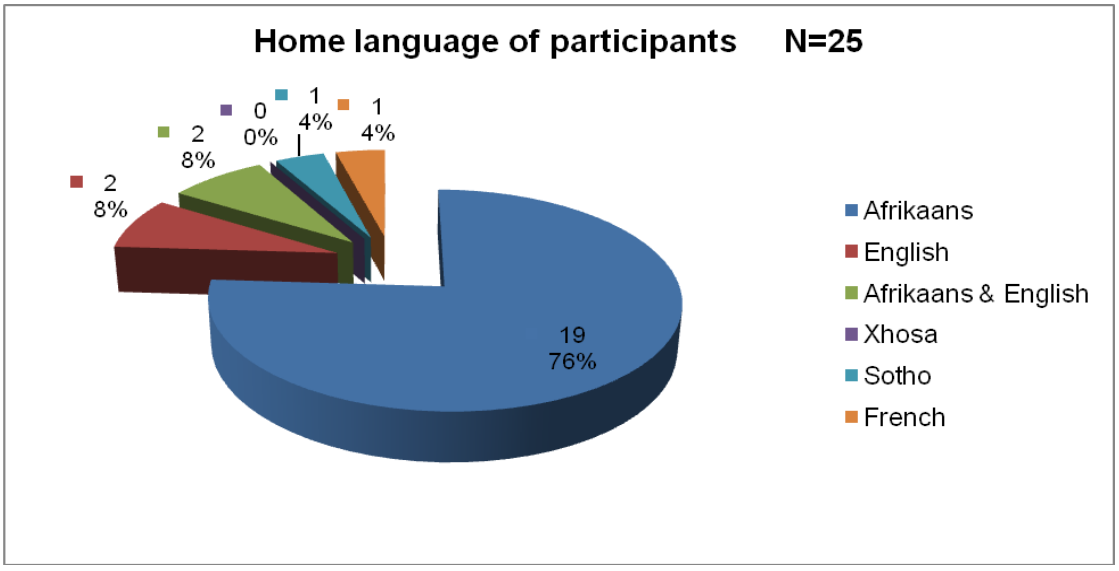

Figure 6.2 Home language of participants

The findings illustrated in figure 6.2 indicate that the majority, 19 (76%), of the mothers are Afrikaans-speaking, two (8%) of the mothers are English-speaking and two (8%) are bilingual, speaking both English and Afrikaans. There was no Xhosa-speaking participant, but one (4%) of the mothers was Sotho-speaking. One (4%) of the mothers indicated her home language as French for she originally comes from the Democratic Republic of Congo.

The Safe Passage Study of which this study is an ancillary, focuses mainly on the Cape Flats areas including Bishop Lavis, Belhar, Netreg, Kalksteenfontein and Valhalla Park. The distribution of home language in this figure correlates with the fact that people living

in these areas come from the Cape Coloured ethnic group who tends to be more Afrikaans-speaking.

6.4.1.3 Relationship or marital status

Participants of the study were asked to indicate whetherthey were in a relationship or married during the loss, as well as currently (between six and 18 months after the loss). The reason the current relationship status as well as the status during the loss needed to be recorded was to explore the effect of a stillbirth on a relationship. In chapter 3 the difference in the way the mother and father grieve about their baby was described and the term “incongruent grieving” was used to elucidate this. Wallerstedt and Higgins, (1996:389), Wing *et al*., (2001:63) and Hughes and Riches, (2003:108) are of the opinion that experiencing a stillbirth can put extra tension on a relationship and without the necessary coping mechanisms and support, it may have a negative bearing on the relationship.

Table 6.1: Indication of relationship statuses during the loss as well as the current status of the mothers

Relationship status	**During loss**	**Distribution of current statuses**	
Single	**0**		*****
Married	**7**	Married	**9**
Widow	**0**		
Divorced/separated	**0**		
Not married, living together	**10**	Not married, living together	**6**
		Not married, living separately	**3**
Not married, living separately	**8**	Not married, living separately	**1**
		Not married, living together	**1**
		Married	**2**
N=25		Single	**3**

(The movement between the different statuses is recorded.)

Table 6.1 specifies that during the loss seven (28%) of the mothers were married with an increase to nine (36%) participants currently. This indicates that two participants felt their relationship has improved after the loss and they have become even closer to their partners and wanted to commit to them.

During the loss, ten or 40% of the participants were living with their partners, but currently (after the loss) only six or 24% of participants stayed together. During the loss, eight (32%) of the participants were together but were living separately, while currently only one (4%) of the participants are together but live separately. Three (12%) of the participants broke up with their partners and are currently single. These statistics show that the relationship status of 12 (48%) participants changed after the loss. Two (8%) of the participants got married to the same partner while three (12%) of the participants broke up with their partners and are currently single. This correlates with the literature (Säflund & Wredling, 2006:1197) that experiencing a stillbirth can have a serious effect on a relationship and can add tension to the relationship.

6.4.1.4 Number of years married or length of current relationship

Participants were asked about the length of their current relationship or marriage. This was asked in order to establish at what stage of the relationship participants are.

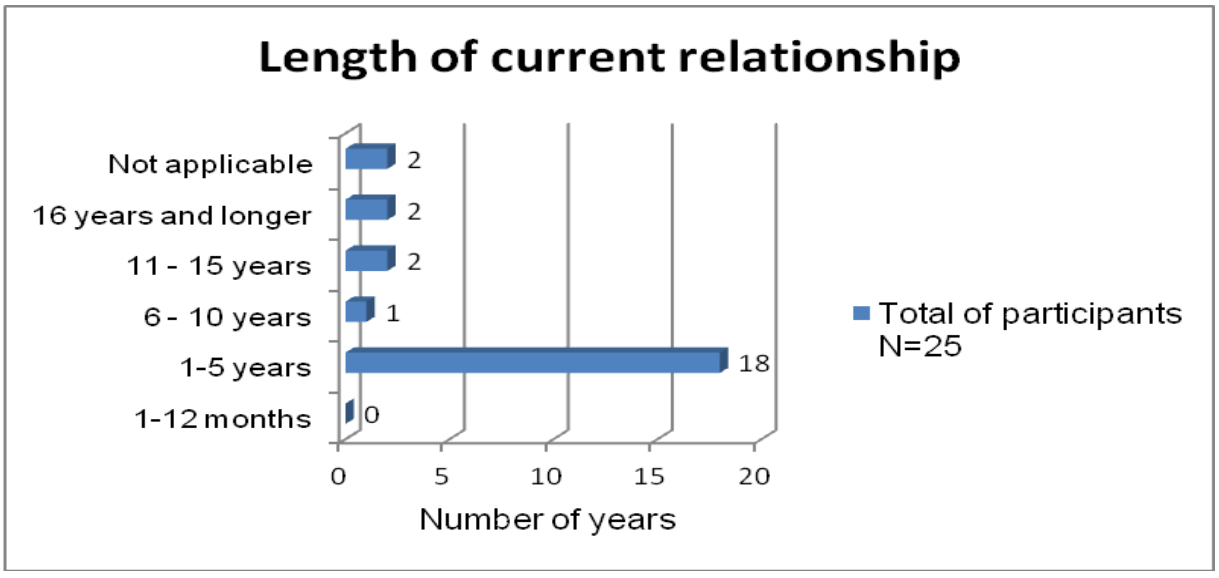

Figure 6.3: Length of current relationship or years married

Figure 6.3 illustrates the distribution of the duration of the current relationship of the participants. Eighteen (72%) of the participants are in their relationship for between one and five years. This correlates with Erikson's' stage theory where he identified starting and establishing a relationship as an important task of early adulthood (Weiten, 1995:458). Therefore one would expect the duration of the relationship to be not longer

than five years. None of the participants was involved with each other for less than one year.

One (4%) of the participants was in a relationship for between six and ten years while within the categories of 11 to 15 years together, and the 16 and more years, there were both two (8%) participants in each. Two (8%) of the participants indicated that the question was not applicable to them because they were not in a new relationship yet.

6.4.1.5 Highest educational qualification

Participants were asked to indicate what their highest level of education. The rationale behind this question was to determine whether a higher education level leads to a better economic status and employment, the next two questions in this section. The researcher also wanted to establish whether these mothers really perceived their loss as a crisis and whether understood the term “crisis”, and the complexity of it. The better qualified the participants, the more likely that they would understand the bereavement process, as well as such factors as being approached for an autopsy.

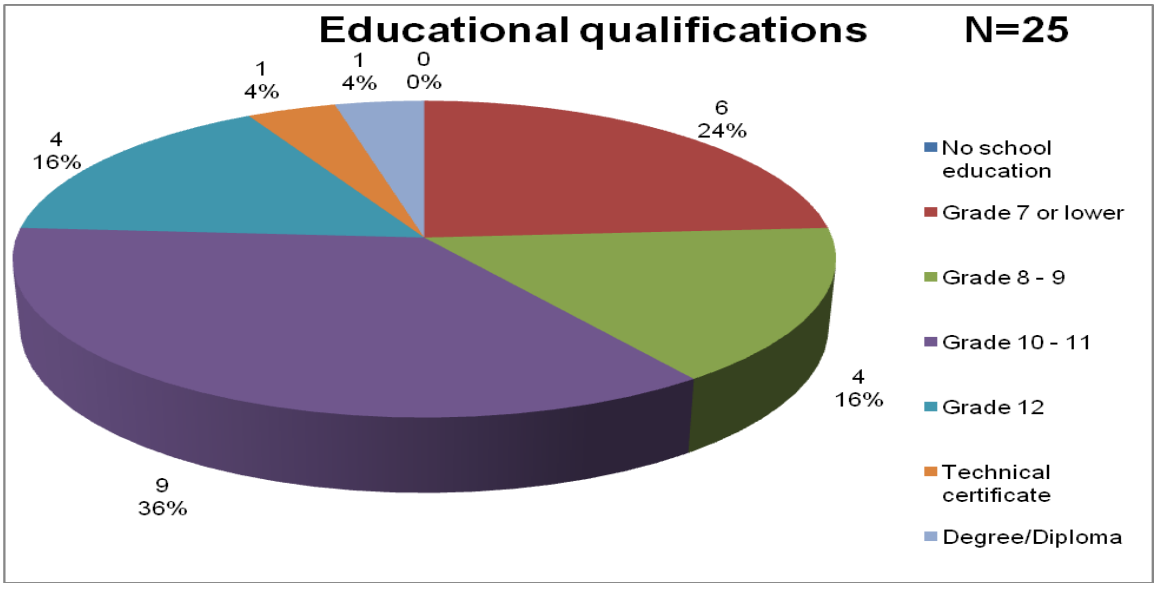

Figure 6.4: Pie chart illustrating the educational qualification of the participants

The chart indicates that the largest category, nine (36%) of the mothers, left school during Grade 10 – 11, with the second largest category of six (24%) mothers who only

has a primary school qualification of Grade 7 or lower, making literacy and employment a challenge. In the categories Grade 8 – 9 and Grade 12 there were both four (16%) mothers. Only one (4%) participant has a technical certificate and one or 4% has a degree or diploma.

This information shows that only six or 24% of the mothers have matriculated or have a tertiary education which will help with job seeking. The relationship between their qualification and current work status will be discussed in the next section.

6.4.1.6 Current occupation of participants

Weck, Paulose and Flaws, (2008:349) pointed out that several studies indicate that societal factors may impact on some pregnancy outcomes. Such societal factors include toxicant exposure, maternal habits (smoking and alcohol consumption), occupational hazards, psychosocial factors, socioeconomic status (SES), racial disparity, chronic stress and infection. Hobel, Goldstein and Barret, (2008:337) agree with Weck (2008) and suggest that a wide array of maternal psychosocial stressors can contribute to poor pregnancy outcomes. He identified the following potentially problematic stress variables: life events, anxiety, depression, perceived stress, racism, self-esteem, work or household strain and social support.

The following data will focus on these stressors such as occupation, income and housing, and support will be discussed. Literature regarding the impact of the above-mentioned stress variables on grief and grief responses is meagre. Does coming from a low or average socio-economic status (SES) restrain a bereaved mother from engaging in a proper grief process, or are these household and financial problems too overwhelming to even start with grief work? Respondents were asked to indicate their current occupation.

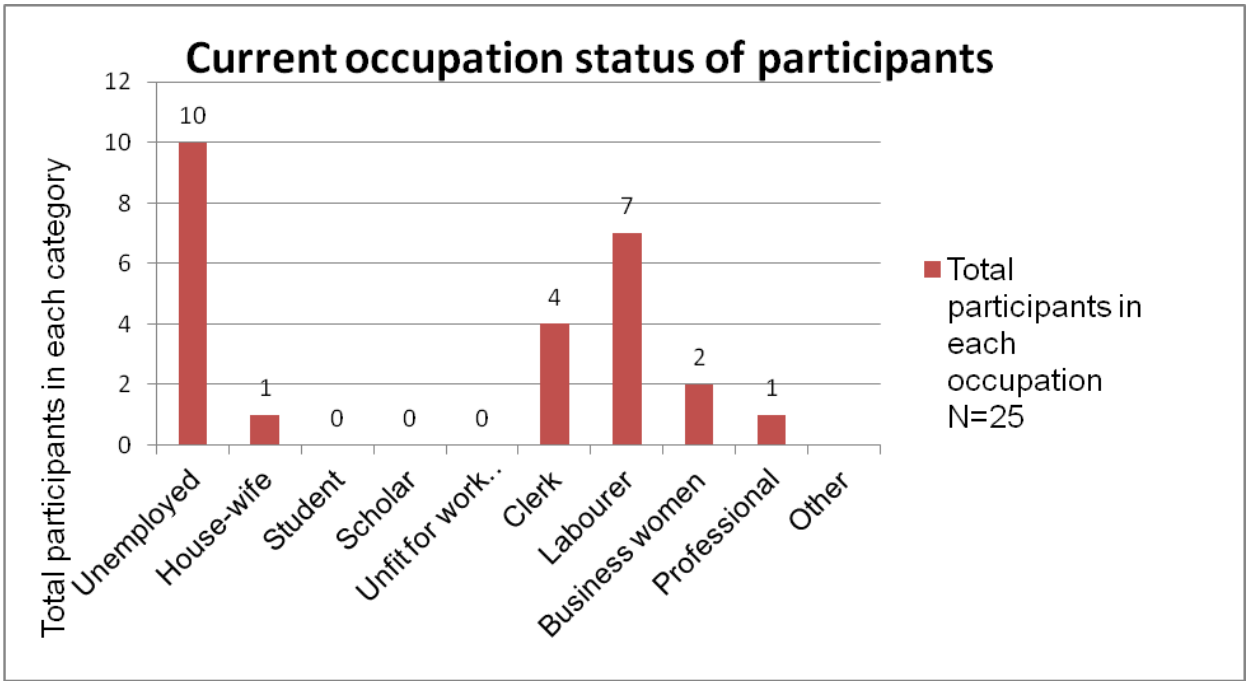

Figure 6.5: Chart indicating the current occupations of participants

Ten (40%) of the total number of participants (N=25) indicated that they were unemployed. This formed the biggest category. Seven (28%) of participants were employed as labourers, with most of the participants in this category working as cleaners or machinists. These seven participants indicated that they were not completely satisfied with their salary and were looking for other opportunities. The third largest category consisted of four or 16% of the participants working as clerks. These four participants experienced job satisfaction and earned an average salary.

Two (8%) of the participants were working as businesswomen while one (4%) of the participants claimed to be a professional person, running her own Edu-Care centre. One (4%) of the participants is a housewife. She did not identify with the unemployed category because she is not seeking work and would rather stay at home and look after her children. No participants fit these categories: student, scholar and unfit for work (disabled).

From the above chart it is clear that the unemployment rate is high. If the category “labourer” is added to unemployment, because of the dissatisfaction with a salary or small salaries, the total participants would be 17 (68%). A postulation can be made that

68 % (17) (N=25) of the participants are not financially stable which can lead to poverty and psychosocial stress. This may have an effect on pregnancy outcome and the grief process.

6.4.1.7 Income distribution of family

Participants were asked to indicate the income distribution of the family. The rationale behind this question was to identify whether a participant has an income and who else in the family is also earning a salary. This will specify if there would be extra support for the participant where needed. The following figure illustrates the primary source of income for the participant and whether there is a secondary source of income as well.

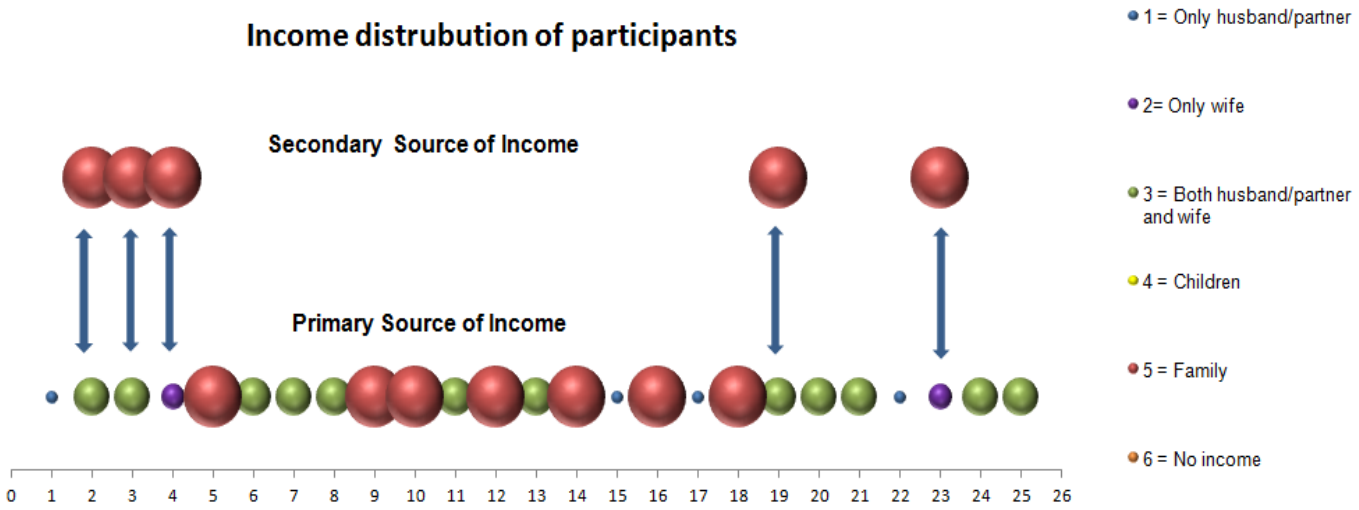

Figure 6.6 Bubble-diagram indicating the income distribution of participants.

The figure indicates that all 25 (100%) of the participants have a source of income. There was no participant without some sort of income. Only five or 20% of the respondents have a secondary source of income. In all the cases the secondary source of income is the family of the participant, in which case the participant is still living with her family either in the house or in her own house (Wendy house) in the backyard.

The primary sources of income can be divided into the following categories: Four or 16% of the participants are relying on their partners/husband solely for an income, while just two or 8% of the participants are responsible for earning a salary. Twelve or 48% of the participants are earning a salary as did their partners. This could be attributed to the current economic situation and to the fact that previously disadvantaged communities are now being given more opportunities than previously to better education and employment. There is also a special focus on empowerment of women in South Africa and this is leading to more opportunities for women. The current target group of the PASS study in South Africa focuses on socially disadvantaged populations, therefore providing the researcher with the ideal information for this research.

None of the participants' older children is currently working and earning money. Twelve (48%) of the participants indicated that their families are also working and that they are dependent on a part of that salary. In such cases the families will most of the time provide meals to participants while the participant in turn will perhaps pay for her own electricity. Seven (28%) of the participants are exclusively dependent on the family's income while five (20%) rely on the family's income as a secondary source of income.

6.4.1.8 Information regarding social grants

Participants were asked whether any member of the household was receiving a social grant from SASSA (South African Social Security Agency). This will further indicate the financial stability of the respondents and their families.

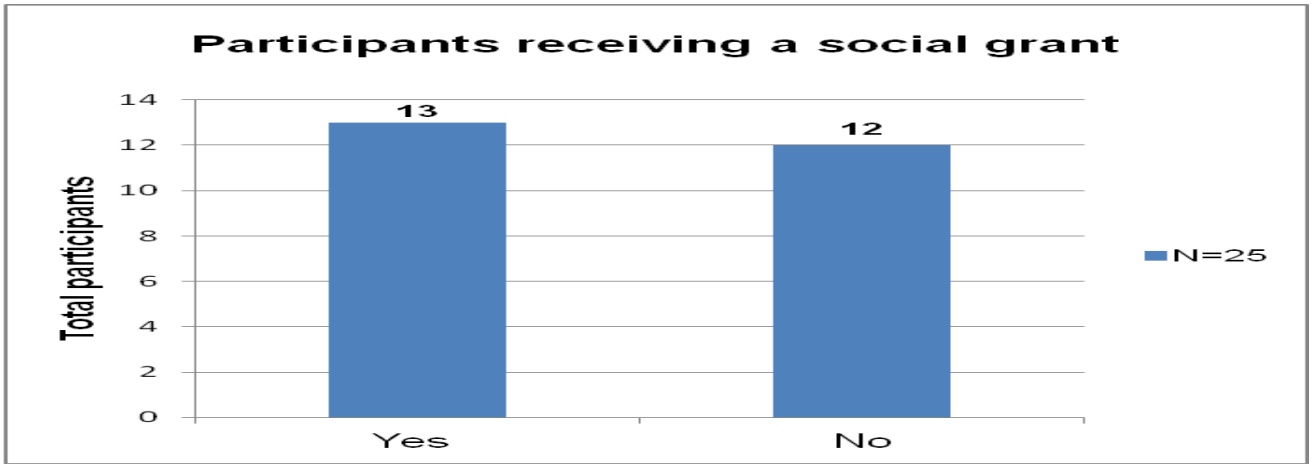

Figure 6.7: Distribution of participants receiving a social grant

Figure 6.7 points outs that 13 (52%) of the 25 participants (N=25) are currently receiving a grant. Twelve (48%) of the participants are not receiving a social grant. This illustrates that more that half of the participants are receiving a social grant although with only a four per cent (4%) difference between the two groups. Because of the similarity between the two groups, it is probably not noteworthy to assert that most participants rely on a social grant.

6.4.1.8.1 Distribution of grants received by participants

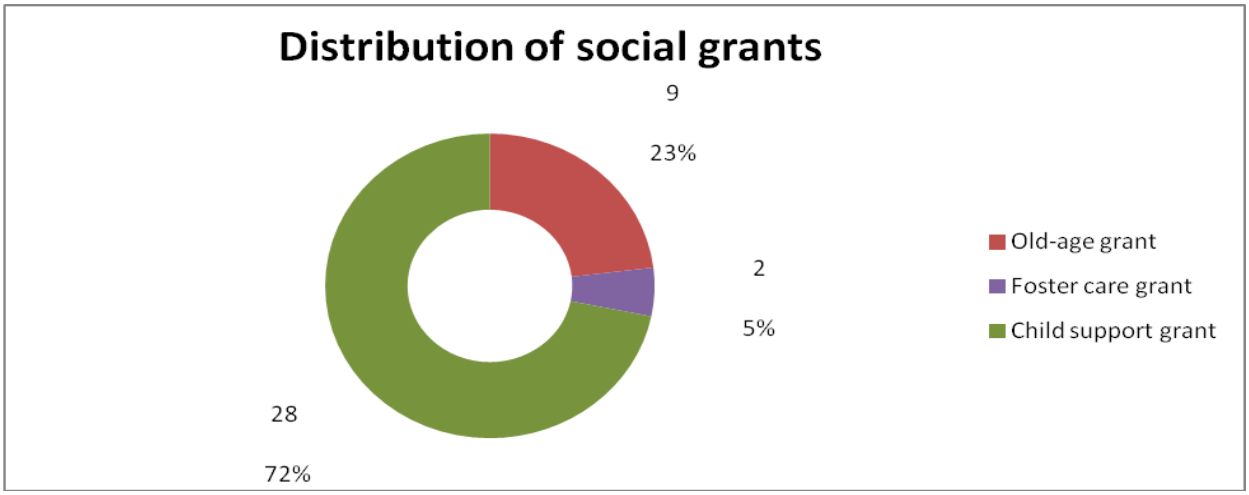

Figure 6.8: Distribution of social grants received by participants and their households.

Figure 6.8 depicts the three main social grants received by participants. Participants were also given the choice to indicate whether they or somebody else in their household receives a disability, war veteran, care dependency, grant-in-aid and social relief of distress grant but none of the participants were receiving the grants mentioned.

As illustrated in figure 6.8 the three main grants are old-age, foster care and child support grants. Among the 25 (N=25) participants who were interviewed, there a total of 28 (72%) received child support grants, while there were nine (23%) old-age grants received in their households. Only two (5%) (n=25) of the participants have someone in their household receiving a foster care grant.

It is significant that 72 % of the grants are child support grants because a definite link can be made to societal factors that may impact on some pregnancy outcomes. Here, socio-economic status (SES) may have an influence on grief responses as mentioned by Weck *et al*., (2008:349). Brownlee and Oikonen, (2004:523) mentioned that despite the apparent role of social support in grieving, little attention has been paid to the influence of poverty on the grief process, even though it must be accepted as a significant factor affecting access to social supports. Southard (1991) reported only references to poverty and none relating to grief and stillbirth. Recent searches of the social work and psychology abstracts found that this dearth of literature on poverty and grief continues to exist.

Black and Rubinstein (2000:207) point out that poverty is intricately linked to all experiential domains, such as self-concepts, regrets and hopes, opinions about others, and thoughts about God, thus the very experience of grief. Poverty may also be implicated in environmental conditions that contribute to the pregnancy loss and may convey to the mother a heightened sense of failure. Brownlee and Oikonen, (2004:523) added that the implication of poverty as a critical variable in the grief process reinforces the contribution and role that social work could play in identifying women at risk, reducing social isolation and addressing the complete well-being of families who have lost a child in the stillbirth period.

6.4.1.9 Total gross monthly income of family

Gross monthly income of participants and their households indicates the socio-economil status (SES) of an individual. Participants were asked to give an indication of the household's income in order to estimate the ratio. The figure below illustrates these incomes and the total of each category is.

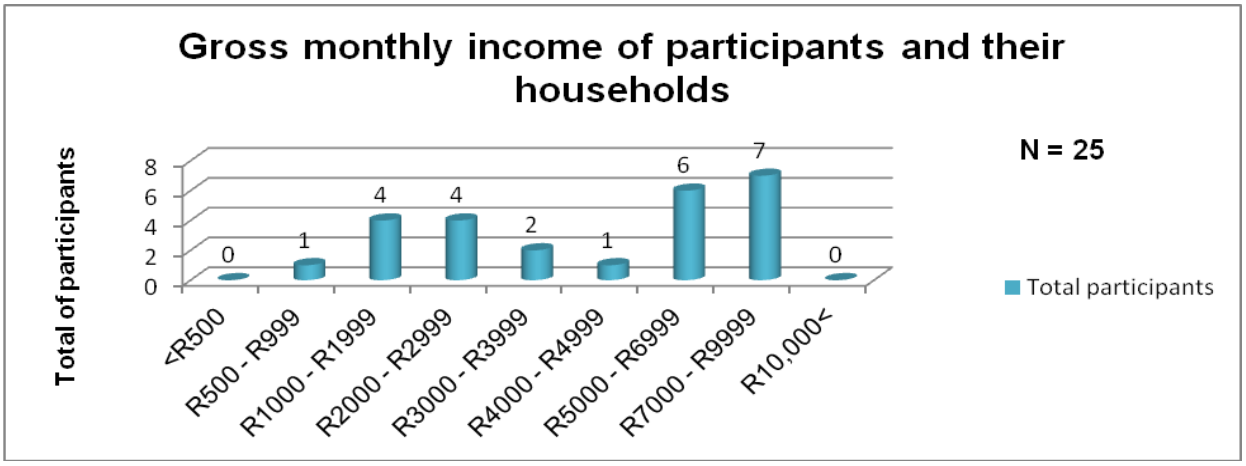

Figure 6.9: Gross monthly income of participants including their households

In the figure above, it is observed that there is rather an even distribution of gross monthly income among participants. The two income groups with the highest total participants in the group are the group earning between R7000 – R9999 per month, with seven (28%) of the participants (N=25) in this group, while six (24 %) of the participants are in the R5000 – R6999 income group are.

In the income groups, R1000-R1999 and R2000-R2999 there are both four (16%) participants. Two (8%) of the participants are in the R3000 – R3999 income group and one (4%) participant is in the R500 – R999 and in the R4000 – R4999 groups. There are no participants in the less than R500 or R10, 000 and above categories.

Referring to figure 6.6, five families have two sources of income and that may contribute to the fact that 28% and 24% are in a bigger income group. This is the gross monthly income for the whole family which means it is still very low considering the current economic environment.

6.4.1.10 Number of other (living) children

Participants were asked to indicate whether they have any other children.

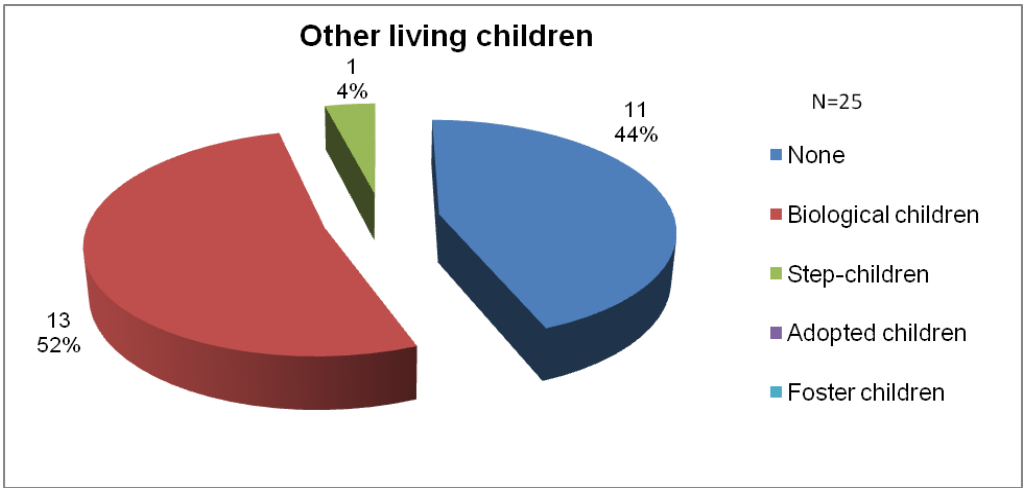

Figure 6.10: Other living children

Eleven or 44% of the participants have no other children and the stillborn baby was their first. Thirteen or 52% of the participants have other biological children. The sample size of the biological children is 23 with a sample mean of 1.7. One (4%) of the participants has step-children.

6.4.1.11 Distribution of children in different age groups

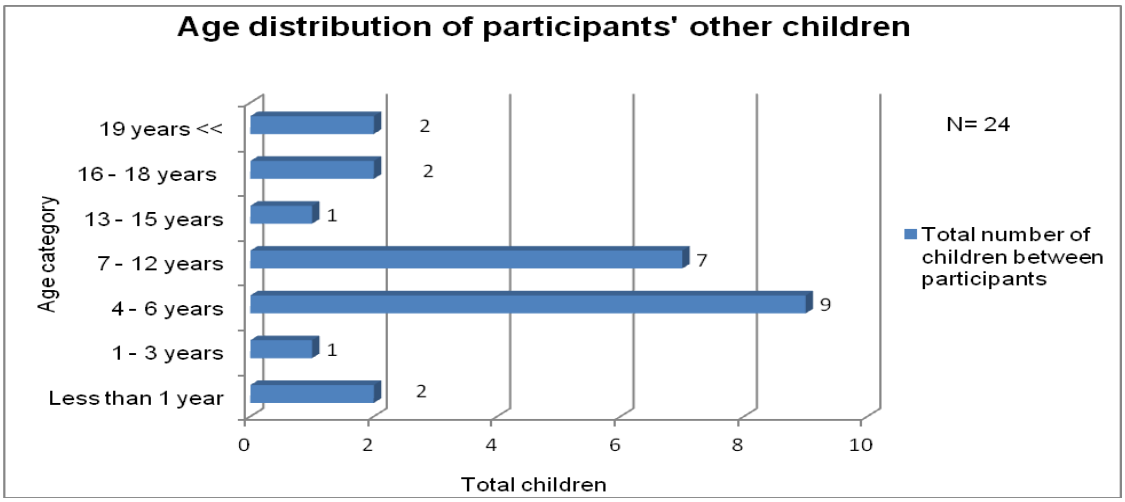

Figure 6.11: Age distribution of participants' other children

As shown in figure 6.11 above, it is clear that the majority of other living children of participants fall in the following two groups: Nine (37,5%) of the children fall under the four to six years category, while seven (29,16%) of the children fall under the seven to 12 year category. The total number of children in this sample is 24, (N=24). It is significant that in the category less than one year there were two (8,3%) children and in

the one to three years age group there was only one (4,16%) of children. This may indicate that participants have not thought of another baby yet.

In the age groups 13 to 15 years there was one (4,16%) child and in both the age groups 16 to 18 and 19 and older there were two (8,3%) children. The participants who already had much older children indicated that this pregnancy was unexpected and that they did not want to go through such a tragedy or loss again.

6.4.1.12 Religion of participants and partners/husbands

Religion and spirituality were found to be significant in the way an individual grieves and experiences the loss of a loved one. Literature (Capitulo, 2005:395; Cacciatore, 2010:144; Callister, 2006:229) indicates that it is common for parents who have a spiritual belief to want to connect their baby with God, often through religious rituals. If, for instance, a family desires a memorial service, care should be taken to create a service that is positive and healing and has special meaning for them.

Participants were asked to the religion they and their partners belong to. This was to establish whether religion plays a role in the participant's life and whether this is something she shares with her partner or husband. When a couple belong to different religions or church groups, it may lead to further tension in the relationship. The following graph illustrates the different church groups represented.

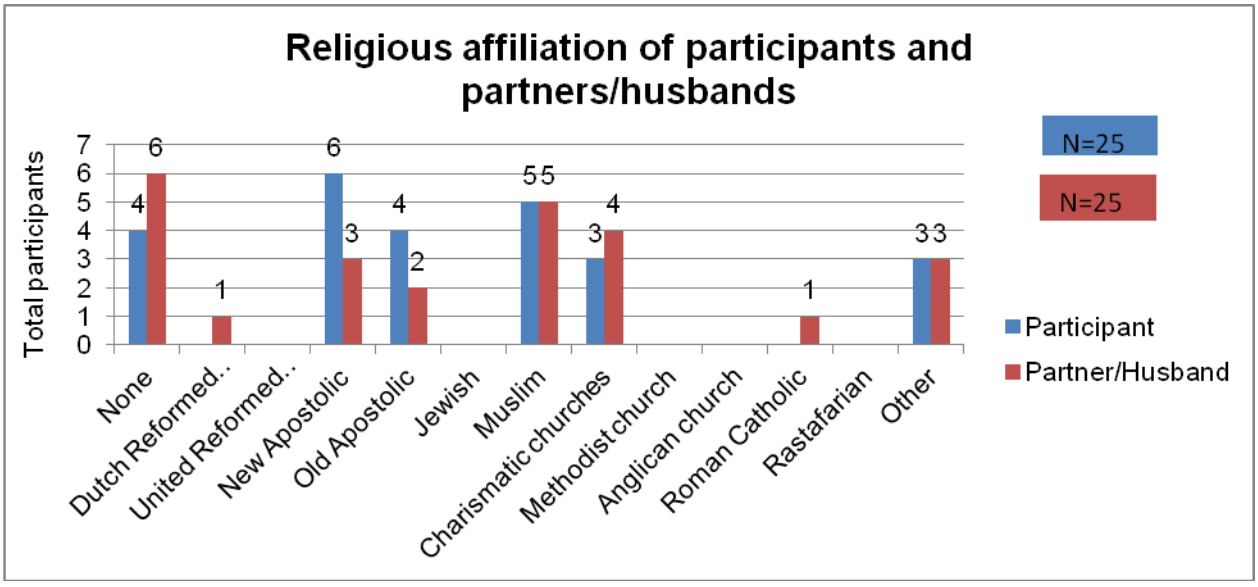

Figure 6.12: Religious affiliation of participants and partners/husbands

The above figure shows that the three groups with the most respondents are the

groups “none” (not attending any church or belonging to any religion), New Apostolic and Muslim. The group that professes no religion (None) includes respectively four (16%) (N=25) of the participants and six (24%) (N=25) of the partners/husband, with a total of 40% when combining the two groups (N=50).

Participants belonging to the New Apostolic church number six (24%) (N=25) respondents and three (12%) (N=25) partners/husband, with a total of 36% when combining the two groups (N=50). The other group to which a number of respondents belong is the Muslim group with five or 20% participants and five or 20% partners, with a total of 40% when combining the two groups. These statistics confirm that the two main groups are the non-religious group, and the Muslim group.

Figure 6.12 further illustrates that one (4%) of the partners/husband belongs to the Dutch Reformed church and one (4%) to the Roman Catholic church. Four (16%) of the participants and two (8%) of the partners/husbands belong to the Old Apostolic church, with a total of six or 24% when combining the two groups. Three (12%) participants and four (16%) partners/husbands belong to a charismatic church, with a total of seven (28%) when combining the two groups. Lastly the above figure shows that three (12%) of the participants and their partners/husbands belong to other groups such as the Seventh Day Adventist church. The statistics illustrate that participants and their partners/husbands do not necessarily belong to the same religious groups and that there are also indications that one of the partners or participants belongs to a church group while the other doesn’t. This may have an effect on the grief process from a religious viewpoint because while some participants or partners could turn to religion for strength during this difficult time, some won’t have this extra support.

6.4.1.13 Type of housing

Participants were asked to indicate the type of housing they currently reside in. This was asked to gain information and to establish whether poor housing conditions could contribute to low social support and possibly absent or delayed grief. Literature reports (Brownlee & Oikonen , 2004:523; Hobel *et al*., 2008:337) also show that little research has been done on socio-economic situations (housing and

income) of individuals that may affect the way individuals experience such a crisis.

Figure 6.13 depicts the current housing circumstances.

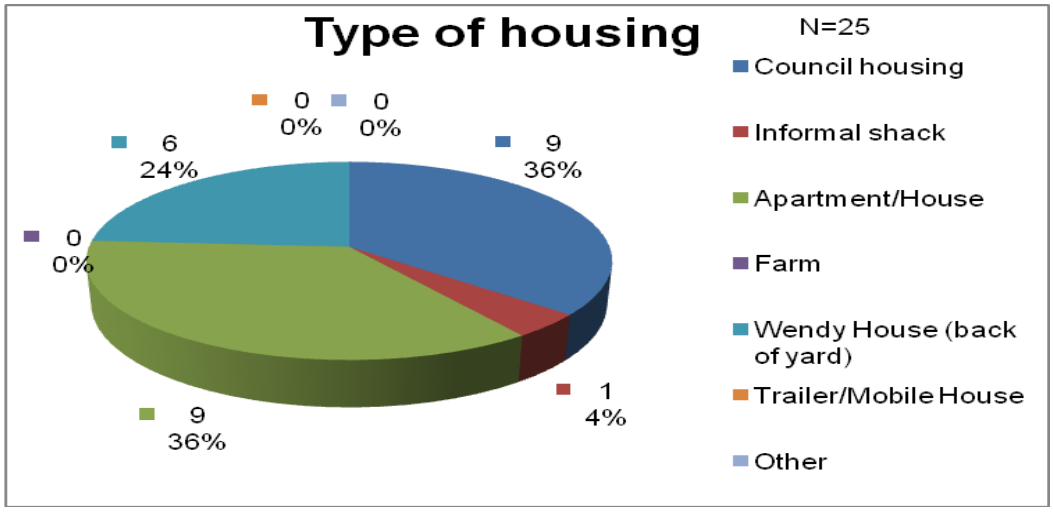

Figure 6.13: Housing circumstances of participants

In figure 6.13, nine (36%) participants are living in council houses while the same number, also nine (36%) live in regular houses/apartments. This shows that more than half of the participants, 18 (72%), live in safe structures, although this might not be interpreted that these 72% of participants are financially stronger than the other participants. Housing circumstances must be linked with financial income, as done in figure 6.9. The two income groups with the highest total participants in figure 6.9 were the group earning between R7000 – R9999 per month. Seven (28%) of the participants (N=25) were in this group while six (24%) of the participants were in the R5000 – R6999 income group. Referring back to figure 6.6, five families have two sources of income and that may account for the fact that 28% and 24% of participants are in a larger bigger income group. This is the gross monthly income for the whole family which makes it still very low considering the current economic environment.

Six (24%) participants are currently living in a Wendy house in the back of someone's yard, while one (4%) of the participants lives in an informal shack. No (0%) participants fall in the categories of farm, trailer or other.

6.4.1.14 Number of occupants in the house

Size of living space can be seen as a potentially problematic stress

variable. It can also be indicative of a low socio-economic status and household strain (Hobel *et al.,* 2008:336). Participants were asked to indicate how many participants they are living with.

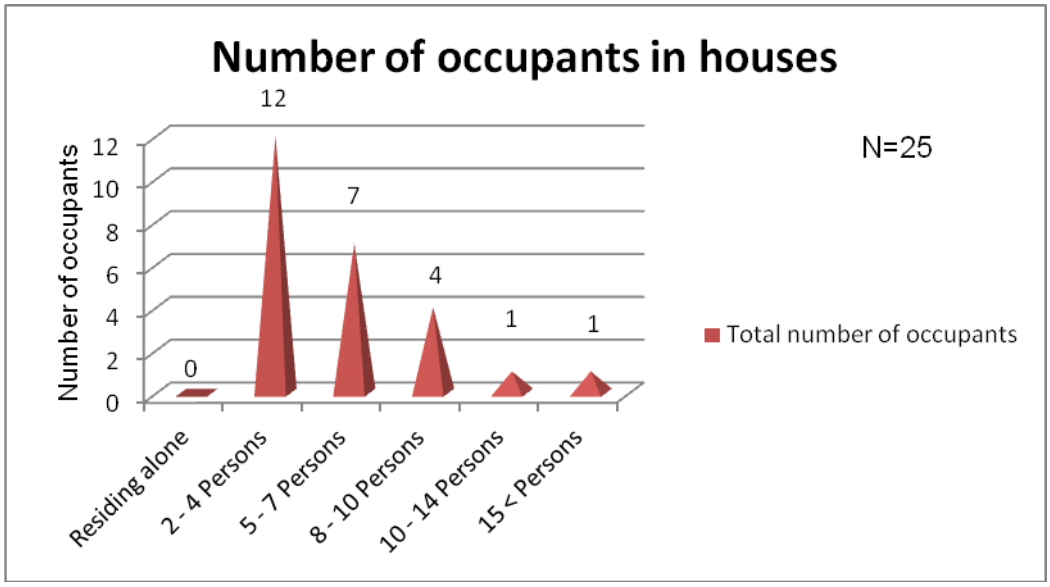

Figure 6.14: Number of occupants in the house

Figure 6.14 illustrates that most respondents, 12 (48%) together, live in households with two to four persons. The second biggest group is the group with five to seven occupants in the house. Seven (28%) of the participants belong to this group. Four (16%) of the participants were living in houses together with between eight and ten occupants. One (4%) of the participants was living in a house with ten to 14 occupants and 15 or more occupants. None of the participants was residing alone.

Although almost half, 48% of the participants fall in the "two to four occupants category", the rest of the participants combined, which add up to 52%, fall in the categories with more occupants. This may suggest household strain and low socio-economic status, especially in the last two groups, each with more than ten occupants, and most council houses having only two bedrooms.

6.4.1.15 Access to basic services

Participants were asked to indicate whether they have access to basic services. This information can be beneficial in providing a background on socio-economic

status of participants.

Table 6.2: Indication of respondents' access to basic services

Basic Services	No	Yes
Electricity	1	24
Phone/Cellphone	3	22
Running water (inside the house)	5	20
Toilet (inside the house)	7	18

N=25

Table 6.2 presents out respondents' access to basic services. Four basic services were identified namely electricity, phone, running water inside the house and toilet inside the house. The table shows that the majority of the respondents have access to all four services identified. Twenty-four (96%) of the respondents have access to electricity while one (4%) of the respondents has no access. Twenty-two (88%) of the respondents have a cellphone or phone while three (12%) do not. Access to a phone or cellphone is not exclusively for the respondent alone, but for any family member in the household.

Twenty (80%) percent of respondents have running water in the house while five (20%) have no access to running water inside the house. Eighteen (72%) of the respondents have a toilet inside the house while seven (28%) of the respondents do not. Although the rest of the statistics might look positive, it is perturbing that seven (28%) and five (20%) of the participants have no access to basic services like a toilet and running water. When combining these two statistics, it shows that 48% of participants have no proper access to these services. This might be caused by unemployment and low socio-economic status. (See figures 6.6 and 6.9 for earlier discussion of this.)

The identifying information presented above in 6.4, provides the respondents' environmental, financial and family conditions. This information supplies the setting in which the lived experiences of mothers suffering a stillbirth can be best understood. The next section of this chapter will focus on the personal experiences of the bereaved mothers.

6.5 Results of the empirical investigation: Qualitative study

The findings of the empirical study and the interpretation of the data in comparison with the literature review will be presented below according to Section B – G of the administered schedule.

6.5.1 Loss of a baby

The first section, Section B, involves questions regarding the loss of a baby. The information is presented below.

6.5.1.1 Types, number and date of last loss

Respondents were asked to indicate whether they had had any other loss apart from the stillbirth and when that had occurred.

Table 6.3: Types and number of losses of respondents

Type of loss	Number of losses
Ectopic pregnancy	1
Miscarriage	6
Therapeutic abortion	0
Stillbirth	26
Neonatal death	0
SIDS	0
Infant death	1
Total losses	**34**
N=25	

Tabel 6.3 demonstrates that some of the respondents experienced multiple losses with a total of 34. The most losses, 26, are stillbirths. This is not surprising because the focus of this study is on stillbirth exclusively. The fact that there are 26 stillbirths reported out of a sample of 25 participants (N=25) indicates that one (4%) of the respondents has experienced the tragedy of a stillbirth twice.

The other types of losses are one ectopic pregnancy, six miscarriages and one infant death. This is worth mentioning as it can have an impact on respondents' grief reaction.

Callister (2006:230) mentions that once a woman has experienced a perinatal loss she may not perceive a subsequent pregnancy in a normal fashion. She might have ambivalent feelings and doubts with concerns that another liss could occur. (See also Cacciatore, 2010:142 and McCoyd, 2010:144.) The sample mean of losses per respondent is 1,36%.

Eight (32%) (N=25) of the respondents indicated that they suffered a stillbirth 18 months ago. One (4%) of the respondents had a stillbirth 17 months ago while three (12%) had a stillbirth 16 months ago. One (4%) of the respondents had a loss 14 months ago and 12 months ago respectively. Four (16%) respondents had a stillbirth 11 months ago while two (8%) had respectively a loss ten, nine, seven and six months ago. None of the respondents had a loss 15, 13 or 18 months ago. These data correlate with the overall hypothesis of the study which is: "*The loss of a fetus/baby has longterm psychosocial implications for the mother and her family as perceived by the mother and proper social work support is needed to alleviate the grief process during the crisis period as well as the adaption period thereafter."* The research criteria have been met because all the respondents have experienced their stillbirth more than six months ago, which are seen as long term.

6.5.1.2 Current emotions, six or more months after the stillbirth

Participants were asked to describe the emotions they are currently experiencing, six or more months after the loss. This was an open-ended question and the researcher had to take great care to be sensitive of participants' feelings and emotions.

Table 6.4: Current emotions, six or more months after the stillbirth

THEME: CURRENT EMOTIONS SIX OR MORE MONTHS AFTER STILLBIRTH			
Subtheme	**Categories**	**Narratives**	**f (%)**
Ambivalent emotions	Crying privately/openly	*"I don't cry physically, but I'm crying inside myself. Nobody can see me."* *"I still cry a lot, but not as much as in the beginning but a mother will always miss her child."*	11 (42%)
	Trying to go on with life	*"I have moved on. That's why I'm trying for a new baby now."* *"I try to keep myself strong and not to grieve about it any more."*	4 (16%)
	Self-blame	*"I still sometimes blame myself for her death, even though I got the autopsy result back."*	3 (12%)
Reliving the circumstances surrounding the stillbirth	Trying to make sense out of the loss	*"There is still that longing even though it happened a year and a half ago. I still relive the labour and those moments afterwards."* *I'm strong, but everything that happened is still on my mind, especially the doctors saying my baby was already dead inside me.*	2 (8%)
	Need for closure	*"I can't recall what happened. When I woke up in hospital they said that I've lost my baby."*	1 (4%)
Constant triggers	Seeing other healthy babies	*"My sister has a baby now, I'm sad for not being able to experience that kind of joy."* *"When I look at my friends' babies, then I feel jealous."*	5 (20%)
	Hearing of other stillbirths	*"When I hear of other people experiencing a stillbirth, I go through all the pain again."* *"If I hear of a mommy who had a stillbirth, I get that old feeling again."*	2 (8%)
	Anniversary dates	*"I always cry on a Sunday, that's the day she was born."* *"I don't like the anniversary of his death, it's too hard, but we will go to the graveyard."*	3 (12%)
Role of family and friends	Pressure from family and friends	*"My mother mentioned that it's almost four years and she doesn't have a grandchild yet."* *"My colleagues will say it's time to move on now and that I must get pregnant again."*	2 (8%)
	Lack of continuous support	*"They would say 'I'm sorry' and then after a while they would expect you just to be over it."*	1 (4%)
	Positive support	*"My family won't let me think about it and wanted me to talk about other things, but not about the loss."*	4 (16%)

Can't come to terms with the stillbirth	Regret not holding baby after delivery	*"I just looked at her, but I didn't hold her to be honest. But then I regret not holding her."* *"Just feels as if I never had the chance to hold my baby. Everything happened so fast."*	2 (8%)
	Still think of baby every day	*"It is almost two years now, but the thought is still there, it will never go away."* *"I still think of my baby, how it would be if he was alive."*	5 (20%)
Coping mechanisms (Positive and negative)	Denying the loss	*"I don't talk about it. I keep everything to myself."* *"If I don't think of my loss, I don't need to grieve."*	3 (12%)
	Selfharming	*"I wanted to be alone so that I can cut myself and feel some relief of my pain."* *"I thought if I take a few tablets, mix them and drink them, that it will help me to forget."*	4 (16%)
	Acceptance of loss	*"I accept it now, look, it's almost a year and a half ago."* *"I accepted the loss; my tears won't bring my baby back."*	3 (12%)
	Using illegal substances	*"I started using dagga again to help me sleep at night and to help me forget."*	1 (4%)
	Role of religion	*"My husband told me not to worry, because the Lord will help us and give us another child."* *"I made peace with it, it's God's will."*	8 (32%)
	Avoid graveside	*"We tell each other that she is already with God and that he has her in his hands. She is not at the grave any more."*	2 (8%)
Subsequent pregnancies	Fear of losing baby or not being able to have a baby again	*"Like the new baby. Lots of things happen. Sometimes I felt I'm going to lose the baby if I don't feel the baby kicking."* *"I feel excited, but not as excited as the first pregnancy, I'm too afraid of another loss."*	6 (24%)
	Need to acknowledge the stillbirth	*"People ask how many children you have and you can't always hide the loss from them, and you don't want to."* *"The other day a woman asked me how many children I've got, and I told her about the stillbirth. She was my child."*	2 (8%)
	Subsequent loss	*"Sometimes I wonder why it had to happen to me twice, first the stillbirth and now a miscarriage."*	1 (4%)
	Avoidance of a subsequent pregnancy	*"I don't want another child, because I don't want to go through the pain again."*	1 (4%)

N = 25

During this question, 19 (76%) of the participants were crying while describing their current emotions. This is a sign that even though the stillbirth occurred more than six months ago, it is still a very emotional topic to discuss. Seven subthemes were identified during these interviews. The percentage indicated in table 6.4 is an indication of how many participants had the same experience, and several participants displayed emotion at more than one subtheme.

(i) Ambivalent emotions

According to table 6.4, 11 (46%) of the participants mentioned that they are still crying a lot openly or that they are trying to cry privately. Only four or 16% of participants indicated that they were actively trying to go on with life *("I have moved on. That's why I'm trying for a new baby now.").* Furthermore three (12%) participants still blamed themselves for the stillbirth. These three categories show that participants are experiencing ambivalent emotions.

(ii) Reliving the circumstances surrounding the stillbirth

Table 6.4 illustrates that two (8%) of the participants still relive the circumstances surrounding the stillbirth, in order to make sense of the loss *("There is still that longing even though it happened a year and a half ago. I still relive the labour and those moments afterwards."*). One (4%) of the participants explained that she relives the stillbirth because she needs to get closure ("*I can't recall what happened. When I woke up in hospital they said that I've lost my baby.").*

(iii) Constant triggers

According to table 6.4, participants experience constant triggers which lead to different emotions. Constant triggers are seen as the third subtheme. Five (20%) struggle to control their emotions when seeing other healthy babies *("When I look at my friends and their babies, then I feel jealous.").* Two (8%) of the participants experience it very negatively when hearing of other stillbirths *("When I hear of other people experiencing a stillbirth, I go through all the pain again."*). Table 6.4 also indicates that three (12%) of the participants see anniversary dates as constant triggers *("I don't like the anniversary of his death, it's so hard, but we will go to the graveyard.").*

(iv) Role of family and friends

Participants mentioned that the role of family and friends was important. Two (8%) of the participants mentioned that they have experienced pressure from family and friends to fall pregnant again *("My colleagues will say it's time to move on now and that I must get pregnant again".)*. Lack of continuous support was also mentioned by one (4%) participant *("They would say "I'm sorry" and then after a while they would expect you just to be over it.").* Four (16%) of the participants indicated that they felt their family and friends really understood them and gave positive support. Stringham *et al.,* (1982) pointed out that sometimes family members and friends do not respond because they feel they are being helpful by doing nothing. Perhaps they are told by someone, or they tell others, to refrain from calling the bereaved parents so as not to upset them. They avoid the mother or grow impatient with her continued sadness (Stringham *et al.,* 1982).

(v) Can't come to terms with the stillbirth

Table 6.4 illustrates that two (8%) of the participants regret not holding their baby and that this has a major influence on them coming to terms with the stillbirth (*I just looked at her but I didn't hold her to be honest. But then I regret not holding her.")*. Five (20%) of the participants still think of their baby every day since the loss *("I still think of my baby every day, how it would be if he was alive.").*

(vi) Coping mechanisms (Positive and negative)

As shown in table 6.4, subtheme six is about coping mechanisms. Six categories are identified under this theme, namely: Three (12%) participants show denial of the loss which is a negative coping mechanism (*If I don't think of my loss, I don't need to grieve.").* Another negative coping mechanism is that of selfharming. Four (16%) participants explained that they tend to hurt themselves to forget about their pain ("*I want to be alone so that I can cut myself and feel some relief of my pain."*). Acceptance of the loss was identified as a positive coping mechanism. Three (12%) of the participants mentioned that they accepted the loss (*"I accepted it now, look, it's almost a year and a half ago.").*

One (4%) of the participants started using illegal substances to help her cope. (*"I started using dagga again to help me sleep at night and to help me forget."*). This is a negative coping mechanism. Mahan and Calica (1997:16) mentioned that the bereaved

mother blames herself and feels guilty that she might be the cause of the stillbirth. She might have irrational thoughts such as that she was too stressed, working too hard, eating unhealthily, and using illicit substances, smoking and having feelings of not wanting the pregnancy at the beginning.

Two (8%) of the participants mentioned that they avoided the graveside because their baby was not there any more. The role of religion as a positive coping mechanism was indicated by eight (32%) of the participants, which is an overall high score ("*My husband told me not to worry, because the Lord will help us and give us another child.")*.

(vii) Subsequent pregnancies

According to table 6.4 four categories were identified under the subtheme of subsequent pregnancies. Six (24%) participants mentioned that they had a fear of losing another baby or of not being able to have a baby again *("I feel excited but not as excited as the first pregnancy, I'm afraid of another loss.")*. Two (8%) participants identified a need to acknowledge the stillbirth. Furthermore one (4%) participant had a subsequent loss and because of the fear of another loss, mentioned that she is avoiding a subsequent pregnancy *("I don't want another child because I don't want to go through the pain again."*). This correlates with literature of Mahan and Calica (1997:16) who mentioned that there may be a pervading sense of anxiety and insecurity, ambivalence and doubt, with concern that the loss of another child will occur. The "vulnerable child" syndrome, where parents are overprotective of a subsequent child, can easily occur.

6.5.1.3 Current health issues, six or more months after the stillbirth

Participants were asked about health issues six or more months after the loss.

Table 6.5: Health issues of respondents six or more months after loss

Health Issue	n (%)
Currently pregnant	6 (24%)
Weight loss	3 (12%)
Headaches	6 (24%)
Kidney problems	1 (4%)
High blood pressure	1 (4%)
Weight gain	1 (4%)
Menstrual problems	2 (8%)
No health problems	5 (25%)

N=25

Grief, especially complicated grief, can lead to certain health issues (Stroebe *et al.,* 2005:55). According to table 6.5, six (24%) of the participants are currently pregnant which can lead to higher levels of stress and anxiety due to fear of a subsequent loss (Callister, 2006:230). Three (12%) of the participants had significant weight loss, while one (4%) reported weight gain. Headaches were also a prominent health issue with six (24%) participants reporting this. Kidney problems and high blood pressure were represented by one (4%) participant each, while two (8%) of the participants experience menstrual problems. Lastly five participants didn't have any health issues.

6.5.1.4 Comparing thoughts experienced directly after the loss with thoughts experienced a few months later

Participants were asked to indicate which thoughts were in their minds after the loss and whether they still felt the same six months or longer after the loss.

Table 6.6: Comparing thoughts experienced directly after the loss and current thoughts

	Yes - I did experience it	No - I did not experience it	I am still having these thoughts
I am afraid to fall pregnant again.	21 (84%)	4(16%)	12 (48%)
I wanted to fall pregnant again as soon as possible.	5 (20%)	16 (64%)	10 (40%)
I feared another loss.	21 (84%)	4 (16%)	19 (76%)
When I saw other babies, I longed for my own baby.	23 (92%)	2 (8%)	22 (88%)
I have/had nightmares about my baby (or babies).	12 (48%)	13 (52%)	7 (28%)
I had thoughts of committing suicide.	7 (28%)	18 (72%)	3 (12%)
I felt nobody understood me or cared for me.	15 (60%)	10 (40%)	8 (32%)
I had thought of stealing another baby.	1 (4%)	24 (96%)	0 (0%)
I avoided other babies.	13 (52%)	12 (48%)	5 (20%)
I was unable to pack my baby's clothes away -left it just like it was for a very long time.	16 (64%)	7 (28%)	8 (32%)
I tried to be strong and not show my hurt.	20 (80%)	3 (12%)	17 (68%)

N=25

Twenty-one (84%) of the respondents indicated that they were afraid of falling pregnant again, while four (16%) participants mentioned that they were not afraid. Twelve (48%) participants mentioned that they are still feeling afraid of falling pregnant even though it was more than six months ago. According to table 6.6, five (20%) of the participants indicated that they wanted to fall pregnant as soon as possible, while 16 (64%) mentioned that they would rather not fall pregnant so soon. This shows that the vast majority of participants rather wanted to wait before falling pregnant again. Currently only 10 (40%) of the participants still want to fall pregnant as soon as possible. Twenty-one (84%) participants indicated that they feared another loss soon after the stillbirth and 19 (74%) mentioned that they still felt this way. Only four (16%) participants did not fear another loss at any stage after the loss.

Table 6.6 illustrates that 23 (92%) participants longed for a baby when they saw other babies shortly after their own stillbirth, while 22 (88%) participants still felt the same way even though six months or more have passed. A minority of only two (8%) of the participants did not express a longing for their own baby. Table 6.6 furthermore signifies that 12 (48%) participants had nightmares of their babies shortly after the loss, with

seven (28%) of the participants still experiencing this. Thirteen (52%) participants never experienced any nightmares. Seven (28%) participants had thoughts of committing suicide while three (12%) participants still had these thoughts. Eighteen (72%) of the participants never had these thoughts. This correlates with Hughes and Riches (2003) opinion on pathological grief. They identified two types of pathological grief: *prolonged grief* and *absent grief*. Thoughts of suicide fall under *prolonged grief,* with no improvement after six months.

Fifteen (60%) of the participants felt that nobody understood them after the loss, with eight (32%) participants indicating that they still felt this way. Ten (40%) of the participants felt cared for and understood. According to table 6.6 only one (4%) participant had thoughts of stealing a baby soon after the loss but no (0%) participants still felt like doing this. The majority of participants, 24 (96%), never felt like stealing another baby at any stage after the stillbirth. Thirteen (52%) of the participants avoided the babies soon after the loss while 12 (48%) participants never felt like avoiding any baby at any stage after the loss. Five (20%) participants still avoided other babies.

Table 6.6 shows that 16 (64%) of the participants were unable to pack away the baby clothes, while eight (32%) participants mentioned that they were still unable to pack away the clothes, six months or more after the loss. Seven (28%) of the participants were able to pack away the clothes. Finally 20 (80%) of the participants reported that they tried to be strong and not show any hurt. Seventeen (68%) participants reported still doing this, with only three (12%) of the participants not hiding their emotions. According to Hutti (2005:633) family members do not know how to respond appropriately and the bereaved mother/couple tend to pretend that they are coping well.

6.5.1.5.1 Participants' views on their own possible depression

Participants were asked to indicate whether they felt depressed at any stage of the loss. This was to establish the participants' knowledge of depression, as well as to distinguish between a normal grief process and depression or pathological grief. More than half of the respondents, 13 (52%) indicated that they saw themselves as being depressed at some stage after the loss. The following narratives show this: *("Yes, there*

were times that I felt depressed. Then I don't want to eat, can't sleep and I just want to be alone in my room because I'm irritated with everybody.") and *("I felt depressed. I started feeling like this in the hospital already. That is why I took an overdose of pills. I think that is a sign of depression.")* The last narrative points to pathological grief because of the suicidal thoughts.

Eight (32%) participants reported that they were not depressed, but that they would feel sad for a few days and then feel better again. They mentioned that they were experiencing a normal grief reaction and process *("No, I didn't feel depressed, but I had my off days which I guess is part of the grief process.")*. Three (12%) of the participants reported just feeling lonely or wanting to be alone some days, but they didn't perceive themselves as being depressed. One (4%) participant mentioned that she did not feel depressed, just more stressed after the loss.

6.5.1.5.2 Participants' views on possible depression of their partners

Literature (Hutti, 2005:63; Stringham *et al*., 1982:323) observed that bereaved fathers experiencing a stillbirth with their partner cope in different ways and tend to keep their emotions to themselves. To test this postulation, participants were asked about their views on possible depression of their partners. The following ways of coping were identified according to the narratives of participants:

(i) Supportive and strong

Three (12%) of the participants indicated that their partners were very supportive and helped them to be strong (*"He was strong, he was encouraging me."*).

(ii) Crying and being angry, but not depressed

Five (20%) participants mentioned that they saw their partners crying a lot after the stillbirth and some of the partners were angry, but not with anybody in particular, that the baby has died *("He was different and angry. I saw him crying a lot.")*.

(iii) Keeping their feelings to themselves.

The most participants, nine (36%), reported that their partners did not really talk about their feelings and that they did not really know how their partners were feeling inside.

("He wasn't depressed, but just wanted to be on his own and didn't want to talk about it."). These findings correlate with literature (Hutti, 2005:631; Stringham *et al.,* 1982:323) because the incidence of not sharing their feelings with the partners, was the highest in this research.

(iv) Behavioural change

Three (12%) of the participants explained that their partners started using alcohol excessively and one partner started smoking tik *("He acted normal, but after a while he started drinking and just didn't care any more.").*

(v) Continued normal behaviour

("He was sad, but I don't think he was depressed…He wasn't so low. He continued as normal."). Four (16%) participants mentioned that they perceived their partners as continuing with life as usual, without any significant change in behaviour.

(vi) Depressed

("He looked forward to his first child. He denies that his baby is dead. I think he is depressed."). Only one (4%) participant indicated that she perceived her partner as being depressed because of his total denial of his baby's death. (See Capitulo, 2005:390.)

6.5.1.6.1 Participants' knowledge regarding the symptoms of their depression

Participants were asked to identify one or more of the symptoms of depression they have been experiencing after the loss. Six main symptoms were classified.

Table 6.7: Symptoms of depression as identified by participants

Symptoms of depression as identified by participants	f (%)
Longing to be alone	8 (32%)
Crying all the time	7 (28%)
Poor appetite	11 (44%)
Sleeping problems/Can't sleep	13 (52%)
Overdose of pills	1 (4%)
Suicidal thoughts	1 (4%)

N=25

Eight (32%) participants felt a ***"Longing to be alone"***, while ***having a poor appetite*** (11=44%) and ***sleeping problems*** (13=52%) also scored a high percentage. ***Wanting to cry all the time*** was reported by seven (28%) participants. More serious symptoms like ***suicidal thoughts*** and ***taking overdose of pills*** were identified by one (4%) participant each.

6.5.1.6.2 Medication prescribed for depression

Participants were asked whether any medication was prescribed to them to help them cope better with the stillbirth and grief. If medication was prescribed, this might be an indication of complicated grief. Moody and Arcangel (2002:97) explain that fixated grief, for instance, causes survivors to remain stuck at one point. They slide into an unhealthy, prolonged withdrawal. This can necessitate the use of anti-depressants. Information gained from the interviews, shows that 21 (84%) participants **did not receive any medication** and also did not see the necessity for it. One (4%) participant felt **talking to a psychologist helped**, one (4%) **didn't return to hospital** after her overdose, one (4%) participant believed using dagga will help her forget about her tragedy, and lastly only one (4%) participant was **prescribed anti-depressants and sleeping pills** after the loss.

6.5.1.7 Pregnancy history

Subsequent losses, struggling to fall pregnant and difficult pregnancies can have a significant impact on the way an individual experiences a stillbirth.

Table 6.8: Pregnancy history of participants

Pregnancy history	**f (%)**
I fell pregnant easily.	13 (52%)
Pregnancy was preceded by a period of infertility.	8 (32%)
Only fell pregnant with medical assistance.	1 (4%)
I had a difficult pregnancy.	3 (12%)

N=25

According to table 6.8 the majority of participants, 13 (52%), indicated that they fell pregnant easily, while eight (32%) participants mentioned that their pregnancy only followed after more than a year of infertility. One (4%) fell pregnant after medical assistance. Table 6.8 furthermore illustrates that three (12%) participants have had a difficult pregnancy. The three participants who indicated that they had a difficult pregnancy have suffered from kidney problems, problems with cervix and bleeding during pregnancy.

6.5.2 The effect of the stillbirth on the marriage/relationships

The second section, Section C involves questions regarding the effect of the stillbirth on the marriage or relationship. The findings are presented below.

6.5.2.1 Participants' views on communication between partners: before, during and after the stillbirth

To establish whether the stillbirth had a significant effect on the relationship of a couple, participants were asked to identify which of the following statements apply to them. Table 6.9 presents the results:

Table 6.9: Statements regarding communication in a relationship

Statement regarding communication	Before stillbirth	During the stillbirth	Six months or longer after the stillbirth
We can discuss our feelings openly	17	15	19
We listen to each other with attention	15	17	19
We will ask each other about the day's happenings	19	17	17
We share the same interests	16	13	17
We have nothing to talk about	5	6	4
I can't share my emotions with my husband	8	8	6
We only talk about general issues	7	5	5
I can not confide in my husband	16	16	16

N=25

In table 6.9 the first four statements apply to positive communication and the bottom four indicate negative communication. Table 6.9 indicates that the majority of participants mentioned that the positive statements applied to their relationships and that the stillbirth didn't have a serious impact on their relationship with their partners. Table 6.9 also shows that the minority of participants indicated that they could not share their emotions with their partners and that they felt they have nothing to talk about. Lastly, table 6.9 shows that the final negative statement **"I can't confide in my husband"** was chosen by half the participants. When comparing the first statement, **"We can discuss our feelings openly"** and the last statement, **"I can't confide in my husband"** the participants who chose these two options are on average, the same. This implies that 50% of relationships stayed the same after a stillbirth, but that in the other 50% the bereaved parents still could not confide in their partners.

6.5.2.2 Participants' description of their marriage/relationship

An objective of this study is to ascertain the nature and consequences of the stillbirth on marital and/or family relationships as perceived by the mother. Table 6.10 below describes participants' perception of their relationship at different stages of experiencing a stillbirth.

Table 6.10: Description of the marriage/relationship during the time periods before and after the stillbirth

Time period before and after stillbirth	Description of Marriage			
	Very unhappy	**Somewhat unhappy**	**Fairly happy**	**Very happy**
Before the stillbirth	1 (4%)	3 (12%)	8 (32%)	13 (52%)
At the time of the stillbirth	8 (32%)	8 (32%)	6 (24%)	3 (12%)
One month after stillbirth	3(12%)	11 (44%)	7 (28%)	4 (16%)
Six months after stillbirth - Currently	2 (8%)	3 (12%)	10 (40%)	10 (40%)

N=25

As shown in table 6.10, more than half, 13 (52%), of the participants, reported that they were very happy in their relationship before the stillbirth. At the time of the stillbirth, the majority of the respondents were either very unhappy, eight (32%) participants, or

somewhat unhappy, eight (32%) participants. Only six (24%) of the participants were fairly happy, with only three (12%) participants very happy.

One month after the loss, there was a noticeable shift from negative descriptions of marriage to more positive descriptions again. Only three (12%) of the participants indicated that they were still very unhappy in their relationship, while 11 (44%) of the participant were somewhat unhappy. Seven (28%) participants mentioned that they were fairly happy again and four (16%) participants reported feeling very happy and supportive in their relationship again. Lastly table 6.10 illustrates that six months or longer after the loss the participants tended to feel positive about their relationship again. Ten (40%) of the participants mentioned that they were fairly happy in their marriage or very happy (10=40%) in their marriage/relationships. Three (12%) of the participants were somewhat unhappy, with just two (8%) participants very unhappy six months after the stillbirth. These two (8%) participants also mentioned that they had broken up with their partners.

The findings above correlate with literature on this subject. Hutti (2005:632) reports that women who think their partners are not supporting and caring enough after the loss, also perceive greater distance between each other. Those who perceived their partners as caring and engaged in mutual sharing of feelings and experiences perceived their relationship as closer. According to Callister (2006:228), stillbirth may create an added strain on the couple relationship, or the couple may grow closer and the bond may be strengthened. The author uses the term “incongruent grief” to refer to gender differences in how stillbirth is experienced by each parent (see chapter4).

6.5.2.3 Partner’s involvement during the pregnancy

Table 6.11 illustrates five subthemes which were identified when participants were asked to describe their partner/husband’s involvement during pregnancy. This question was important in order to compare any change in the relationship before and after the stillbirth.

Table 6.11: Partner/husband's involvement during the pregnancy

THEME: PARTNER/HUSBAND'S INVOLVEMENT DURING THE PREGNANCY			
Subtheme	**Categories**	**Narratives**	**f (%)**
Supportive and excited	Talking and touching baby in stomach	*"When he comes home from work, he always touched my stomach and greeted our baby."* *"He was more excited than me. He would talk to our baby all the time."*	13 (52%)
	Attending clinic/hospital visits with her	*"He went with me to every doctor's appointment or clinic visit."*	3 (12%)
	Asking how clinic visits went	*"He couldn't go with to the clinic because he was working, but he always remembered when my clinic dates were."*	8 (32%)
	Availability for me	*"He was always there if I phoned him or needed anything. When nobody wanted to accept the pregnancy, he was there for me."* *"He was there for me a 100% of the time."*	7 (28%)
Non-supportive and not involved	Not interested in the unborn baby	*"He never came to the clinic with me and he never touched my stomach to feel the baby kicking."* *"He won't always remember that I'm pregnant. He would go on as normal."*	3 (12%)
	Not interested in the relationship any more	*"He was almost never there and when he came, I ignored him."*	1 (4%)
Contributed financially	Buy clothes and necessities for unborn baby	*"He cared a lot for me and bought stuff for the unborn baby."* *"He was supportive and bought me everything I needed."*	3 (12%)
Easily influenced by friends	Sometimes chooses to be with friends, not with her	*"But when his friends come, he would rather spend time with them."* *"He was always with his friends. They were more important to him than me."*	2 (8%)
Chose not to involve partner in pregnancy	Not informing partner about the onset of labour	*"I didn't inform him that I'm going to hospital and that I'm in labour. I just felt he didn't care, so why does he need to know."*	1 (4%)

N = 25

(i) **Supportive and excited**

Four categories were identified under this subtheme. More than half, 13 (52%), of the participants indicated that their partners were talking and touching the baby in the stomach ("*He was more excited than me. He would talk to our baby all the time."*). Three (12%) of the participants mentioned that their partners attended clinic/hospital visits with them *("He went with me to every doctor's appointment or clinic visit."*). Eight (32%) participants reported that although their partners weren't able to attend the clinic with them due to work responsibilities, they would always ask how it went. The last category under this subtheme was identified as "availability". Seven (28%) of the participants mentioned that their partners/husbands were always there for them ("*He was there for me a 100% of the time."*). Literature (Armstrong, 2001; Puddifoot *et al.*, 1997; Wagner *et al.,* 1997; Borg & Lasker *et al.,* 1981; Cacciatore, 2009:91; Worth, 1997) has indicated a growing investigation of the paternal experience of stillbirth. Intense feelings of loneliness, isolation, and pain have been described by fathers.

(ii) **Non-supportive and not involved**

Three (12%) participants indicated that their partners/husbands didn't show any interest in the unborn baby *("He never came to the clinic with me and he never touched my stomach to feel the baby kicking.")*. One (4%) participant mentioned that after her partner learned about the pregnancy, he was not interested in the relationship any more ("*He was almost never there, and when he came, I ignored him.")*.

(iii) **Contributed financially**

Three (12%) participants reported that they were very satisfied in the way their partners would buy clothes and necessities for the unborn baby *("He was supportive and bought me everything I needed.").*

(iv) **Easily influenced by friends**

Two (8%) participants felt that their partners/husband chose to be with friends rather than with them *("He was always with his friends. They were more important to him than me.").*

(v) **Chose not to involve partner in pregnancy**

One (4%) participant explained that she did not inform her partner about the onset of labour, because she felt unsure about their relationship *("I didn't inform him when I went in to hospital and that I'm in labour. I just felt he didn't care, so why does he need to know.").*

6.5.2.4 Problems or changes in relationship after the stillbirth

Participants were asked to identify any changes, positive or negative in their relationship after the loss. The following were identified.

Table 6.12: Problems or changes in relationship after the stillbirth

THEME: PROBLEMS/CHANGES IN RELATIONSHIP AFTER THE STILLBIRTH			
Subtheme	Categories	Narratives	f (%)
No changes in relationship	Continued stability	*"We were alright with each other after the loss."* *"He still came to visit and nothing changed between us."*	5 (20%)
Communication	Improved communication	*"We both were able to verbalize our feelings towards each other. We felt safe within our marriage to share our feelings."* *"We were planning to get married just after the birth of the baby, but then we got married a few months later. Our relationship improved."*	7 (28%)
	Less communication: Didn't want to talk about the stillbirth	*"He still came to visit, but we spoke less than previously."* *"He never spoke about it or shared his feelings about it."*	9 (36%)
Insecurity	Fear of breaking up	*"Because now I lost the baby and he won't like that. Maybe he will leave me."*	2 (8%)
	Tension in relationship	*"The stillbirth created tension in our relationship."*	1 (%)
Fury or blame towards each other or oneself	Blaming participant for the stillbirth	*"He was angry towards me for having a stillbirth. I could see it in his behaviour."* *"For me it felt as if he blamed me for the stillbirth."*	4 (16%)
	Feelings of guilt	*"He made me feel guilty by saying that I shouldn't have picked up heavy things."* *"He said that the tik abuse caused the stillbirth. That makes me feel guilty even though he also smokes."*	3 (12%)
Poor coping mechanisms	Abuse of alcohol	*"He started drinking heavily."*	2 (8%)
Wanted distance in the relationship	Temporary distance	*"He stayed away for three months. He said he needed some time alone."* *"For me it felt that he thought there is no more baby, so why does he need to stay with me."*	4 (16%)
	Ended relationship	*"I ignored him and told him that there is nothing holding us together and that it's the end of the relationship."* *"We broke up. I saw him with another girl so I told him he better take his things and leave."*	2 (8%)

N = 25

To fully achieve the objective mentioned in 6.5.2.2, the problems and changes which occurred after a stillbirth in a relationship were explored. Table 6.12 provides a summary of these findings. Six subthemes were identified:

(i) **No changes in relationship**

Five (20%) participants indicated that they experienced continued stability in their relationship *("We were alright with each other after the loss, nothing changed.").* According to Wallerstedt and Higgins (1996:389) society's expectations that the father remain stoic and strong may affect his grief, because he responds in a manner he feels the culture demands. This may contribute to the fact that no significant changes take place in the relationship.

(ii) **Communication**

Table 6.12 illustrates that seven (28%) participants mentioned that their communication improved, while nine (36%) of the participants experienced that they were talking less and that especially their partner did not want to talk about it *("He never spoke about it or shared his feelings about it.").*

(iii) **Insecurity**

Two categories were identified under the subtheme insecurity. "Fear of breaking up" was identified by two (8%) participants *("Because now I lost the baby and he won't like that. Maybe he will leave me."*). One (4%) participant explained that the stillbirth created insecurity in their relationship because of extra tension in the relationship.

(iv) **Fury or blame towards each other or oneself**

Two categories were identified as shown in table 6.12. Four (16%) participants reported that their partner was blaming them for the stillbirth *(He was angry towards me for having a stillbirth. I could see it in his behaviour.").* Three (12%) participants mentioned that they themselves had feelings of guilt *("He made me feel guilty by saying that I shouldn't have picked up heavy things.").*

(v) **Poor coping mechanisms**

Two (8%) participants mentioned that their partners started drinking heavily and that changed the relationship negatively *("He started drinking heavily.").*

(vi) **Wanted distance in the relationship**

According to table 6.12, four (16%) participants experienced temporary distance in their relationship *("He stayed away for three months. He said he needed some time alone.").* Two (8%) participants reported that their relationships ended after the stillbirth *(I ignored him and told him that there is nothing holding us together and that it's the end of the relationship.").*

Table 6.12 demonstrates clearly that more than half, i.e. four, of the subthemes are negative and illustrate a negative change in a relationship. This correlates with Borg and Lasker (1981:85) who mentioned that many couples experience tensions after a stillbirth. He also mentioned that these tensions usually fade eventually, which explains the seven (28%) participants experiencing improved communication.

6.5.3 The effect of the stillbirth on other children/siblings

To ascertain the nature and consequences of the stillbirth on family relationships, especially those of siblings and other children, participants were first asked to identify any physical and emotional reaction the participants' other children presented with.

6.5.3.1 Physical and emotional reaction of siblings/other children after the stillbirth

More than half, 14 (58%) of the participants had other children and responded to this section of the interview. The other 11 (42%) didn't answer Section D of the Interview Schedule (see appendix B1 & B2). Table 6.13 shows that three subthemes were identified.

Table 6.13: Physical and emotional reaction of siblings/other children after the stillbirth

THEME: PHYSICAL AND EMOTIONAL REACTION OF SIBLINGS/OTHER CHILDREN AFTER THE STILLBIRTH			
Subtheme	**Categories**	**Narratives**	**f (%)**
No significant reaction	Normal reaction	*"He acted normal. There was nothing he could do about it."* *"He didn't yet understand what had happened."*	5 (20%)
Showing emotional reaction	Sad and reserved	*"I could see their faces looked quiet and sad."*	3 (12%)
	Crying a lot	*"I saw them crying a lot."* *"My daughter was very sad and cried a lot."*	5 (20%)
	Actively taking part in visiting the graveside and mourning	*"She talks to her brother when we are at the graveyard. She will tell him what is happening to her."*	1 (4%)
Continued questioning	Asked where baby is	*"She always asked me where the baby was and then I need to explain. It was so hard."* *"My twelve-year old still asks me where the baby is."*	4 (16%)
	Asking what happened all the time	*"My son wanted to know more of what happened to the baby."*	3 (12%)

N=14

(i) **No significant reaction**

Only one category was identified, that of a "normal reaction". *("He didn't yet understand what happened.")* Five (20%) participants reported that their other children acted normally.

(ii) **Showing emotional reaction**

Three (12%) participants mentioned that their children were sad and reserved, while five (20%) participants said that their other children cried a lot about the loss ("*My daughter was very sad and cried a lot.").* One (4%) participant mentioned that her daughter would actively take part when they went to the graveside *("She talks to her brother when we are at the graveyard.").*

(iii) **Continued questioning**

According to table 6.13, four (16%) participants reported that their children were always Asking where the baby was *("She always asked me where the baby was and then I need to explain. It was so hard.").* Three (12%) participants mentioned that their children wanted more technical detail of where the baby was now *("My son wanted to know more of what happened to the baby.").*

These subthemes correlate with findings by (Wolfenstein, 1966; McConville, 1974; Borg & Lasker,1981) that the psychosocial impact of the stillbirth on children/siblings depends on the developmental stage of the child. The age group 0- 4 years of age will probably fall under the first subtheme, that of no significant change.

6.5.3.2 Manner in which the stillbirth influenced the participants' relationship with other children

Table 6.14 indicates seven possible reactions that participants may experience which may influence their relationship with their children.

Table 6.14: Manner in which the stillbirth influenced the participants' relationship with other children

Possible reaction	f (%)
I found it difficult to react to their emotional needs	9 (36%)
I neglected them for a period	8 (32%)
I could, as in the past, satisfy their needs	6 (24%)
They irritated me easily	7 (28%)
I did not know how to explain the death	4 (16%)
Caring for my children helped me to deal with my loss	6 (24%)
I appreciate my children much more now	11 (44%)

N=25

Nine (36%) participants **found it difficult to react to their children's emotional needs,** while eight (32%) participants acknowledged that they had **neglected their children for a period.**

Only six (24%) participants reported that they **could, as in the past, satisfy their children's needs**. Seven (28%) participants confessed that their **children irritated them easily**, while four (16%) participants **didn't know how to explain the stillbirth to their children**. Lastly, two positive reactions were also identified. Six (24%) participants indicated that caring **for their children helped them to deal with their loss** and 11 (44%) participants reported that they **appreciated their children much more now.**

The high number of participants who indicated the first two reactions reported that they either ignored the children or sent them to stay with others until they themselves felt better. Callister (2006:229), suggests that siblings who experience grief at the death of a younger sibling have been termed "forgotten mourners", which confirms with the above.

6.5.3.3 Manner in which participants informed their children about the stillbirth

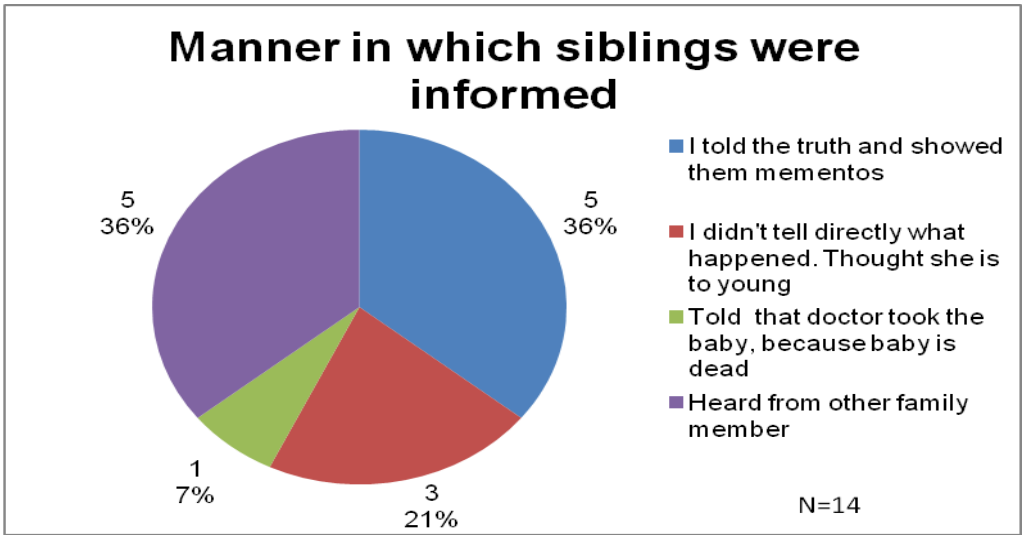

Figure 6.15: Manner in which siblings were informed about the stillbirth

Figure 6.15 shows that the majority of siblings were informed of the stillbirth by either their mother (five or 36%) or by another family member. Participants who indicated that a family member had told their child about the stillbirth, confessed that they were relieved about this, because they couldn't face doing it themselves. Three (12%) participants mentioned that they did not tell their children directly what had happened,

because they thought they were too young. One (4%) participant reported that she told her son that the doctor took the baby. By not revealing the facts, she wanted to make it easier for herself and her son. She confessed that she wanted to deny what had happened.

6.5.4 Coping mechanisms playing a role during the acceptance/non-acceptance of the loss

The following section of the empirical study focused on the crisis period after the stillbirth as well as long-term effects and coping mechanisms. This connects with the overall hypothesis of the study: "*The loss of a fetus/baby has long-term psychosocial implications for the mother and her family as perceived by the mother and proper social work support is needed to alleviate the grief process during the crisis period as well as the adaptation period thereafter."*

6.5.4.1 Participants' description of the stillbirth

One of the objectives/aims of the study is to investigate and gain information regarding the lived experiences of mothers who had a stillbirth and their perceptions of the crisis. Therefore participants were asked to indicate how they would describe the stillbirth.

Table 6.15: Severity of crisis according to the participant

Severity of crisis	f (%)
I didn't perceive my loss as a crisis	1 (4, 1%)
I perceived my loss as a slight crisis	4 (16, 6%)
I saw the loss of my baby as a crisis and needed help	17 (70, 8%)
I perceived my loss as a severe crisis	2 (8, 3%)

N=24

According to table 6.15 the majority of participants, 17 or 70,8%, saw the loss of their baby as a crisis and needed help from somebody. Most of the participants admitted that they needed help from a professional person. Two (8,3%) participants experienced the stillbirth as a severe crisis, while four (16,6%) participants perceived the stillbirth as a slight crisis and one (4%) did not perceive her loss as a crisis. Table 6.15 thus clearly

shows that a stillbirth can be perceived as a crisis and extra help and support can help the individual with this loss. This concurs with the theory of crisis intervention in social work.

According to Gilliland and James (1993:4), individuals can react in any one of three ways to a crisis. Under ideal circumstances, many people can cope effectively with a crisis by themselves and develop strength from the experience. They change and grow in a positive manner and come out of the crisis both stronger and more compassionate. Other people appear to survive the crisis, but effectively block the hurtful effect from their awareness, only to have it haunt them in innumerable ways throughout the rest of their lives. Lastly there are those who break down psychologically at the onset of the crisis and need immediate and intensive assistance. Table 6.15 shows that, as Gilliland and James (1993*)* mentioned, the majority of participants needed for help to manage their crisis.

6.5.4.2 Activities which helped participants to cope with stillbirth

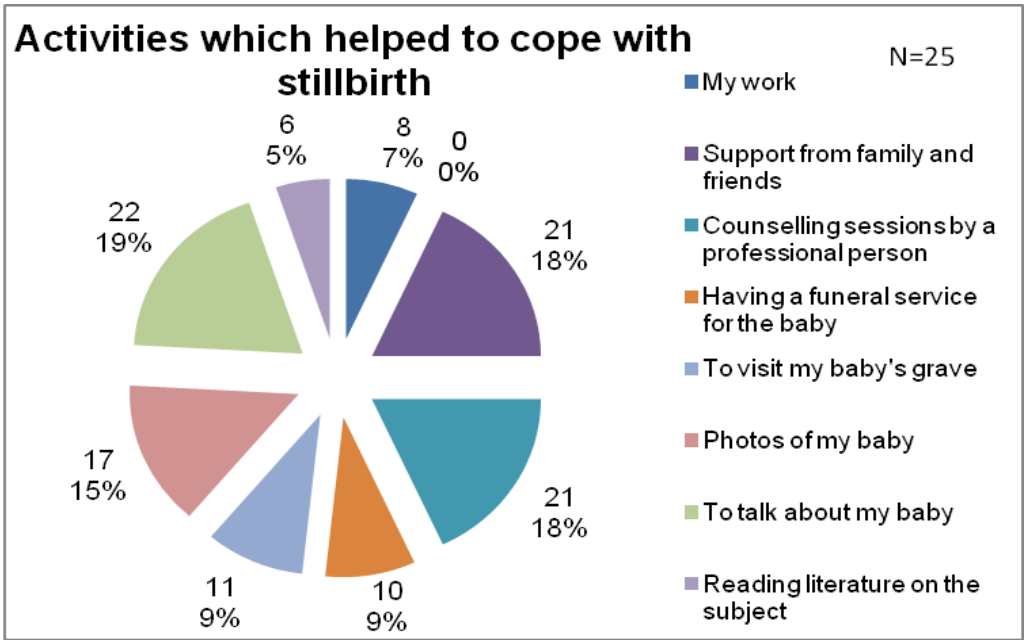

Figure 6.16: Activities which helped participants to cope with stillbirth

In to figure 6.16, eight activities were identified which helped participants to cope with the stillbirth. Participants were allowed to choose more than one activity. The three main activities identified, were "**to talk about my baby",** as 22 (19%) participants

indicated this option. The other two activities, with respectively 21 (18%) participants each, were **"counselling sessions by a professional person"** and **"support from family and friends**".

Other activities worth mentioning are **"photos of my baby",** indicated by 17 (15%) participants and "**to visit my baby's grave**", indicated by 11 (9%) participants. Ten (9%) participants mentioned that "**having a funeral service"** for their baby helped them a lot to acknowledge the fact that they did indeed have a baby. Eight (7%) participants stated that "**going back to work"** helped them to not continuously think of their baby, and lastly six (5%) participants mentioned that "**reading literature about stillbirth"**, helped them to understand their loss better. One (4%) participant also confided that she was keeping a diary, writing down her thoughts and feelings when she was experiencing a sad day. This helped her to cope.

6.5.4.3 The importance of certain actions:

Although very controversial and personal, the participants were asked how they felt about seeing, holding and naming the baby.

6.5.4.3.1 Seeing your baby

Table 6.16 illustrates participants' views on the importance of seeing their babies.

Table 6.16: Participants' views on the importance of seeing their babies

THEME: IMPORTANCE OF SEEING THEIR BABIES			
Subthemes	**Categories**	**Narratives**	**f (%)**
Saw baby	Longing to see baby	*"Yes, it was very important for me to see my baby."* *"I wanted to see my baby and when I looked, he was so beautiful."*	19 (76%)
	Only wanted to see baby briefly	*"I was in too much pain to take everything in."*	1 (4%)
Did not see baby	Not after birth, too overwhelmed.	*"I didn't see my baby."*	1 (4%)
	No, only at funeral	*"I didn't want to see my baby at birth, only at the funeral."*	1 (4%)
	No, never	*"I didn't want to see my baby. But now I regret it."* *"I didn't want to see my baby's face, because I don't want to keep that image in my head all the time."*	3 (12%)

N=25

(i) **Saw baby**

According to table 6.16 the majority of participants (19 = 76%), indicated that they wanted to see their baby and longed for this. One (4%) participant reported that she also wanted to see her baby, but only very briefly.

(ii) **Did not see baby**

One (4%) participant reported that she did not want to see her baby after birth because it was too overwhelming, one (4%) participant mentioned that she only wanted to see her baby at the funeral and three (12%) participants were adamant that they never wanted to see the baby because *"I didn't want to see my baby's face, because I don't want to keep that image in my head all the time."*

6.5.4.3.2 Holding your baby

Participants were asked about their views on holding their baby.

Table 6.17: Participants' views on the importance of holding their babies

THEME: IMPORTANCE OF HOLDING THEIR BABY			
Subthemes	**Categories**	**Narratives**	**f (%)**
Held baby	Only for short while	*"I thought it was important to hold her, but I was able to do it only for a short while."* *"I held her for a short while because I got cross with her. Why did she have to leave me?"*	3 (12%)
	Wanted/longed for holding my baby	*"I thought it was important to hold her, I wanted to feel how my own baby feels."*	8 (32%)
Did not hold baby	Circumstances were not right	*"I didn't hold my baby, but now I regret it. Everything happened so fast, I didn't even think I was allowed holding her."* *"They took my baby away too fast, maybe if I was able to hold him, it would be easier to get closure."*	3 (12%)
	Didn't want to hold baby	*"I didn't want to hold my baby."* *"I was too afraid to hold my baby."*	11 (44%)

N=25

(i) **Held baby**

Table 6.17 illustrates that the first subtheme can be divided into participants who only wanted to hold their baby for a short while (three = 12%), and those participants (eight = 32%) who wanted and longed to hold their babies.

(ii) **Did not hold baby**

Table 6.17 indicates the first category as those participants whose circumstances were not right and now regreted not holding the baby (three = 12%) and 11 (44%) participants who indicated that they didn't want to hold their baby. Thus table 6.17 clearly shows that the majority of participants did not hold their baby. Findings agree with literature that it is a highly debatable topic due to the extremely sensitive nature thereof. Stringham *et al.,* (1982:324) and Wretmark (1993:59) indicate that spending time with your stillborn baby, promotes a healthy grief process because the baby was a reality for the mother. Badenhorst and Hughes (2007:249) disagree with Stringham *et al.,* (1982:324) and believe that contact with a stillborn may have adverse effects including inducing symptoms of posttraumatic stress disorder.

6.5.4.3.3 Photographs of your baby

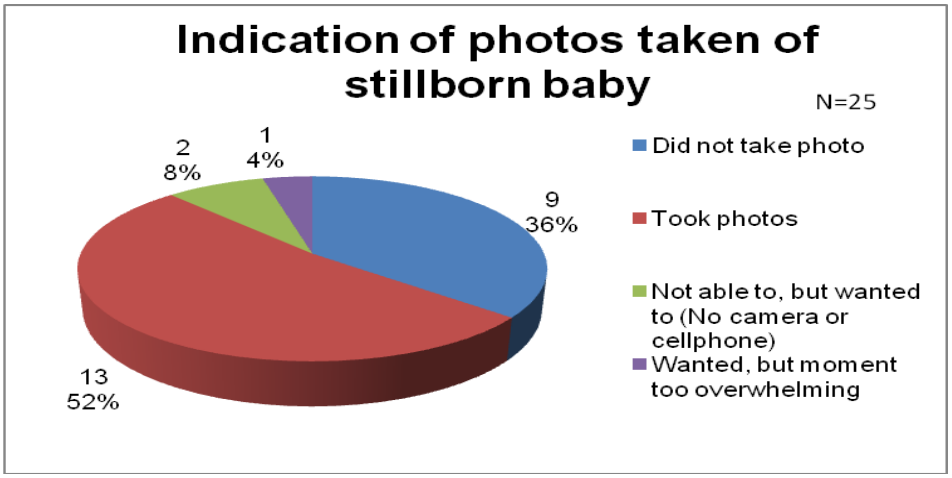

Figure 6.17: Indication of photos taken of stillborn baby

According to figure 6.17,13 (52%) participants took photos of their babies, nine (36%) participants did not take photos, two (8%) participants wanted to take photos but were not able due to lack of financial resources. This clearly proves again that low social economic status can have a negative impact on grieving, for there are no mementos for

the bereaved parents. Lastly one (4%) participant also wanted to take a photograph but was too overwhelmed by what has happened.

6.5.4.4 The point of acceptance and making sense of things

Participants were asked to identify the way they currently felt about stillbirth.

Table 6.18: Indication of when feelings of sadness lessened

Option	f (%)
I still feel very sad	2 (8%)
I started feeling better after six weeks	2 (8%)
I started feeling better after three months	2 (8%)
I started feeling better after hearing the autopsy results	4 (16%)
I started accepting the loss after six months	8 (32%)
I don't think I will ever feel better again	7 (28%)

N=25

Two opposimg outcomes are illustrated in table 6.18 with eight (32%) participants mentioning that they started accepting the loss after six months, while seven (28%) participants reported that they thought they would never feel better. Two (8%) participants indicated that they started feeling better after six weeks and three months respectively, and four (16%) participants felt better after hearing the autopsy results. Two (8%) participants reported still having feelings of great sadness. Combined, the majority of participants, 16 (64%), did indicate that their feelings of sadness had lessened.

6.5.4.5 Person/s playing a prominent role in the healing

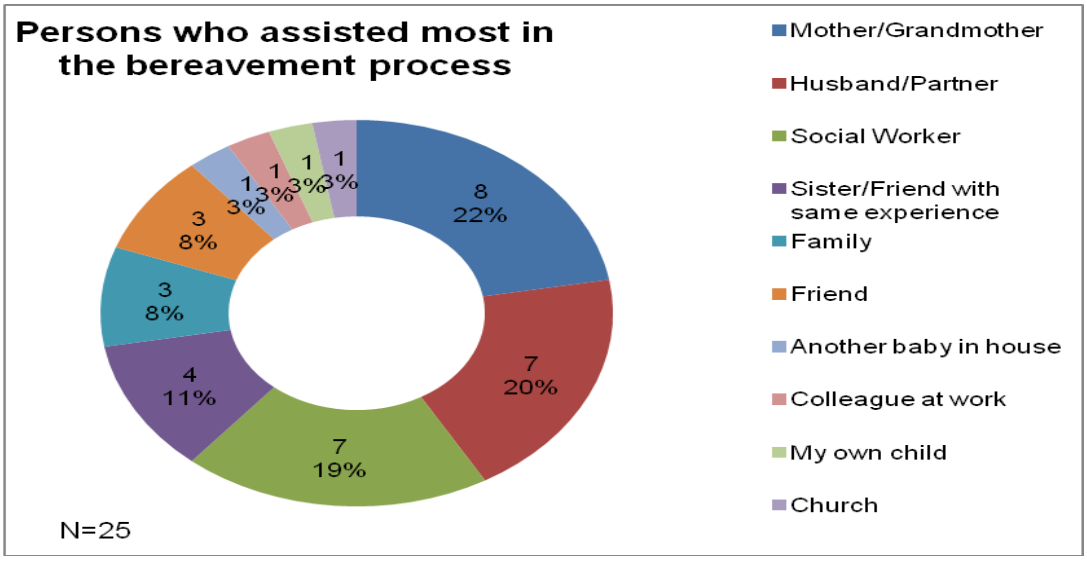

Figure 6.18: Persons who assisted most in the bereavement process

Participants were asked to indicate who they felt helped them the most during their bereavement process and were currently still helping them. Figure 6.18 illustrates that eight (22%) participants mentioned that specifically their mother or grandmother gave them the most support, while seven (20%) indicated that they received support from their husband/partner or a social worker respectively. Four (11%) participants found support in sisters/friends who had had the same experience and three (8%) participants reported that their families overall gave them support. Lastly figure 6.18 indicates that the following options: having another baby in the house, colleague at work, own child and the church were chosen by one (3%) participant each.

6.5.4.6. Crisis intervention evaluation

Participants were asked whether they had received a crisis intervention session and their perception of it. This was important, in order to obtain the following objective of the research: "*To develop pilot data about potential mechanisms concerning how social work intervention from a crisis intervention approach can be used to assist patients who have experienced a stillbirth and assist the family to adjust constructively."*

6.5.4.6.1 Indication whether participant received a crisis intervention session

Twenty-three (92%) of the participants had received a crisis intervention session shortly after the loss, while **two (8%) had not** received any crisis intervention after the stillbirth. It was found that those women who had been able to express their emotional reactions right after the death of the child had a shorter period of insufficiency than those who suppressed their feelings (Wretmark, 1993:56).

6.5.4.6.2 Degree to which the crisis intervention was beneficial to participants

Participants were asked to indicate how they had experienced the crisis intervention session with a social worker at the hospital, at work or the social worker at the Safe Passage Study. Table 6.19 illustrates the findings:

Table 6.19: Degree to which the crisis intervention was beneficial to participants

THEME: DEGREE TO WHICH THE CRISIS INTERVENTION WAS BENEFICIAL TO PARTICIPANTS			
Subthemes	**Categories**	**Narratives**	**f (%)**
Emotional support	Empathy	*"I could talk to somebody who understands me."* *"Yes, it was private and I was able to cry without somebody looking strangely at me."*	12 (48%)
	Encouragement	*"Yes, it did encourage us and it gave us some hope. We felt we didn't need to worry about anything because there is somebody close to us."*	1 (4%)
	Objectiveness of support	*"I wasn't able to speak to my family so for me it was easier to speak to a stranger at that point. It was easier sharing my feelings."* *"Most people, even my family, were afraid to speak to me, so I enjoyed the interest shown in me and the opportunity to talk about how I'm feeling."*	3 (12%)
Needed ongoing support	Indicated a need for further counselling	*"I had two sessions with the social worker at work. It helped me to talk about my feelings."* *"It helped me a lot, but only for a week, and then I felt so sad again."*	2 (8%)
Timing of support	Too overwhelmed to talk after the stillbirth	*"The idea is good, but the timing was not. It was too soon. Maybe just a day or two later would be better."* *"I can't remember much of our session."* *No, it was too soon after the stillbirth. I can't recall anything which we have spoken about."* *"I was still hurting too much to talk about it."*	7 (28%)

N=25

(i) **Emotional support**

Under this subtheme, three categories were identified. The majority of participants, 12 (48%), indicated that they had experienced **empathy** during the crisis intervention session ("*I could talk to somebody who understands me.*"). One (4%) participant felt **encouraged** after seeing a social worker and three (12%) participants appreciated the **objectiveness of the support** *("Most people, even my family were afraid to speak to me, so I enjoyed the interest shown in me and the opportunity to talk about how I'm feeling."*).

(ii) **Needed ongoing support**

Two (8%) participants mentioned that they still had a need for **ongoing counselling**, (*"It helped me a lot, but only for a week, and then I felt so sad again.").* This might be an

indication that although the crisis intervention approach is very beneficial, a bereaved mother who have had a stillbirth, needs ongoing counselling and support.

(iii) **Timing of support**

Table 6.19 illustrates that seven (28%) did not find the crisis intervention approach to be positive, as they were still **too overwhelmed to talk** about the stillbirth, (*"I was still hurting too much to talk about it").* The third premise for the Crisis-in-Context theory model concerns time (Myer & Moore, 2006:84). Literature (Bronfenbrenner, 1995; Brewin, 2001) validates the need to include the element of time in crisis theory. Early beliefs were that an event has varying degrees of impact on an individual's development and this impact decreases with the passage of time. Caplan (1961) was of the opinion that time played an important role in recovery from a crisis.

6.5.4.6.3 Recommendation of crisis intervention by a social worker according to participants

Participants were asked whether they would recommend crisis intervention as being an important part of the healing process of bereaved parents. A vast majority of 22 (88%) participants (N=25) agreed that they would definitely recommend crisis intervention to every bereaved mother/couple after a stillbirth. Excerpts attained from the interviews:

- *"Yes, is part of the process, it is better to talk to someone than keeping your feelings in."*
- *"It is better talking to a stranger than your family."*
- *"It helped me to prepare for leaving for home and be strong without my baby."*

Three (12%) participants indicated that they thought the timing of the crisis intervention was a problem. They suggested that any form of counselling or support must rather be provided a while after stillbirth when they could not cope.

- *"It was too soon after my loss. Maybe counselling will be more appropriate when time has passed since my stillbirth."*

Crisis situations are totally new, unpredictable, psychologically paralyzing and they pose a shock to the emotional system. They catch the victim unprepared and lacking a

ready response, according to Kfir (1989:5). With this in mind, those participants who indicated that they would rather receive counselling and support a while after the stillbirth, might not be in a crisis situation any more but rather in a severely stressful period, which differs from a crisis situation.

6.5.5 Medical care and autopsy-related issues during the loss

The second last section of the empirical study focused on participants' perceptions around medical care and their feelings regarding autopsy-related issues. This connects with the following objective of the study: *"To investigate the bereaved mother's attitudes regarding autopsy, whether she has consented to an autopsy or not, and what the significance of autopsy is during the bereavement process."*

6.5.5.1 Perceptions of participants regarding the service/treatment received in hospital

The participants were asked about their reactions upon receiving the autopsy results

Table 6.20: Opinions regarding the service/treatment received in hospital

STATEMENTS	AGREE	DISAGREE
The nursing staff treated me/us with special care	22 (88%)	3 (12%)
The medical personnel sympathized with my loss	22 (88%)	3 (12%)
I was informed throughout my loss what procedures I should expect next (For example why I receive certain medication)	16 (64%)	9 (36%)
The medical personnel weren't hesitant to embrace me after my loss	15 (60%	10 (40%)
The choice was given to me/us to see the baby	23 (92%)	2 (8%)
The choice was given to me/us to hold the baby	21 (84%)	4 (16%)
Counselling services were offered to me/us	17 (68%)	8 (32%)
I was informed about the burial/cremation procedures	17 (68%)	8 (32%)
I was offered to have autopsy done on my baby	17 (68%)	4 (16%)
I was moved to a separate room after delivery, to avoid facing other mothers with living babies	20 (80%)	5 (20%)

N=25

Table 6.20 illustrates that with all ten different options involving medical care, the number of participants agreeing positively with the statements was very high while the minority of participants disagreed with the statements. The statements all concerned positive and high-quality medical care and five of these statements received scores of 80% and higher. The other five statements received scores of 60% and higher. All the

"disagree" statements scored 40 % or less. Table 6.20 thus clearly indicates that the majority of participants were satisfied with the care they received, which again is beneficial for the healing process. *"These bereaved mothers take nothing home except memories. It is our task to create positive/caring memories for them as far as possible."*

6.5.5.2 Perceptions regarding autopsy after the loss and six or more months later

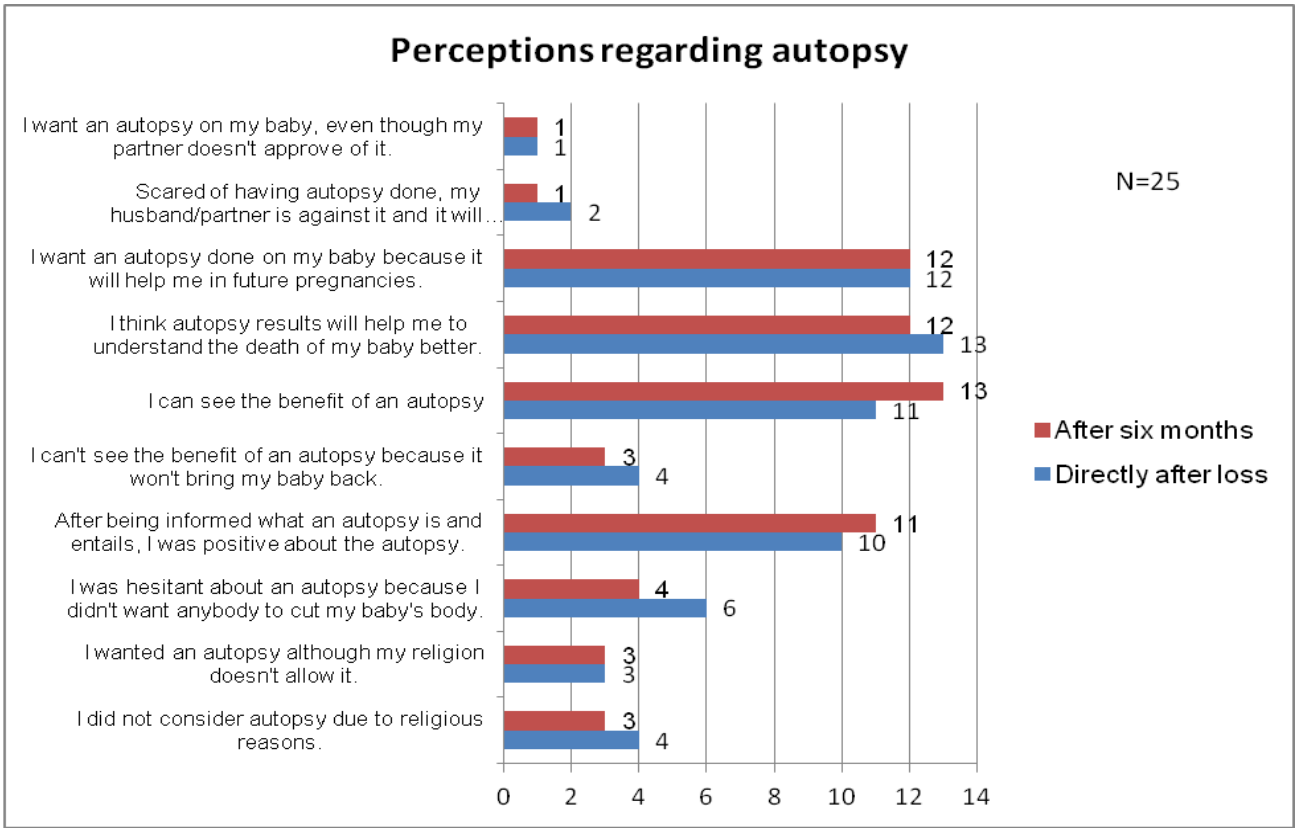

Figure 6.19: Perceptions regarding autopsy

For parents who have lost a baby through stillbirth it is important to obtain an adequate explanation of the cause of the baby's death in order to come to terms with their loss (Holste *et al*., 2011:1287). Autopsy in combination with placental examination is the most valuable analysis to identify the cause of stillbirth (Bohra, Regan, O'Connell, Geary, Kelehan & Keane, 2004:133). Participants were asked to indicate their perceptions regarding autopsy directly after the loss and more than six months later. The aim of this question was to establish whether participants had any regrets regarding their initial indication and whether it assisted them in the healing process. Participants were allowed to indicate more than one option if applicable.

One participant reported that she *wanted an autopsy directly after the loss and still feels the same, even though her partner didn't approve of it*. Two participants were *scared of having an autopsy done because their partners were against it, which would influence their relationship*, but after six months the one participant revealed that she regretted not doing the autopsy.

Twelve participants *wanted an autopsy done, because it would help them with future pregnancies* and after six months they still felt the same about the autopsy. Thirteen participants thought that *autopsy results will help them understand the stillbirth better* and after six months 12 participants still felt this way, showing that one participant probably still struggled with answers surrounding the stillbirth. Eleven participants reported that they *could see the benefit of an autopsy* directly after the loss, while this number increased to 13 participants after six months. The two participants joining this group acknowledged that they gained more knowledge regarding autopsy and now regretted not having an autopsy done.

Figure 6.19 also illustrates that four participants *couldn't see the benefit of an autopsy because it would not bring their babies back.* This number only dropped with one to three participants after six months. This correlates with Oluwasola, Fawole, Oteqbayo, Ogun, Adebamowo and Bamigboye (2009:78) viewpoint on different barriers to giving consent for autopsy. Ten participants felt *that when being informed about what an autopsy entailed, they were positive about it* directly after the loss, while this increased to 11 participants feeling this way after six months.

Six participants indicated that they were *hesitant about an autopsy because they didn't want' anybody to cut their baby's body.* This number decreased to four after six months. The two participants indicating that they did not feel the same any more mentioned that they now regretted not having an autopsy done. Three participants *indicated that they wanted an autopsy even though their religion did not allow it,* being from the Muslim religion. The number stayed unchanged six or more months later. Lastly, figure 6.19 indicates that *due to religious reasons, four participants mentioned that they didn't consider an autopsy directly after the stillbirth*, changing to three participants, six or more months later. The one participant who changed her mind after a few months

revealed that at this stage she was desperate for closure and she would go against her religion to have some results but now it was too late.

6.5.5.3 Reaction upon receiving the autopsy results

Participants were asked about any positive or negative reactions they had upon hearing the autopsy results.

Table 6.21: Reaction upon receiving the autopsy results

THEME: REACTION UPON HEARING THE AUTOPSY RESULTS			
Subthemes	Categories	Narratives	f (%)
Peace of mind	Relief	*"It made me feel at peace."* *"We took the positive out of it, which is that our baby was completely normally formed, it was only the lungs that were underdeveloped."*	4 (16%)
	Hope	*"It brought me some peace and gave me hope that I still can carry a baby full term."* *"My first question to the professor when he phoned me with the results was if I will be able to fall pregnant again."*	2 (8%)
	Normal	*"I acted normal. I can't remember the results anymore."*	2 (8%)
Blame	Alleviated feelings of blame	*"I was blaming myself throughout the first few weeks, but the autopsy really just explained to me what really happened, things that weren't spoken to me when I left the hospital."* *"I blamed myself but now I feel more at peace."*	5 (20%)
Anger	Towards partner	*"They told me I had an infection and my baby passed away from this. I was very angry towards my partner."*	1 (4%)
Unable to comprehend	Struggling to understand	*"I didn't understand the results so well."*	1 (4%)
No results yet	Non-acknowledgement of feelings	*"I haven't received any written results yet and feel it is my right to have these results."*	3 (12%)
No autopsy done			7 (28%)

N=25

(i) **Peace of mind**

According to table 6.21, four (16%) participants felt **relieved** after hearing the autopsy results ("*It made me feel at peace".).* Another category was that of **hope.** Two (8%) participants indicated that they had experienced hope ("*It brought me some peace and gave me hope that I still can carry a baby full term.").* Two (8%) participants also indicated that they felt **normal** after hearing the results *("I acted normal. I can't remember the results any more.").*

(ii) **Blame**

Five (20%) participants mentioned that the autopsy results helped to **alleviate their feelings of blame**. *("I was blaming myself throughout the first few weeks, but the autopsy really just explained to me what really happened, things that weren't spoken to me when I left the hospital.").*

(iii) **Anger**

One (4%) participant mentioned that she was **angry towards her partner** upon hearing the results (*"They told me I had an infection and my baby passed away from this. I was very angry towards my partner.").*

(iv) **Unable to comprehend**

Table 6.21 indicates that one (4%) participant mentioned that she **didn't understand the results** so well when explained to her. Holste *et al.,* (2011:1289) found that information given, is often perceived as difficult to understand and may provoke mixed or adverse feelings.

(v) **No results yet**

Three (12%) participants mentioned that **their feelings and emotions were not acknowledged** because they have not received any feedback (*"I haven't received any written results yet and feel it is my right to have these results."*). This narrative correlates with Holste *et al.,* (2011:1289) statement that mothers experienced lack of information regarding different aspects in the communication of the autopsy findings and would have appreciated the opportunity to talk to the pathologist who performed the autopsy. Borg and Lasker (1981:58) found that 80 per cent of bereaved mothers were dissatisfied with the information they had been given after an autopsy. Fortunately advances in medical technology have changed this.

(vi) **No autopsy done**

Seven (28%) participants chose not to have an autopsy done. Odendaal *et al.,* (2011:168) refers in an article to the possible barriers to autopsy consent, which links to this subtheme.

6.5.6 Attitudes regarding support in the community/support groups

The last section of the empirical study focused on participants' perceptions around support in the community and support groups. This connects with the overall hypotheses exploring their lived experiences.

6.5.6.1 People in the community's reaction towards the stillbirth.

Participants were asked about what the people in the community had to say about the stillbirth.

Table 6.22: Reactions of people in the community

THEME: PEOPLE IN THE COMMUNITY'S REACTION ON HEARING THE AUTOPSY RESULTS			
Subthemes	**Categories**	**Narratives**	**f (%)**
Positive reactions	Supportive	*"Some people were very supportive."* *"Most of my friends were sms'ing me. It's safer because you can hide your feelings."*	7 (28%)
Negative reactions	Teased	*"Some people made fun with us and said that I'm not the right wife for him"*	3 (12%)
	Mentioned subsequent children	*"They told me I'm still young and that I can easily have another baby."* *"They came to visit and told me that I don't need to worry for I can have another baby."*	10 (40%)
	Avoidance	*"People came to me, but explained that they can't support me or talk to me about it, because they haven't experienced something like this."* *"People were too afraid to talk to me and I needed them to talk to me. I needed that acknowledgement."*	5 (20%)

N=25

(i) **Positive reactions**

Table 6.22 indicates that seven (28%) of the participants experienced **support** and understanding from the people in the community *("Some people were very supportive.").*

(ii) **Negative reactions**

Three (12%) participants explained that they were **teased** *("Some people made fun with us and said that I'm not the right wife for him.").* The majority of participants stated that people **mentioned subsequent children** all the time (*"They told me I'm still young and that I can easily have another baby.")*. Lastly five (20%) of the participants mentioned

that most of the people **avoided them** *("People were too afraid to talk to me and I needed them to talk to me. I needed that acknowledgement.").*

6.5.6.2 Participants' attitudes towards a support group

According to Stringham *et al.,* (1982:327) support groups give women an opportunity to share their feelings in an atmosphere of acceptance and understanding, to realize that their grief was not unusual or abnormal and to meet others who were resolving a loss. Participants were asked about their attitudes towards support groups.

Table 6.23: Attitudes regarding support groups

STATEMENT	f (%)
I attended a support group in my area.	
There was no support group available in our area.	25 (100%)
I was hesitant to join a support group.	
I did not feel it was necessary for me to join a group.	5 (20%)
I will advise anyone experiencing the same to join a support group.	20 (80%)

Table 6.23 indicates that as a result of low socio-economic circumstances where "to be able to grieve" is seen as a luxury, none of the participants attended a support group as there was no support available in the area. Five (20%) participants mentioned that they did not see the necessity or benefit of such a group while 20 (80%) of the participants would advise someone to attend such a group.

6.6 Conclusion

The aim of this study was to explore the psychosocial implications of stillbirth for a mother and her family from a crisis intervention approach in social work. Special focus was placed on the long-term effect of the stillbirth on the mother and whether crisis intervention was suitable to use at the time. This chapter presented the results of the empirical study. First, a general profile was given of the participants' ages, living arrangements, schooling and employment situation and the status of their relationship, currently and more than six months ago.

Then the theme of the impact of stillbirth on the participant was introduced. Under this theme current emotions were discussed, current health issues, the experience of the

stillbirth then and now, depression and pregnancy history. The research findings in general indicated that participants still felt very emotional about the stillbirth even though it has been more than six months.

The theme that followed was the effect of stillbirth on marriage/relationships. The research findings indicated that during the loss most of the participants struggled to have positive communication with their partners, but that after a while they did tend to support each other again. The next theme was the effect of stillbirth on siblings. The research findings indicated that most of the participants found it difficult to react to their children's emotional needs and felt easily irritated by them. Most of the participants informed their children about the stillbirth themselves, while being informed by a family member was also indicated.

The theme that followed was about coping mechanisms playing a role during the acceptance of the loss. The research findings indicated that the majority of participants perceived the stillbirth as a crisis and needed help. The findings also show that talking about the stillbirth, support from family and friends and counselling sessions helped participants to cope with their loss. The research findings furthermore illustrated that all but two participants received crisis intervention support from a social worker. Although the majority of participants were positive about this session, a significant number of participants indicated that they would prefer to receive counselling after a while only.

The second last theme was about medical care in the hospital. The majority of participants were satisfied with the special care they received. The findings also indicate that most of the participants felt positive about an autopsy. A few participants that did not consent now regretted not being able to get closure on the stillbirth. The last theme was about support in the community and support groups. The research findings showed that support from members in the community is meagre, thus making stillbirth a "*silent loss*". The findings also indicated that participants felt they would benefit from a support group. The conclusions and recommendations based on the research findings will be discussed subsequently in chapter 7.

CHAPTER 7

CONCLUSIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

The purpose of the previous chapter, chapter 6, was to present the results of the empirical study. Seven themes were explored. First, a general profile of the participants was formed. Second, the theme of the impact of stillbirth on the participant was discussed. Then followed the effect of stillbirth on the marriage/relationships. The fourth theme dealt with the effect of stillbirth on siblings. Theme five focused on coping mechanisms playing a role during the acceptance of the loss. The second last theme was about medical care in the hospital, and finally the last theme was about support in the community and support groups.

The aim of this study was to explore the psychosocial implications of stillbirth on a mother and her family from a crisis intervention approach in social work. Special focus was given to the long-term effect of the stillbirth on the mother and whether crisis intervention is suitable to use at this time. The need for this study originated from an identified gap in the literature, especially from a South African context, regarding the long-term effect of stillbirth on the mother and whether the bereaved mother gained from crisis intervention during the stillbirth.

The aim of the study was achieved through the following goals:

- In chapter 1 an introduction to and motivation for the study were provided.
- In chapter 2 a theoretical overview of the medical causes of stillbirth as a foundation for understanding its psychosocial impact in this study was provided.
- In chapters 3 and 4 comprehensive literature reviews of current understanding of the psychosocial implications of stillbirth for a mother and her family were discussed. This review included information from multiple disciplines including social work, theology and psychology.

- In chapter 5 a theoretical overview of a crisis, crisis models and the crisis intervention approach in social work was provided.
- In chapter 6 the lived experiences of mothers who had a stillbirth and their perceptions of the crisis were empirically investigated by means of a questionnaire and semi-structured interviews. In this chapter the nature of the loss on marital and/or family relationships was also empirically explored as well as the bereaved mother's attitude regarding autopsy, whether she consented to an autopsy or not and the significance of autopsy during the bereavement process.

The aim of chapter 7 is to present the conclusions drawn from the study and to make appropriate recommendations. The recommendations will serve as a guideline for social work interventions to improve the support and service rendered to bereaved mothers and their families from a crisis intervention approach. In doing so, this chapter meets the final objective of the study, namely to develop pilot data about potential mechanisms concerning how crisis intervention as a social work method can be used to assist bereaved mothers and the family to adjust constructively after the stillbirth.

Through a thorough literature review and an empirical study, conclusions can be drawn and recommendations can be made. The conclusions and recommendations relate to the aim and objectives of the study, and fulfil the objectives of the study as summarised in table 7.1.

Table 7.1: Conclusions and recommendations as evidence of meeting the objectives of the study

OBJECTIVE	CONCLUSIONS AND RECOMMENDATIONS
Objective 1: To conduct a comprehensive literature review of the medical causes of stillbirth as a foundation.	Chapter 2
Objective 2: To conduct a comprehensive literature review of current understanding of the psychosocial implications of stillbirth for a mother and her family.	Chapter 3 and chapter 4
Objective 3: To perform a theoretical overview of crisis and crisis intervention.	Chapter 5
Objective 4: To investigate and gain information regarding the lived experiences of mothers who had a stillbirth and their perceptions of the crisis by means of a questionnaire and semi-structured interview.	7.2.1.1 Age and home language 7.2.1.2 Marital/relationship status 7.2.1.3 Education and employment 7.2.1.4 Income distribution of participants and their families 7.2.1.5 Other (living) children 7.2.1.6 Religious background of participants 7.2.1.7 Housing circumstances of participants 7.2.2 Loss of baby 7.2.2.1 Stillbirth and when it occurred 7.2.2.2 Emotions still affecting the mother more than six months after stillbirth 7.2.2.3 Feelings/thoughts and emotions experienced after the stillbirth and currently 7.2.2.4 Physical and mental health issues 7.2.5 Coping mechanisms playing a role during the acceptance/non-acceptance of the stillbirth loss 7.2.5.1Participants' depiction of the stillbirth as crisis and what helped them cope with the stillbirth 7.2.5.2 Participants' attitude towards seeing, holding and taking photos of their babies. 7.2.5.3 The point of acceptance 7.2.5.4 Persons playing a role in the healing process 7.2.6 Medical caring during the loss 7.2.7 Support groups
Objective 5: To ascertain the nature and consequences of the loss on marital and/or family relationships as perceived by the mother.	7.2.3 Effect of stillbirth on marriage/relationship 7.2.4 Effect of stillbirth on other children of participant 7.2.5 Coping mechanisms playing a role during the acceptance/none-acceptance of the stillbirth loss. 7.2.5.4 Persons playing a role in the healing process
Objective 6: To investigate the bereaved mother's attitude regarding autopsy, whether she has consented to an autopsy or not and the significance of autopsy during the bereavement process.	7.2.6 Medical care during the loss 7.2.6.1 Perceptions regarding autopsy 7.2.6.2 Reaction upon receiving the autopsy results
Objective 7: To develop pilot data about potential mechanisms concerning how crisis intervention as method in social work can be used to assist patients who have experienced a stillbirth and assist the family to adjust constructively.	7.2.5.5 Crisis intervention evaluation 7.4 Further research 7.5 Summary (Chapter 7 as a whole)

7.2 CONCLUSIONS AND RECOMMENDATIONS

The following conclusions and recommendations are based on the findings of the empirical investigation. The conclusions and recommendations are presented in a similar format to that in chapter 6, the empirical study, hence following the sequence of the questionnaire, from Section A to Section G. The chapter summarizes the results of the survey study based upon 25 women participants.

7.2.1 Particulars of female respondents

The identifying particulars of participants are going to be explicated below. Where relevant, some details will be combined.

7.2.1.1 Age and home language

All the participants who took part in the study were between the ages of 16 and 39 years of age, thus classified as being of childbearing age. The findings show that a majority of the participants, 56% (14/25), were within the age bracket of 20 to 29 years. This indicates that pregnancy is more prevalent when young women have completed their adolescent life phase and are now in their young adult life phase. Three of the participants were under the age of 20 years, which indicates that they were in the adolescence life stage.

From these findings it can be concluded that the life stage when most of the participants fell pregnant, is generally that time when individuals' energy is focused on intimate relationships, learning to live with a marriage partner, starting a family and managing a home. A stillbirth during this time can thus have a significant loss on the mothers' emotional well-being. Another conclusion is that for the participants under the age of 20 years who have lost a baby it can be extremely stressful as the mother is still searching for her own identity and probably not mature enough to deal with the impact of such a grave loss.

The findings indicated that the majority of the mothers were Afrikaans-speaking, two were English-speaking and two were bilingual, speaking both English and Afrikaans. One of the mothers was Sotho-speaking. The distribution of home language correlates with the fact that people living in these areas belong to the Cape Coloured ethnic group who tends to be more Afrikaans-speaking.

Recommendations

With regard to service aimed at support it is recommended that:

- The social worker needs to be aware of the age group of the bereaved mother, for the stillbirth might have different meanings for a mother under the age of 20 than for a mother aged 20 and older. A mother in the category of 20 years and older can be more isolated from society because of the tendency of the public to underestimate the impact of such a loss. The mother may have other children and therefore public opinion could be that these children should compensate for her loss.
- Extra support is needed by the younger mother, less than 20 years old, for she may experience extreme stress during the loss, as she is still searching for her own identity and probably not mature enough to deal with the impact of such a grave loss.

7.2.1.2 Marital/relationship status

During the loss, 40% (10/25) of the participants were living with their partner, but currently (after the loss) only 24% (6/25) of participants were still together. During the loss, 32% (8/25) of the participants were together but were living separately, while currently only 4% (1/25) of the participants is together but lives separately. Twelve per cent (12%) (3/25) of the participants broke up with their partners and are currently single. Eight per cent (2/25) of the participants got married to the same partner while 12% (3/25) of the participants broke up with their partners and are currently single.

The conclusion that can be drawn from these findings is that the relationship status of 48% (12/25) participants changed after the loss proving that a stillbirth can have a serious effect on a relationship and can add tension to the relationship. Only 8% (2/25) participants felt that their relationship has improved after the loss and they have become even closer to their partners and wanted to commit to them.

Seventy-two per cent (18/25) of the participants have been in their relationship for between one and five years. Only 20% (5/25) participants indicated that they have been in a relationship for longer while two of the participants were not in a new relationship yet. It can be concluded that starting and establishing a relationship is an important task

in early adulthood and therefore one would expect the length of the relationship to be not longer than five years.

Recommendations

With regard to service aimed at support and crisis intervention, it is recommended that:

- Special focus needs to be given by the social worker to not just the bereaved mother during crisis intervention, but also to the partner or husband. It is important to not overlook the partner/husband's grief and his specific grief reactions.
- Possible couple counselling by the social worker needs to take place after the stillbirth to assist the couple because this might be the first real crisis they experience in their time together.

7.2.1.3 Education and employment

The findings indicated that the largest number of the mothers left school during Grade 10 – 11, with the second largest category of mothers being those with only a primary school qualification of Grade 7 or lower, making literacy and employment a challenge. Sixteen percent (4/25) of participants completed Grade 12 and only 8% (2/25) participants had received tertiary education.

The research furthermore revealed that the biggest number of participants indicated that they were unemployed. The second largest group were employed as labourers with most of the participants in this category working as cleaners or machinists. The third largest category consisted of participants working as clerks.

It can be concluded that unemployment rate is high and that only 24% (6/25) of the mothers matriculated or had a tertiary education which could help with job seeking. It can furthermore be concluded that potentially problematic stress variables like life events, anxiety, depression, perceived stress, self-esteem, work or household strain and social support can contribute to poor pregnancy outcomes and an inability to start the grief process. The question whether these mothers really perceive their loss as a crisis and whether they understand the complexity of it, is relevant.

Recommendations

With regard to service aimed at support and crisis intervention during the assessment phase, it is recommended that:

- The social worker needs to be aware of the socioeconomic status of the bereaved mother while engaging in crisis intervention with her. Identifying the socio-economic status can be a helpful tool in assessing the mother's attitude towards grief and her ability to grieve without other constraints.
- Preventative and awareness programmes need to be implemented at schools, educating learners on the benefit of completing their school careers because early school leavers are a big problem in the community in which the research was done. This will not be the task of the crisis interventionist, but needs to be rendered by the local social service organisation in the community or the Department of Education.

7.2.1.4 Income distribution of participants and their families

The research findings indicate that all the participants have a source of income. Only 20% (5/25) of the respondents have a secondary source of income. In all the cases the secondary source of income is the family of the participant, in which case the participant was still living with her family either in the house or in an own house (Wendy house) in the backyard. The primary sources of income can be divided into the following categories: a) the partner/husband being solely responsible for an income, b) participants themselves are earning a salary, c) both participant and partner are earning a salary, d) participants' families are working and participants are dependent on a part of that salary, e) participants are exclusively dependent on the family's income, and f) the last group relies on the family's income as a secondary source of income.

Research findings furthermore show that the difference between participants receiving a social grant from SASSA (South African Social Security Agency) and those who do not receive a grant was only by 4%. The majority of social grants were child support grants. Because of the similarity of the two groups, it is probably not noteworthy to assert that most participants rely on a social grant. Findings also indicate that there was rather an even distribution of gross monthly income between participants. The two income groups with the highest total participants were the group earning between

R7000 – R9999 per month and the R5000 – R6999 income group. This is the gross monthly income for the whole family which makes it still very low considering the current economic environment.

It can be concluded that previously disadvantaged communities are now being given more opportunities than before to better education and employment, provided that all the participants had a source of income. This could be owing to the fact that there is special focus on empowerment of women in South Africa, leading to more opportunities for women. Furthermore it can be concluded that the socioeconomic status /income group of participants is still considered to be low. Because of the dearth of literature on poverty and grief further research is needed.

Recommendations

With regard to service aimed at support and social advocacy, it is recommended that:

- Social workers should identify women at risk and provide them with early intervention in order to eliminate environmental factors contributing to poor pregnancy outcomes.
- Social workers should advocate for the woman's needs by reducing social isolation and addressing the complete well-being of families who have lost a child in the stillbirth period.
- Because of the dearth of literature on poverty and grief further research is needed.

7.2.1.5 Other (living) children

Because of the similar numbers of participants having no other children and those having other children, it is not noteworthy to make an assertion on this. The age groups in which most of the children fall is the four to six year, and the seven to 12 year categories.

The conclusion that can be drawn from these findings is that participants and their partners were not swift in deciding on a subsequent pregnancy. They either indicated that they were not emotionally ready for another baby or that they doubted that they would ever try for another baby, owing to them not being able to face losing another

baby. Especially the participants who already had much older children indicated that this pregnancy was unexpected and that they did not want to go through such a tragedy or loss again. Another conclusion that can be made is that birth order can be significant when experiencing a stillbirth. Those participants, who lost their first baby, did not deal with the grief of the stillbirth alone, but with feelings and fears of not being able to ever give birth to a healthy baby in future.

Recommendations

With regard to service aimed at crisis intervention and social support in the practice setting, it is recommended that:

- The social worker needs to pay special attention when talking about subsequent pregnancies and fears regarding the possibility of another stillbirth. The social worker needs to be skilled to approach this subject with sensitivity and needs to be aware of the right timing.
- Skills like reflection and clarification can be used by the social worker to help with this special focus (topic). This focus will take place later in crisis intervention or even during further intervention when crisis intervention has been completed and equilibrium has been obtained.

7.2.1.6 Religious background of participants

Religion and spirituality were found to be significant in the way an individual grieves and experiences the loss of a loved one. The church has always been a source of support for those in need of care, consolidation and comfort. Findings of the study confirm that the three main groups are not church-going, the Muslim religious group and New Apostolic churchgoers. The statistics show that participants and their partners/husbands do not necessarely belong to the same religious groups and there were also indications that one of the partners or participants belongs to a church group while the other one does not.

It can be concluded that religion does play an important role, as more than two-thirds of the participants attend church. It can also be concluded that participants and their partners/husbands do not necessarely belong to the same religious groups and one

of the partners or participants may belong to a church group while the other doesn't.This may have an effect on the grief process from a religious viewpoint because while some participants or partners will turn to religion for strength during this difficult time, some won't have this extra support. It can also put extra strain on the relationship.

Recommendations

With regard to service aimed at support and crisis intervention in the practice setting, it is recommended that:

- The social worker needs to be aware of the bereaved couples' religious orientation in order to assist and give support when funeral arrangements are made and important decisions regarding autopsy are taken by the bereaved parents.
- The social worker needs to assume the role of social broker and serves as a link between the client and other community resources. Activities of the worker are directed toward making connections that will enable the bereaved parents to get the best support available. The social worker needs to speak to the relevant church to give religious support where needed.

7.2.1.7 Housing circumstances of participants

Housing circumstances were investigated in order to gain information around this and to establish whether poor housing conditions can contribute to low social support and possible absent or delayed grief. The majority of participants indicated that they were living in safe structures, half of the participants living in their own houses and the other half in council houses. The third largest group reported that they were living in a Wendy house in the back of someone's yard.

The availability of living space should be seen as a potentially problematic stress variable. Most participants reported living in households with two to four other persons. The second biggest group contained five to seven occupants in the house. Although less prevalent, there were participants living in a house with ten to 14 occupants and 15 or more occupants. Access to four basic services was identified namely electricity,

phone, running water inside the house and toilet inside the house. The majority of the respondents had access to all four services identified.

The conclusion that can be drawn from these findings is that although the rest of the findings might look positive, it is disquieting that there are seven and five participants respectively, with no access to basic services like a toilet and running water. Causes for this lack may be unemployment and low socio-economic status. Overcrowding does not seem to be a problem because most council houses have only two bedrooms. It must be mentioned that these statistics are only indicative of the occupants in the house and not in the yard, for example an extra Wendy house.

Recommendations

With regard to service aimed at support and crisis intervention, it is recommended that:

- Social workers should promote the social welfare services available to the community and explain the role of the social worker to the participants where needed.
- Pregnant mothers should also be educated at prenatal clinics about social workers and how they can be of assistance during stressful life events, and particularly during pregnancy, in order to be able to be proactive with regards to social issues.
- Social workers need to be aware of the circumstances of the bereaved mother, even during crisis intervention, to be able to render effective and appropriate services.

7.2.2 Loss of the baby

The identifying information portrayed above provides a backdrop of the participants' environmental, financial and family conditions. The next section of this chapter will focus on the personal experiences of these bereaved mothers.

7.2.2.1 Stillbirth and when it occurred

Twenty-six stillbirths were reported out of a sample of 25 participants (N=25) which indicates that one participant has experienced the tragedy of a stillbirth twice. Some

participants indicated that they had suffered other types of losses as well, among others, one ectopic pregnancy, six miscarriages and one infant death. This is worth mentioning as it can have an impact on participants' grief reaction. All the participants had suffered a stillbirth more than six months ago and less than 18 months ago. The research criteria were met because all the participants experienced their stillbirth more than six months ago which are seen as long term. This data correlate with the overall hypothesis of the study which is: "*The loss of a fetus/baby has long-term psychosocial implications for the mother and her family as perceived by the mother and proper social work support is needed to alleviate the grief process during the crisis period as well as the adjustment period thereafter."*

It can be concluded that findings in general indicated that participants still felt very emotional about the stillbirth even though it happened more than six months previously. Those participants who have experienced multiple losses, for example a stillbirth and a miscarriage, presented with poor self-concept and self-esteem and the majority had a belief that they were not meant to become parents at all.

Recommendations

It is recommended that, with regard to services aimed at support and crisis intervention in the practice or hospital setting:

- The social worker needs to do a proper and thorough assessment of the bereaved mother's previous pregnancies, if any, and needs to take this into consideration during crisis intervention with the mother and her partner/husband. Complicated grief like re-activated or delayed grief may occur and overlooking previous losses might cause poor progress during crisis intervention.
- The social worker needs to form part of the multi-disciplinary team in the hospital to be able to get feedback on the patient's condition and history that may be important to know during crisis intervention.

7.2.2.2 Emotions still affecting the mother more than six months after the stillbirth

The majority of participants were crying while describing their current emotions. This is a sign that even though the stillbirth occurred more than six months ago, it was still a very emotional topic to discuss. With regards to ambivalent emotions, some participants mentioned that they still blamed themselves for the stillbirth while only a few indicated that they were actively trying to get on with life. The majority of participants also indicated that constant triggers in their everyday life had an immense impact on them. When they saw other babies, heard of other stillbirths and anniversary dates of their own baby's birth date, a lot of negative and intensely sad emotions are triggered.
Almost two-thirds of the participants mentioned that they did not see themselves as "coming to terms with their baby's death yet", for not one day passed without them thinking of their babies. With regards to reliving the circumstances surrounding the stillbirth, a third of the participants still relive the stillbirth in order to make sense of the loss.

Thinking of subsequent pregnancies was also a major issue for almost half of the participants. The fear of another loss and the fear of not being able to have children played a major role in the emotional healing and wellbeing of the participants. The role that family and friends played was also highlighted by half of the participants. A quarter of these participants indicated that they felt a lack of support from their family and also that they put unnecessary pressure on them to fall pregnant again. With regard to coping mechanisms, the majority of participants indicated that they made use of some form of coping mechanisms. Positive coping mechanisms like acceptance and the role of religion were identified, while negative coping mechanisms like denial, use of illegal substances or other substance abuse and selfharm were identified.

The conclusion that can be drawn from these findings is that ambivalent feelings, constant triggers, reliving the stillbirth, coping mechanisms, subsequent pregnancies and the role of the family all appear to be significant factors when long-term emotional effects of the bereaved mother were explored. Although these issues are all addressed during the crisis intervention period, it is suggested that owing to the incomparability of

stillbirth with any other loss, long-term emotions do exist and not one of the participants were symptom/grief-free at six months.

Recommendations

With regard to service aimed at support and crisis intervention directly after the loss in the practice or hospital setting, it is recommended that:

- A framework for intervention needs to be established for the social worker doing crisis intervention with the bereaved mother and partner, in order to ensure that the above-mentioned factors are being discussed during crisis intervention, depending on the need of the individual. This will help to lessen feelings of guilt and other ambivalent feelings which may occur.
- The social worker needs to address effective coping mechanisms as soon as possible during crisis intervention in order to restore some form of equilibrium.
- Because findings clearly show that crisis intervention alone is not sufficient, the social worker needs to have a system in place where follow-up interventions can take place, whether telephonically or individual/couple session. This will take place after crisis intervention during the adjustment phase.
- Awareness programmes concerning possible negative outcome of pregnancy, for example preterm delivery, sick neo-natal infants, post-natal depression and stillbirth should be made available by clinics to all women who visit clinics. Although this a sensitive subject and would rather be avoided, greater public awareness regarding stillbirth needs to be developed. An informative video needs to be made with utmost empathy and compassion, focusing on the overall wellness of the mother during different pregnancy outcomes. All expectant mothers need to be aware of the availability of social work intervention and help in the case of a negative pregnancy outcome.
- Social workers should take the three main themes from the qualitative research in consideration when dealing with a stillbirth and should equip the mother to be aware of
    1. The need for validation of the loss and bereavement
    2. The importance of internal and external recognition of the baby's identity
    3. The imperative for social support and compassionate interventions.

7.2.2.3 Feelings/thoughts and emotions experienced after the loss of the baby and currently

The majority of the participants expressed that they were afraid of falling pregnant again shortly after the stillbirth, and almost half of these participants still felt afraid of falling pregnant even though it was more than six months ago. All the participants, barring four, expressed that they feared another loss soon after the stillbirth and 19 mentioned that they still felt this way. The primary reason for this is that they did not feel themselves strong enough to go through another loss and to relive all the emotions again. These emotions included feelings of fear, anger, denial, guilt and worthlessness.

Nearly all the participants said that they longed for a baby when they saw other babies, just after the loss and subsequently. The majority of participants did not report having nightmares of their babies shortly after the loss although those participants who reported this, were still experiencing it. A third of the participants had thoughts of committing suicide while three participants still had these thoughts. The primary reason for still having thoughts of suicide was because of prolonged grief, with no improvement after six months. All the participants, barring one never felt like stealing another baby at any stage after the stillbirth. Half of the participants avoided babies soon after the loss while 12 participants never felt like avoiding any baby at any stage after the loss.

Two-thirds of the participants were unable to pack away the baby clothes, while a third of the participants were still unable to pack away the clothes, six months or longer after the loss. Finely all the participants, but five, reported that they tried to be strong and not show any hurt. Seventeen participants reported still doing this because of family members not knowing how to respond appropriately.

In conclusion, the above-mentioned thoughts correlate with the emotions mentioned in 7.2.2.2. Because of being overwhelmed by all these thoughts and feelings, these bereaved women did not always know that it was normal to experience some of these emotions. There were many feelings participants shared, but each participant found her own way of coping. No one approach worked for everyone. No one set of feelings was more appropriate than any other.

Recommendations:

With regard to tasks relating to assessment during crisis intervention, it is recommended that:

- When dealing with bereaved mothers social workers should determine how acutely the mother perceives her loss as a crisis. The social worker should carry out the crisis intervention process for balance to be restored and for the intervention to proceed.

With regard to intervention in the practice setting, it is recommended that:

- Social workers should assist the bereaved mother to work through the negative emotions relating to possible prolonged grief or complicated grief. This would aid the mother in realising that she did undeniably have a stillbirth and is allowed to experience certain feelings and emotions although these emotions and thoughts may seem unacceptable to her.
- The social worker, when dealing with a bereaved mother or couple, should equip the mother/couple with skills and techniques to work through feelings of shock, denial and anger, which form the first few stages of the grief process.

7.2.2.4 Physical and mental health issues

The two major health issues which stood out were headaches experienced by participants, and being pregnant currently. With regard to physical health, participants reported that they were worried about severe headaches, because they were afraid that they might still be suffering from high blood pressure or pre-eclampsia. Being pregnant again also created underlying stress and emotions of anticipation within the participants. They were afraid of the outcome of this pregnancy. The conclusion that can be drawn from these findings is that a quarter of the participants did not see themselves as having any health problems after the stillbirth, while headaches and a current pregnancy was a source of stress for participants. Other issues were identified (see table 6.5) but were too nominal for any conclusion. Hence there was not one specific characteristic regarding health, except for pregnancy and headaches, which stood out.

This study was concluded with questions regarding participants' views of their own depression. This was to establish the participants' knowledge regarding what depression was as well as to distingiush between a normal grief process and depression or pathological grief. More than half of the respondents indicated that they felt depressed at some stage after the loss. The second largest group reported feeling sad but not depressed. They experienced normal grief reactions and processes. It can also be concluded that the majority of bereaved fathers were perceived as not talking and keeping their feelings and emotions to themselves. The second largest group were bereaved fathers who cried openly and were angry, but not depressed. The third largest group were fathers who were perceived by the partners as continuing with life as normal, without any significant change in behaviour. The number of bereaved fathers, who were supportive, depressed or had a negative behavioural change was small.

Findings further concluded that participants' knowledge of signs of depression was very restricted. A poor appetite, sleeping problems and a need to want to cry all the time were reported by only a few participants. Only one participant was prescribed anti-depressants and sleeping pills after the loss, while one medicated herself by using dagga obtained from a natural healer. The majority of participants indicated that they had fallen pregnant easily, while a third of the participants mentioned that their pregnancy only followed after more than a year of infertility. Pregnancy history can have a significant impact on the way an individual experiences a stillbirth.

Recommendations

With regard to tasks relating to assessment during crisis intervention, it is recommended that:

- When dealing with bereaved mothers social workers should determine during the sessions that follow the first session, whether the mother feels healthy or have any health problems. The latter can be a sign of an underlying emotional or psychological problem. In cases of acute problems, a referral to a physician or gynaecologist needs to be made.
- The social worker using crisis intervention as method of intervention, must first take a pregnancy history of the mother if possible, for this will provide useful information on the way the bereaved mother copes with loss.

With regard to intervention and prevention in the practice setting, it is recommended that:

- Social workers should promote prevention of depression under pre-natal, post-natal and bereaved mothers by presenting educational talks regarding depression, signs to look out for and where to find help.

7.2.3 Effect of stillbirth on the marriage/relationship

This section will focus on the effect of stillbirth on the marriage/relationship.

The majority of the participants expressed that the positive statements in the questionnaire about communication applied to their relationships and that the stillbirth did not have a serious impact on their relationship with their partner. The minority of participants indicated that they could not share their emotions with their partner and that they felt they had nothing to talk about. The conclusion that can be drawn is that before, during and after the stillbirth the relationship of bereaved couples continued to be stable and regular communication took place. Although the last statement, which can be seen as negative communication, “I can’t confide in my husband”, was been chosen by exactly half of the participants. This may imply that 50% of relationships did change and were not as open and stable as before or had not improved after the loss.

Another conclusion that can be drawn is that more than half of the participants were very happy in their relationship before the loss, but at the time of the stillbirth, the majority of the participants were either very unhappy or somewhat unhappy. Findings furthermore show that there was a noticeable shift from negative descriptions of marriage to more positive descriptions one month after the loss. Six or more months after the loss the majority reported being happy in their relationship again, while only two participants were very unhappy and reported that they had broken up with their partners.

With regards to partners’ involvement in the pregnancy, five subthemes were identified with half of the participants seeing their partners as being supportive and excited about the pregnancy. A smaller group perceived their partners as non-supportive and not

involved, especially after learning about the pregnancy. Other feelings mentioned by mothers were: partner spending more time with friends than with her, not wanting to involve him (partner) in the pregnancy and not contributing financially on a regular basis.

In conclusion, the last findings focused on any positive or negative changes in the relationship after the stillbirth. A third of the participants indicated either no changes in their relationship or positive changes with regard to positive communication. Two-thirds of the participants mentioned that negative communication, insecurity, fury or blame towards each other, poor coping mechanisms and a need for distance in the relationship were identified.

Recommendations

With regard to tasks relating to assessment during crisis intervention in social work practice, it is recommended that:

- The social worker needs to be aware of the individual in a crisis as not being an isolated person, but to see her/him as part of other subsystems. The most important subsystem would (in most of the cases) be the bereaved mothers' relationship with her partner/husband. It is important to assess this relationship and gain as much information during the following sessions as possible. This information can be very beneficial when explaining certain behaviour and reactions from others to the participant.
- The social worker needs to try her utmost best to establish a joint-crisis intervention session for both the bereaved mother and father. This provides the social worker with a large source of information with regards to the participants' coping mechanisms, personality and certain characteristics.
- Social workers should assist the mothers and their partners in learning communicationand conflict-management skills.
- Social workers, when dealing with the bereaved mother and her partner, should encourage the partner to be involved in the healing process and that both parties should offer mutual emotional support to each.
- Social workers should assess the impact of the stillbirth on the mother's friendships and romantic relationships. Poor relationships could indicate areas

for improved support, and strong relationships could indicate areas of support that could be utilised.

7.2.4 Effect of stillbirth on other children of participant

To ascertain the nature and consequences of the stillbirth on family relationships, especially those concerning siblings and other children, participants were asked a few pertinent questions. The conclusions are presented below. More than half of the participants, 14, had other children and took part in this section of the interview.

Conclusions regarding the physical and emotional reactions of the other children were that they were divided into three distinct groups. The first group consisted of just less than a third of the children who showed no significant reaction which was mainly owing to the age of the children. The second group consisted of a majority of children who were showing an emotional reaction. The last group was almost a third of the children who used persistent questioning to deal with their feelings of loss.

A further study conclusion that can be made is that stillbirth influenced the participants' relationship with other children in different ways. Three major groups could be identified, namely a third of the participants who found it difficult to react to their children's emotional needs, while almost another third of participants acknowledged that they had neglected their children for a period. The last group, a little more than a third, mentioned that they appreciated their children much more now.

The final conclusion in this part of the study concerns the way in which siblings were informed about the stillbirth. The majority of siblings were informed of the stillbirth by either their mother or by another family member. Participants, who indicated that a family member told their child about the stillbirth, confessed that they were relieved about this, because they couldn't face doing it themselves. One participant mentioned that she omitted the truth and by not revealing the facts, she wanted to make it easier for herself and her son. She confessed that she wanted to deny what had happened.

Recommendations

With regard to tasks relating to assessment during crisis intervention in social work practice, it is recommended that:

- The social worker should during assessment identify any children of the bereaved mother. Although focus will be on the mother and father at first, it is beneficial to know how many children need to be cared for at home. Coping mechanisms and some bereavement assisting tool, for example, to draw a picture of a deceased baby or write a letter for a brother or sister in heaven, will help the surviving siblings to start their own grief process.

With regard to intervention in the practice setting, it is recommended that:

- When dealing with bereaved mothers social workers should determine during consecutive sessions, whether the mother is currently only dealing with her own emotions or with those of her children as well. If not, it is important to not make the mother feel guilty about it, and rather facilitate for a family member to spend time with the children.
- When dealing with a stillbirth in a family, the social worker should also attend to the siblings as they are often being termed “forgotten mourners”. Little focus is given to them and further long-term research needs to be undertaken on siblings of a stillbirth baby. These siblings need to be old enough to remember the incident and to provide the research study with detailed and useful information.

7.2.5 Coping mechanisms playing a role during the acceptance/non-acceptance of the stillbirth

The following section focuses on the crisis period after the stillbirth as well as on long-term effects and coping mechanisms. This links with the overall hypothesis of the study: “*The loss of a fetus/baby has long-term psychosocial implications for the mother and her family as perceived by the mother and proper social work support is needed to alleviate the grief process during the crisis period as well as the adjustment period thereafter.”*

7.2.5.1 Participants' depiction of the stillbirth as crisis and what helped them cope with the stillbirth

The majority, almost three-quarters, of the participants experienced the stillbirth of their baby as a crisis and needed help from somebody. Most of the participants identified that they needed help from a professional person. Only one participant did not perceive the stillbirth as a crisis. The rest of the participants, a quarter, perceived the stillbirth either as a severe crisis or a slight crisis.

With regards to what helped them cope with the stillbirth, participants were of the opinion that the three main activities were ""*to talk about my baby*", "*counselling sessions by a professional person*" and "*support by family and friends*".

The conclusions that can be drawn from these findings are that a stillbirth creates a severe sense of imbalance and are perceived as a crisis situation. Bereaved mothers need immediate support and intensive assistance at the onset of the crisis. Thus it can be concluded that crisis intervention as method in social work can be very advantageous during such a time.

Another conclusion is that certain activities are more beneficial to bereaved mothers to cope with the loss than others. The following activities have been deemed essential: "*to talk about my baby*", "*counselling sessions by a professional person*" and "*support by family and friends".* Other activities such as returning to work, visiting the graveside of the baby or having a funeral service, should not be overlooked during crisis intervention.

Recommendation

With regard to tasks relating to the assessment phase, it is recommended that:

- Social workers who deal with the bereaved mother shortly after the stillbirth should evaluate the nature of the disequilibrium the mother is experiencing and how she is reacting.
- Social workers need to be well trained and confident in using a crisis intervention model compatible with the specific situation.

With regard to tasks relating to intervention in the practice setting, it is recommended that:

- Social workers should assess the impact of the stillbirth on the mother's friendships and relationships. Poor relationships could indicate areas for improved support, and strong relationships could indicate areas of support that could be utilised.
- Social workers should assess the possible activities that may help the mother cope better with her loss and focus on these. The following social work roles are deemed essential to help motivate the mother to engage in helping activities: facilitator, enabler, guide, counsellor and teacher.

7.2.5.2 Participants' attitude towards seeing, holding and taking photos of their babies

In evaluating the highly emotional topic of seeing, holding and taking photos of their babies the majority of the participants expressed that they wanted to see their baby and longed for this. Only three participants indicated that they did not at any point want to see their baby. With regard to actually holding their baby, there was a shift in outcome for the majority of participants did not hold their baby. Reasons for this were mainly that they felt too overwhelmed and that the situation was not right. Three participants mentioned that they regreted now not holding their baby. Finaly, more than half of the participants took photos of their babies, with two participants wanting to take photos but not being able due to not having the means, which could be attributed to low socio-economic circumstances.

It can be concluded that contrary to the findings of previous research, more bereaved parents will choose to see their baby, than to see and not hold their baby due to feeling overwhelmed and not having the emotional energy to still hold the baby as well. The minute physical touch occurs, a connection has been established, which will be seen by some bereaved mothers as different from the connection while still being pregnant. Seeing, holding and taking photographs of a stillborn baby stays a highly debatable topic due to the extremely sensitive nature thereof.

On the other side of the scale the conclusion can be drawn that seeing and holding the baby could help to acknowledge the fact that the baby existed and could help to start the grief process. The findings further suggest that participants felt positive about taking photos of their babies to keep as a memento and help the bereaved couple with acknowledging the fact that they did have a baby. These photos were very private and personal to the bereaved mothers and were mostly kept in a drawer or inside their Bible. A final conclusion can be drawn that low socio-economic status can have a negative impact on grieving, for there are no mementos for the bereaved parents.

Recommendations

With regard to tasks relating to the assessment phase in crisis intervention, it is recommended that:

- The social worker who renders crisis intervention to the bereaved couple, needs to be aware of the highly sensitive nature of this topic and needs to have the necessary knowledge to handle the situation.
- The social worker needs to suggest that it is possible to see and hold the baby and to take a photo of the baby so that the bereaved couple can take an informed decision of what they want to do. The correct timing of discussions of such nature is important because the baby cannot stay indefinitely in the delivery ward.
- In cases where the baby's heartbeat cannot be found just before delivery and the mother is aware of this before going into labour, the social worker can discuss and motivate the parents even before birth to see and hold their baby, but taking into account the personal circumstances of every individual and the severity of the crisis.

With regard to tasks relating to intervention in the practice setting, it is recommended that:

- Training courses by a social worker should be presented to all the medical staff in the obstetrics ward, in order to broaden their knowledge regarding the psychosocial implication of a stillbirth on the mother, and how seeing and touching the baby can play a positive or negative role in the healing process.

7.2.5.3 The point of acceptance

When considering the point of acceptance or the point when participants started feeling less sad, two opposing outcomes became clear with the same number of participants mentioning that they started accepting the loss after six months and the other half of the participants reporting that they thought they would never feel better. A small number of participants started feeling better after six weeks, and three months respectively, after hearing the autopsy results, but the number is not significant, hence there is not one specific characteristic regarding acceptance that stands out. Interestingly, the largest numbers of participants (32% and 28%) indicated that they thought they would never feel better (the latter percentage), or either felt better after six months.

From these findings it can be concluded that, the majority of participants did indicate that their feelings of sadness lessened although they felt only marginally better because of continuous reminders and triggers that hinder them from accepting and moving forward with their lives.

Recommendations

With regard to tasks relating to the evaluation phase in crisis intervention, it is recommended that:

- Proper evaluation of the bereaved mothers is necessary by the social worker rendering crisis intervention to estimate whether further intervention is necessary and whether it would take the form of long-term or short-term support.
- The social worker needs to evaluate the level of acceptance of the stillbirth by the bereaved mother after crisis intervention, to detect possible forms of complicated grief which may be present and need to be addressed urgently.

7.2.5.4 Persons playing a role in the healing process

When considering persons playing a role in the healing process, three significant groups can be mentioned. These groups helped during the crisis period and some are currently still helping, and consisted of a) mother or grandmother, b) husband/partner or a social worker and, c) support of sisters/friends who had the same experience.

It can be concluded that bereaved mothers tend to find support in their mothers/grandmothers or another female rather than in her partner. This may be because the partner is going through his own grief and healing process. Although they need to grieve and heal together, it is important to heal individually as well.

Recommendation

With regard to tasks related to the intervention phase in crisis intervention in the practice setting, it is recommended that:

- The social worker needs to motivate the bereaved mother to use any support she feels safe and comfortable with if this will aid her in the healing process. The social worker needs to highlight the importance that the bereaved mother needs to feel emotionally safe while being supported by this person.

7.2.5.5 Crisis intervention evaluation

Nearly all the participants, except two, had a crisis intervention session with a social worker shortly after the stillbirth. Participants were asked to indicate how they had experienced the crisis intervention session with the social worker from the hospital, from their place of employment or the social worker at the Safe Passage Study.

The majority of participants felt that the emotional support they received during the crisis intervention was very valuable at the time. The majority of participants reported that they had experienced empathy, felt encouraged and appreciated the objectiveness of the support. Some participants mentioned that they still had a need for ongoing counselling. A small, but significant number of participants mentioned that they did not find the crisis intervention approach positive, as they were still too overwhelmed to talk about the stillbirth.

Asked whether they would recommend crisis intervention as being an important part of the healing process of bereaved parents, the vast majority of participants agreed that they would definitely recommend crisis intervention to every bereaved mother/couple. Only three participants indicated that they thought the timing of the crisis intervention was a

problem. They suggested that any form of counselling or support should rather be provided a while after stillbirth if they could not cope.

In conclusion, the findings show that crisis intervention as social work method is highly recommended by bereaved parents themselves and that they found it valuable soon after the stillbirth. These findings serve as potential mechanisms on how crisis intervention as method in social work can be used to assist patients who have experienced a stillbirth, and assist the family to adjust constructively. Furthermore women who could express their emotional reactions right after the stillbirth had a shorter period of insufficiency than those who suppressed their feelings. Finaly, another important conclusion is that for some individuals ongoing counselling and support are needed and crisis intervention is only the first intervention before further support will be given.

Recommendations

With regard to tasks relating to crisis intervention in the practice setting/hospital setting, it is recommended that:

- The hospital setup must be of such a nature that a social worker or crisis worker would be available when a stillbirth occurs to offer crisis intervention if the patient is in need of support. In circumstances where no social worker is available, the patient needs to be referred to a social worker working in the community or given a contact number of a therapist or organisation, for example Life Line, in case of emergency.
- The social worker needs to be aware of her/his own emotions regarding stillbirth in order to be able to stay empathetic and objective during support.
- The social worker needs to provide the bereaved parents with bereavement counselling and supportive interventions enabling the mother/family to accept the reality of death.

7.2.6 Medical care during the loss

The second last section of the empirical study focused on participants' perception regarding medical care. Ten different options involving medical care were given, ranging from being cared for with special care, medical personnel sympathizing with the loss,

proper information given of what to expect when medicine was given, having a choice to see or hold the baby, offering counselling services, given information regarding burial and autopsy and to be moved to a separate room. The statements were all geared towards positive and high-quality medical care. Most participants agreed positively with the statements, while a minority of participants disagreed.

It can thus be concluded that the majority of participants were satisfied with the care they received and that this again was beneficial to the healing process. Unfortunately due to a shortage of medical/nursing staff and also uninformed staff, there were still incidents where participants were not satisfied with the treatment they had received.

Recommendations

With regard to tasks relating to medical staff/social worker in the practice setting/hospital setting, it is recommended that:

- Awareness programmes should be presented by the social worker to all the medical staff and personnel working in the maternity wards, providing a short background on the psychosocial effects of a stillbirth in order to equip them with better skills when working with a bereaved mother.
- Death and grief education, particularly surrounding stillbirth and perinatal losses, needs to be included in multidisciplinary professional education.

7.2.6.1 Perceptions regarding autopsy

Participants were asked to indicate their perceptions regarding autopsy directly after the loss and more than six months later. The majority of participants wanted an autopsy done, because they either thought it would help them with future pregnancies, help them understand the stillbirth better, or they just understood in general that it would be beneficial for them or other in the same circumstances. The number of participants feeling this way after six months was basically unchanged with not more than three participants joining or leaving this group.

A small, but significant group of bereaved mothers perceived that although they had not had an autopsy done on their baby after the loss, they now felt positive about autopsy

after six months and regretted not having an autopsy done. This is an important finding because it can be concluded that enough information needs to be given to the bereaved couple before a decision can to be made, although time is a factor.

Another conclusion that can be drawn from the findings is that in most cases an autopsy is not only the mother's or the father's decision but a decision they need to make together if possible. Participants indicated that they declined an autopsy because the partner did not consent to it, just to regret it later on, and causing instability in the relationship.

Findings also show that many, although by far not the majority indicated that they could not see the benefit of an autopsy because it would not bring their baby back. They also did not want anybody to cut their baby's body. Having an autopsy done is not allowed in some religions, but again after six months the findings has showed that they nevertheless wanted an autopsy. A conclusion was drawn that at this stage the bereaved mother was desperate for closure and she would go against her religion to have had some results.

Final conclusions that can be drawn from these findings are that having an autopsy done is a very personal decision and needs to be made after being informed of what exactly would take place. It is best if the bereaved mother and father can support each other in making this decision, in order to avoid future relationship instability and regret.

Recommendations

With regard to tasks relating to medical staff/social workers in the practice setting/hospital setting, it is recommended that:

- A doctor/medical personnel/research personnel or social worker needs to be identified as persons who are equipped enough to approach the bereaved couple when asking for consent for an autopsy.
- Preferaby the person who approaches the couple for consent, needs to be available for future questions and support and needs to be willing to discuss any questions again before consent is granted.
- Awareness programmes should be considered by either social workers or medical staff in the form of an educational video to show to expectant mothers. This is a highly sensitive subject and needs to be combined with information on

issues like post-natal depression, stillbirth, sudden infant death syndrome and depression, in order to educate the public on the benefits of an autopsy for themselves and for other pregnant women.

7.2.6.2 Reaction upon receiving the autopsy results

With regard to participants' reactions upon receiving the autopsy results the following reactions were identified. Most participants mentioned that the results gave them peace of mind and that they felt relieved. A smaller, but also significant group of participants mentioned that the autopsy results helped to alleviate their feelings of blame. One participant felt angry towards her partner after hearing the results for she felt the stillbirth was his fault.

Negative reactions after receiving autopsy results, were reported when participants were unable to comprehend the results and participants who have not yet received any results, which caused them to feel that their emotions were not acknowledged. It can be concluded that most of the reactions participants displayed upon hearing the autopsy results were positive and played a functional role in the healing process.

Recommendation

With regard to tasks relating to future support, it is recommended that:

- The social worker or counsellor needs to be available when the autopsy results are given to the couple in order to give emotional support where needed.

7.2.7 Support groups

The last section of the study focused on participants' perception of support in the community and support groups. This connects with the overall hypotheses where their lived experiences were to be explored.

The majority of participants reported that they had received negative reactions from people in the community. These included that they were teased; they were told that they could have children again and some people even avoided them because of feeling uncomfortable in their presence. Positive reactions which included support and understanding were only experienced by seven participants.

With regard to support groups**,** none of the participants attended a support group owing to no support group being available in the area. The majority of the participants would advise someone to attend such a group while only five participants mentioned that they did not see the necessity or benefit of such a group.

It can be concluded that support from members in the community is insufficient, thus making stillbirth a "*silent loss*" or a "*disenfranchised loss*". This reiterates the significance of education and support. Unfortunately it is not something you talk about regularly and is not something widely reported on in the media. It might be easier to find support when one has the means to get support, but because many stillbirths take place in low socio-economic areas, circumstances are not always suitable "to be able to grieve" for there are multiple social problems to face. These participants won't be able to benefit from support groups. Only five participants mentioned that they did not see the necessity or benefit of such a support group.

Recommendations

With regard to tasks relating to future support and awareness, it is recommended:

- Greater awareness about stillbirth as a psychosocial issue needs to be created in order to break the silence of this tragic loss as was done in the recent campaign regarding stillbirth done by "The Lancet", a medical journal, during 2011.
- Support groups need to be established in cooperation with day clinics and other support structures in the community, so that it is accessible for women of all socio-economic levels.

7.3 General comments

The women's determination to complete the interview supports the contention that this study offered women a rare opportunity to talk about their loss and a chance to help other families in future. This appeared to give the women a sense of closure. The mothers had no further questions after the interviews.

7.4 Further research

In the light of the results of the investigation with regard to the psychosocial implications of stillbirth on a mother and her family, it is suggested that further research be done:

- There is a need for more qualitative data documenting cultural influences, for there is a paucity of research in this area.

- There is a need for the examination of paternal and sibling grief. Paternal grief has been researched in several studies, but the long-term effect of stillbirth on the father has not been studied in depth and research in this area can be beneficial towards understanding of incongruent grief (a term used to refer to gender differences in how stillbirth is experienced by each parent). In-depth interviews with these fathers are suggested.
- Although a good foundation has been laid in this study regarding the effect of a stillbirth on the relationship between the bereaved mother and father, it would be beneficial to do a long-term study about the effect of stillbirth on the marital relationship with special focus on communication, blame and how subsequent pregnancies will be handled.

- A strengths-based theoretical study, done from a social work viewpoint, could be undertaken to further evaluate spirit, disposition, and tendency to humanity, exploring how individuals and families find meaning and renewed purpose after such a uniquely tragic, and largely unrecognized, loss. This will also be seen as long-term adjustment after the loss.

- Further research is needed to establish what kind of intervention would be beneficial after the crisis intervention model has been implemented and a state of equilibrium has been reached, but the client will need further guidance and support to be able to regain a level of functioning that is satisfactory.

- Legitimization for grieving mothers and fathers, through policy changes as well as education, research, and advocacy, is long overdue and needs further investigation and research.

7.5 Summary

It can be concluded from the research that experiencing a stillbirth has psychosocial implications for the mother and her family and that the social worker can effectively use crisis intervention as a method in social work to assist the mother and her family with support and bereavement counselling during this tragic time. During the research it has become clear that the social context of stillbirth and the impact of compounding factors affecting grief such as financial resources, culture and social identity may greatly influence an individual's style of grieving and the meaning he/she attributes to the loss.

Questions that were considered were: "What are the long-term effects of the death of a child on the parents' and family's lives?", "What interventions bring meaning and healing to bereaved families?" and "What interventions are not effective?" By being trained in the field of the social environment in which an individual lives and its impact on social problems and emotional well-being, the researcher was in a good position to address these issues and make a contribution to the theoretical and practice literature on stillbirth and social work theory. Enhanced understanding of the experience and better psychosocial support may help some women and their family systems cope with the long-term effects of this loss. To conclude, it can be generalized that after experiencing a stillbirth the mother never stops searching for a reason, for logic and for meaning.

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APPENDIX A1

Questionnaire 1 – Identifying particulars in English

STELLENBOSCH UNIVERSITY

DEPARTMENT OF SOCIAL WORK

Psychosocial implications of stillbirth on a mother and her family: A crisis intervention approach

All the information recorded in the questionnaire will be regarded as confidential.

Please read the following questions and answer them honestly.

Date of interview: .....

Interviewer: Melanie Human

1. Identifying particulars of respondents after a stillbirth

Section A: Particulars of female respondent

1. *Indicate your age:*

Less than 19 years	20 – 29 years	30 – 39 years	40 – 49 years	50 – 59 years

2. *What is your home language?*

Afrikaans	English	Xhosa

3. *Indicate your relationship/marital status:*

	During loss	Currently
Single		
Married		
Widow		
Divorced/estranged/separated		
Not married, living together		

4. Indicate the number of years married or length of current relationship:

1 – 12 Months	1 – 5 years	6 – 10 years	11 – 15 years	16 years and longer	Not applicable

5. Highest educational qualification:

No school education	Grade 7 or lower	Grade 8 – 9	Grade 10 – 11	Grade 12	Technical certificate	Degree/Diploma

6. Current occupation/work:

Unemployed	
House wife	
Student	
Scholar	
Unfit for work (Receiving Disability Grant)	
Clerk	
Labourer	
Business women	
Professional	
Other (specify)	

7. Who receives income in the family?

Only husband/partner	Only wife	Both	Children	Family	No income

8. Does any member of the household receive a social grant?

Yes	No

8.1 If you indicated a "yes" at the above question, please indicate what type of grant members of the household receive:

Old age pension	Disability grant	War veterans grant	Care dependency grant	Foster child grant	Child support grant	Grant-in-aid	Social relief of distress

9. Please indicate the total gross monthly income of family:

Less than R500		R500 – R999		R1000 – R1999	
R2000 – R2999		R3000-R3999		R4000-R4999	
R5000-R6999		R7000-R9999		R10 000 and more	

10. Number of other (living) children:

	Number of children
None	
Biological children	
Step-children	
Adopted children	
Foster children	

11. Indicate the ages of children by specifying the number of children in each category:

Less than 1 year	1 – 3 years	4 – 6 years	7 – 12 years	13 – 15 years	16 – 18 years	19 years and older

12. To which religion do you and your husband/partner belong?

	Wife	Husband/Partner
None		
Dutch-Reformed church		
United Reformed church		
New Apostolic		
Old Apostolic		
Jewish		
Muslim		
Charismatic churches		
Methodist		
Anglican		
Roman Catholic		
Rastafarian		
Other (Specify)		

13. Indicate current type of housing/housing circumstances:

Council housing		Informal (shack/squatter)		Apartment/House	
Farm		Wendy House – in back of yard		Trailer/Mobile Home	
Other (specify)					

14. Indicate the number of occupants in the house:

Residing alone	2- 4 persons	5-7 persons	8 -10 persons	10 – 14 persons	15 or more

15. Do you currently have the following?
(Please indicate with an "x" for each item)

	No	Yes
Electricity		
Working phone service or cell phone service		
Running water (inside house)		
Toilet (inside house)		

Appendix A2

Questionnaire 1 – Identifying particulars in Afrikaans

STELLENBOSCH UNIVERSITY

DEPARTMENT OF SOCIAL WORK

Psychosocial implications of stillbirth on a mother and her family: A crisis intervention approach

Alle inligting wat versamel gaan word tydens hierdie onderhoud sal as konfidensieël beskou word.

Lees asseblief die volgende vrae en antwoord dit so eerlik as moontlik.

Datum van onderhoud: .....

Navorsser: Melanie Human

Afdeling A: Identifiserende besonderhede van deelnemers

1. *Dui asseblief u ouderdom aan:*

Minder as 19 jaar	20 – 29 jaar	30 – 39 jaar	40 – 49 jaar	50 – 59 jaar

2. *Wat is u huistaal?*

Afrikaans	Engels	Xhosa

3. *Dui asseblief u huwelikstatus/verhoudingstatus aan:*

	Gedurende verlies	Huidiglike
Enkel		
Getroud		
Weduwee		
Geskei/vervreem/Uitmekaar		
Bly saam, nie getroud nie.		
Bly nie saam nie, maar in ‘n verhouding.		

4. Dui asseblief aan hoe lank u getroud is of hoe lank u betrokke is in u huidige verhouding?

1 – 12 Maande	1 – 5 Jaar	6 – 10 Jaar	11 – 15 Jaar	16 Jaar en langer	Nie van toepassing nie.

5. Hoogste opvoedkundige kwalifikasie:

Geen skoolopleiding nie.	Graad 7 of laer.	Graad 8 – 9	Graad 10 – 11	Graad 12	Tegniese sertifikaat	Graad/Diploma

6. Huidige beroep/werksituasie:

Werkloos	
Tuisteskepper/Huisvrou	
Student	
Skolier	
Ongeskik vir werk (Ontvang ‘n ongeskiktheidstoelaag)	
Klerk	
Fisies werker/Ambagspersoon	
Besigheidsvrou	
Proffessionele persoon	
Ander (spesifisieer)	

7. Wie verdien ‘n inkomste in die familie?

Slegs man/kêrel	Slegs vrou/deelnemer	Beide	Kinders	Familie	Geen inkomste

8. Ontvang enige persoon in die huishouding 'n maatskaplike toelaag?

Ja	Nee

8.1 Indien u "ja" aangedui het by die bogenoemde vraag, spesifiseer asseblief watter tipe toelae ontvang word:

Pensioen-toelaag	Ongeskikt-heids-toelaag	Oorlog veteraan toelaag	Versorgings-afhanklikheids-toelaag	Pleegsorg toelaag	Kindersversorg-ingstoelaag	"Grant-in-aid"	Social relief of distress

9. Dui asseblief die totale bruto maandelikse inkomste van u gesin aan:

Minder as R500		R500 – R999		R1000 – R1999	
R2000 – R2999		R3000-R3999		R4000-R4999	
R5000-R6999		R7000-R9999		R10 000 en meer	

10. Aantal ander (lewende) kinders::

	Aantal kinders
Geen	
Biologiese kinders	
Stiefkinders	
Aangenome kinders	
Pleegsorg kinders	

11. Dui asseblief die ouderdom van die kinders aan deur die aantal kinders in elke kategorie aan te dui:

Minder as 1 jaar	1 – 3 jaar	4 – 6 jaar	7 – 12 jaar	13 – 15 jaar	16 – 18 jaar	19 jaar en ouer

12. Aan watter geloof/Godsdienstige oortuiging behoort u en u man/kêrel

	Vrou	Man/Kêrel
Geen		
Nederduits-Gereformeerde kerk		
Gereformeerde kerk/ “United Reformed church”		
Nuwe Apostoliese kerk		
Ou Apostoliese kerk		
Joodse geloof		
Moslem		
Charasmatiese kerke		
Methodiste kerk		
Anglikaanse kerk		
Rooms Katolieke kerk		
Rastafarian		
Ander(Spesifisiëer)		

13. Dui asseblief u huidige behuisingsomstandighede aan:

Raadshuis “Council housing”		Informele nedersetting / Plakkerskamp		Woonstel/Huis	
Plaas		Wendy Huis – in agterplaas		Woonwa/Mobiele huis	
Ander (Spesifisiëer)					

14. Dui aan hoeveel inwoners in die huis is:

Woon alleen	2- 4 persone	5-7 persone	8 -10 persone	10 – 14 persone	15 of meer

15. Het u huidiglik die volgende dienste tot u beskikking?

(Dui aaseblief met 'n "x"by elke item)

	Nee	Ja
Elektrisiteit		
Werkende telefoon diens of selfoon		
Lopende water (binne die huis)		
Toilet (binne die huis)		

Appendix B1

Questionnaire 2.1 – Semi-structured interview schedule in English

STELLENBOSCH UNIVERSITY

DEPARTMENT OF SOCIAL WORK

Psychosocial implications of stillbirth on a mother and her family: A crisis intervention approach

Interviewer: Melanie Human

Date of interview: .....

Section B: Loss of your fetus/baby

1. Indicate whether you had any of the following types of losses besides the stillbirth:

	Type of loss	Number of losses	Year of last loss
Ectopic pregnancy			
Miscarriage			
Therapeutic abortion			
Stillbirth			
Neonatal death			
Possible SIDS (cot death)			

2. Please describe the emotions you are currently experiencing, six or more months after the loss?

_____

_____

_____

_____

_____

3. What bothers you at the moment regarding your health? What are you worried about? (Six or more months after the loss)

_____

_____

_____

_____

4. Which of the following thoughts/feelings/actions did you experienced after the loss and are you still experiencing it?

	Yes - I did experience it	No - I didn't experience it	I am still having these thoughts
I am afraid to fall pregnant again.			
I wanted to fall pregnant again as soon as possible.			
I feared another loss.			
When I saw other babies, I longed for my own baby.			
I have/had nightmares about my baby (or babies).			
I had thought of committing suicide.			
I felt nobody understood me or cared for me.			
I had thoughts of stealing another baby.			
I avoided other babies.			
I was unable to pack my baby's clothes away -left it just like it was for a very long time.			
I tried to be strong and not show my hurt.			

5.1 Did you see yourself as being depressed at any stage after the loss? Please explain.

_____

_____

_____

_____

5.2. Did you perceive you husband/partner as being depressed at any stage after the loss? Please explain.

_____

_____

_____

Please answer question 6 only if you have indicated yes at question 5.1 or 5.2

6.1 What would you describe as the main symptoms of your depression?

_____

_____

_____

_____

_____

6.2 Was any medication prescribed to you? Please indicate if possible which medication if applicable.

_____

_____

_____

7. What is your pregnancy history?

I fell pregnant easily.	
Pregnancy was preceded by a period of infertility.	
Only fell pregnant with medical assistance.	
I had a difficult pregnancy. Explain.	

_____

_____

_____

Section C: Effect of loss on marriage/relationship

1. Indicate which statement applies to your marriage/relationship

	Before the loss/death	During the 6 months after the loss	Six months after the loss and beyond
We can discuss our feelings openly with each other.			
We listen to each other with attention.			
We will always ask each other about the day's happenings.			
We both share the same interests like TV, reading etc			
We have nothing to talk about with each other.			
I can't share my emotions with my husband.			
We only talk about general issues.			
I can't confide towards my husband.			

2. How would you describe your marriage/relationship?

	Very unhappy	Somewhat unhappy	Fairly happy	Very happy
Before the loss				
At the time of the loss				
One month after loss				
Six months after loss-Currently				

3. What was your partner/husband's involvement during your pregnancy? Please mention any significant experiences you recall?

_____

_____

_____

_____

4. Please describe any problems/changes which occurred in your relationship after the loss:

_____

_____

Section D: Effect of loss on your other children (Only to be completed by participants with other children)

1. What would you say was the emotional and physical reaction of your other children to the loss? Please describe the reactions which you can remember or the reactions that are still taking place.

_____

_____

_____

_____

_____

_____

2. How did the loss of your baby influenced your relationship with your other children:

I found it difficult to react to their emotional needs	
I neglected them for a period	
I could, as in the past, satisfy their needs	
They irritated me easily	
I did not know how to explain the death	
Caring for my children helped me to deal with my loss	
I appreciate my children much more now.	
Other	

3. How did you inform your children about the loss?

_____

_____

_____

_____

_____

Section E: Coping mechanisms playing a role during the acceptance/non-acceptance of the loss

1. How would you describe the loss of your baby? Please indicate.

I didn't perceive my loss as a crisis.	
I perceived my loss as a slight crisis.	
I saw the loss of my baby as a crisis and needed help.	
I perceived my loss as a severe crisis.	

Please explain:

_____

_____

_____

2. What helped you to cope with your loss?

My work.	
My sports activity.	
Professional support groups in the community.	
Support by family and friends.	
Counselling sessions by a professional person.	
Having a funeral service for the baby.	
To visit my baby's grave.	
Photos of my baby.	
To talk about my baby.	
Reading literature on the subject.	
Other. Specify please.	

3. Was it important for you to do the following? Please explain:

3.1 To be able to see my baby:

_____

_____

3.2 To be able to hold my baby:

_____

_____

3.3 To take photos of my baby:

_____

_____

4. When did you start feeling less sad ? (The point of acceptance and making meaning of things again.)

I still feel very sad.	
I started feeling better after six weeks.	
I started feeling better after three months.	
I started feeling better after hearing the autopsy results.	
I started accepting the loss after six months.	
I don't think I will ever feel better again.	

5. *Please explain who played a role in helping you in the healing process and to what extent the person/persons helped you in the healing process.*

_____

_____

_____

_____

_____

6.1 *Please indicate whether you had a crisis intervention session with a social worker shorter after your loss?*

Yes	
No	

6.2 *Please explain in your own words whether this crisis intervention counselling session was beneficial for you? Why would you say so?*

_____

_____

_____

_____

6.3 ***Would you agree that an initial crisis intervention counselling interview helped you when you needed support the most?***

_____

_____

_____

6.4 ***Would you recommend it as being an important part of the healing process for bereaved parents?***

_____

_____

_____

Section F: Medical care/issues during the loss

1. Please indicate your perception regarding the service and treatment received in hospital.

	Agree	Disagree
The nursing staff treated me/us with special care.		
The medical personnel sympathized with my loss.		
I was informed throughout my loss what procedures I should next expect (For example why I receive certain medication)		
The medical personnel weren't hesitant to embrace me after my loss.		
The choice was given to me/us to see the baby.		
The choice was given to me/us to hold the baby.		
Counselling services were offered to me/us.		
I was informed about the burial/cremation procedures.		
I was offered to have autopsy done on my baby.		
I was moved to a separate room after delivery, to avoid facing other mothers with living babies.		

2. *Please indicate/compare what your perception regarding an autopsy was shortly after the loss of your baby and after six months?*

	Directly after loss.	After six months
I did not consider autopsy due to religious reasons.		
I wanted an autopsy although my religion doesn't allow it.		
I was hesitant about an autopsy because I didn't want anybody to cut my baby's body.		
After being informed what an autopsy is and entails, I was positive about the autopsy.		
I can't see the benefit of an autopsy because it won't bring my baby back.		
I can see the benefit of an autopsy		
I think autopsy results will help me to understand the death of my baby better.		
I want an autopsy done on my baby because it will help me in future pregnancies.		
I am scared of having an autopsy done, because my husband/partner is against it and it will influence our relationship negatively.		
I want to have an autopsy on my baby, even though my partner/husband doesn't not approve of it.		
Other		

3. What was your reaction after receiving the autopsy results?

_____

_____

_____

4. Would you say that the autopsy results helped you to find peace in your baby's loss or did it make you more frustrated/helpless?

_____

_____

Section G: Attitude regarding support/support groups

1. What reaction by others did you observe the most? Please describe and explain.

_____

_____

_____

_____

_____

2. *What is your attitude regarding support groups? Please indicate.*

I attended a support group in my area.	
There was no support group available in our area.	
I was hesitant to join a support group.	
I did not feel it was necessary for me to join a group.	
I will advise anyone experiencing the same to join a support group.	

Thank you for taking the time to complete this questionnaire and interview. Your contribution is truly valued and will make a valuable contribution to this study, as well as future social work services to parents having to cope with perinatal loss.

Mrs. M. Human

Appendix B2

Questionnaire 2.2 – Semi-structured interview schedule in Afrikaans

STELLENBOSCH UNIVERSITY

DEPARTMENT OF SOCIAL WORK

Psychosocial implications of stillbirth on a mother and her family: A crisis intervention approach

Persoon wat onderhoud voer: Melanie Human

Datum van onderhoud: ……

Afdeling B: Die verlies van jou baba/ongebore baba

1. Dui asseblief aan of u 'n ander tipe verlies gehad het, behalwe die stilgeboorte:

	Tipe verlies	Aantal verliese	Jaar waarin laaste verlies plaasgevind het.
Ektopiese swangerskap			
Miskraam			
Terapeutiese aborsie			
Stilgeboorte			
Neonatale sterfte			
Moontlike SIDS (wiegiedood)			

2. Beskryf asseblief die huidige emosies wat u ervaar, ses of meer maande na u verlies?

_____

_____

_____

_____

_____

3. Wat pla u op die oomblik. Waaroor is u bekommerd oor u gesondheid (Ses of meer maande na die verlies)

_____

_____

4. Watter van die volgende gedagtes/gevoelens/optrede het u ervaar na u die verliese gehad het en wat u steeds ervaar?

	Ja – Ek het dit ervaar.	Nee – Ek het dit nie ervaar nie.	Ek ervaar nogsteeds hierdie gevoelens/gedagtes.
Ek is bang om weer swanger te raak.			
Ek wou so gou as moontlik weer swanger geword het.			
Ek is/was bang ek het nog ‘n verlies.			
Wanneer ek ander babas gesien het, het ek gehunker na my eie baba.			
Ek het nagmerries gehad van my eie baba of van ander babas.			
Ek het selfmoordgedagtes of selfmoordneigings gehad			
Dit het gevoel asof niemand my verstaan het of vir my omgegee het nie.			
Ek het daaraan gedink om ‘n ander baba te steel.			
Ek het ander babas vermy.			
Ek was nie instaat om my baba se babaklere weg te pak nie – ek het dit net so gelos vir ‘n baie lang tydperk.			
Ek het prober om sterk te wees en nie my hartseer vir ander mense te wys nie.			

5.1 Het u uself as depressief beskou tydens enige stadium na die verlies? Verduidelik asseblief?

_____

_____

_____

_____

_____

5.2. Het u u man/saamleefmaat/kêrel as depressief beskou tydens enige stadium na die verlies? Verduidelik asseblief.

_____

_____

_____

_____

Beantwoord vraag 6 slegs indien u 'n "ja" aangedui het by vraag 5.

6.1 Hoe sou u die simptome van u depressie beskryf het?

_____

_____

_____

6.2 Was enige medikasie aan u voorgeskryf? Dui asseblief aan watter medikasie indien moontlik.

_____

_____

_____

7. Wat is u swangerskap geskiedenis?

Ek het maklik swanger geraak.	
Swangerskap het eers gevolg na ‘n baie lang tydperk van onvrugbaarheid.	
Ek het slegs swanger geraak met mediese hulp.	
Ek het ‘n moeilik swangerskap gehad. Verduidelik asseblief?	

_____

_____

Afdeling C: Impak van verlies op u huwelik/verhouding.

1. Dui asseblief aan watter stelling betrekking het op u huwelik/verhouding?

	Voor die verlies/ sterfte	Gedurende die 6 maande na afloop van die verlies.	Ses en meer maande na die verlies.
Ons kan ons gevoelens openlik met mekaar bespreek.			
Ons luister na mekaar met aandag.			
Ons sal altyd mekaar uitvra oor hoe elkeen se dag was.			
Ons deel dieselfde belangstellings soos tv kyk, lees ens.			
Dit voel asof ons niks het om met mekaar oor te gesels nie.			
Ek kan nie my gevoelens/emosies met my man deel nie			
Ons praat net oor algemene kwessies en praat nie oor persoonlike kwessies nie.			
Ek kan my man in my vertroue neem met alles wat ek sê.			

2. Hoe sal u u huwelik/verhouding beskryf?

	Baie ongelukkig	Redelik ongelukkig	Redelik gelukkig	Baie gelukkig
Voor die verlies				
Tydens die verlies				
Een maand na die verlies				
Ses maande na die verlies tot huidiglik				

3. Wat was u man/kêrel/metgesel se betrokkenheid gedurende u swangerskap? Noem asseblief enige spesifieke gebeurtenis wat by u uitstaan.

_____

_____

_____

_____

4. Beskryf asseblief enige probleme/verandering wat plaasgevind in die verhouding na die verlies.

_____

_____

_____

_____

Afdeling D: Die impak van die verlies op u ander kinders (Moet slegs voltooi word as deelnemer wel ander kinders het.)

1. Wat sou u sê was die emosionele en fisiese reaksie van u ander kinders ten opsigte van die verlies? Verduidelik asseblief die reaksies wat u kan onthou of wat steeds plaasvind.

_____

_____

_____

_____

_____

2. Hoe het die verlies van u baba u verhouding met u ander kinders beïnvloed?

Dit was vir my moeilik om te reageer op hulle emosionele behoeftes.	
Dit het gevoel asof ek my kinders afgeskeep het gedurende hierdie tydperk.	
Ek kon, soos in die verlede, in hulle behoeftes voorsien.	
Dit het gevoel asof my kinders my maklik geïrriteer het.	
Ek het nie geweet hoe om die verlies aan my kind/kinders te verduidelik nie.	
Om my kinders te versorg en aandag aan hulle te gee het my gehelp om my verlies te hanteer.	
Ek waardeer my kinders nou baie meer as voor die verlies.	
Ander. Verduidelik asseblief?	

_____

_____

_____

3. *Hoe het u u kind/kinders ingelig oor die verlies van u baba?*

_____

_____

_____

_____

Afdeling E: Hanteringsmeganismes wat ‘n rol gespeel het tydens die aanvaarding/nie-aanvaarding van die verlies.

1. Hoe sou u die verlies van u baba beskryf? Dui asseblief aan.

Ek het nie my verlies as ‘n krisis ervaar nie.	
Ek het my verlies as ‘n matige krisis ervaar.	
Ek het my verlies van my baba as ‘n krisis ervaar en het professionele hulp benodig.	
Ek het my verlies as ‘n intense krisis ervaar.	

Verduidelik asseblief:

_____

_____

_____

_____

2. Wat het u gehelp om u verlies te hanteer?

My werk.	
My sportaktiwiteit.	
Hulpdienste in die gemeenskap.	
Ondersteuning deur my familie en vriende.	
Beradingsessies deur ‘n professionele persoon.	
Om ‘n begrafnisdiens vir my baba te kon gehou het.	
Om my baba se graf te besoek.	
Fotos van my baba /Hand-en-voet afdrukke van my baba.	
Om oor my baba te praat.	
Om literatuur oor die verlies van ‘n baba te lees.	
Ander. Spesifiseer asseblief?	

3. Was dit vir u belangrik om die volgende te doen: Verduidelik asseblief..

3.1 Om u babatjie te sien:

_____

3.2 Om u babatjie vas te hou:

_____

3.3 Om foto's te neem van die baba:

_____

_____

4. Wanneer het u minder hartseer begin voel (Die punt waar aanvaarding plaasgevind het en gebeure weer betekenisvol geword het.)

Ek voel nog net so hartseer.	
Ek het begin beter voel ongeveer ses weke na die verlies.	
Ek het begin beter voel ongeveer drie maande na die verlies.	
Ek het begin beter voel nadat ek die outopsie uitslae gehoor het.	
Ek het begin beter voel ongeveer ses maande na die insident.	
Ek twyfel of ek ooit beter sal voel.	

5. *Verduidelik asseblief watter persoon/persone het 'n rol gespeel om u behulpsaam te wees in die rouproses? Verduidelik in watter mate het hierdie persoon/persone u gehelp?*

_____

_____

_____

_____

_____

_____

6.1 Dui asseblief aan of u wel 'n krisis-ondersteuningsessie met 'n maatskaplike werker gehad het kort na u verlies?

Ja	
Nee	

6.2 Verduidelik asseblief in u eie woorde of hierdie krisis-ondersteunings-beradingssessie voordelig was vir u? Hoekom sou u so sê?

_____

_____

_____

_____

_____

_____

6.3 ***Sou u saamstem dat 'n aanvanklike krisis-ingryping beradingsessie u gehelp het toe u die ondersteuning die meeste nodig gehad het?***

_____

_____

_____

6.4 **Sou u aanbeveel dat 'n aanvanklik beradingsessie kort na die verlies'n belangrike deel van die helingsproses van ouers in rou is?**

_____

_____

_____

Afdeling F: Mediese sorg/kwessies tydens u verlies

1. Dui asseblief aan wat u persepsie was van die diens en behandeling wat u tydens u hospitalverblyf ontvang het.

	Stem saam	Stem nie saam nie
Die verpleegpersoneel het my/ons met spesiale sorg behandel.		
Die mediese personeel het teenoor my gesimpatiseer met my verlies.		
Ek was deurgaans ingelig oor wat om volgende te verwag tydens my verlies. (Byvoorbeeld hoekom ek sekere medikasie moes gebruik.)		
Die mediese personeel het nie gehuiwer om my te troos na afloop van my verlies nie. (Byvoorbeeld om 'n drukkie vir my te gee nie.)		
Ek het die keuse gehad of ek my baba wil sien of nie.		
Ek het die keuse gehad of ek my baba wil vashou of nie.		
Beradingsdienste is aangebied vir my/ons.		
Ek was ingelig oor die begrafnis/verassingsprosedures.		
Daar is aan my die keuse gegee of ek 'n outopsie wil laat doen op my baba of nie.		
EK was na 'n aparte kamer geskuif na afloop van die verlies, ten einde te voorkom dat ek saam met moeders met lewende babas in een kamer is		

2. Dui asseblief aan wat u persepsie oor outopsie was kort na die verlies van u baba in vergelyking met ses of meer maande later na die verlies?

	Direk na die verlies.	Ses maande en meer na die verlies.
Ek het as gevolg van Godsdienstige redes nie oorweeg om 'n outopsie te doen nie.		
Ek wou 'n outopsie gehad het alhoewel my geloof (Godsdienstige oortuiging) daarteen was.		
Ek het baie onseker gevoel oor 'n outopsie, omrede ek nie wou hê dat iemand aan my baba moet sny nie.		
Nadat ek genoegsame inligting ontvang het van wat 'n outopsie is en wat dit behels, het ek meer positief gevoel oor 'n outopsie.		
Ek kan nie die doel van 'n outopsie insien nie, omrede dit nie my baba gaan terugbring nie.		
Ek besef die voordele van 'n outopsie.		
Ek dink die outopsie uitslae sal my help om die dood van my baba beter te verstaan.		
Ek wil 'n outopsie gedoen hê omrede dit my gaan help in toekomstige swangerskappe.		
Ek is bang om 'n outopsie te laat doen, omrede my kêrel/eggenote gekant is teen 'n outopsie en ek is bang dit sal ons verhouding negatief beïnvloed.		
Ek wil 'n outopsie laat doen op my baba, al verskaf my kêrel/eggenoot nie sy goedkeuring nie.		
Ander		

_____

_____

_____

_____

_____

_____

3. Wat was u reaksie nadat u die outopsie uitslae ontvang het?

_____

_____

_____

4. Sou u sê dat die outopsie resultate u gehelp het om u verlies beter te aanvaar or het dit u meer hulpeloos/gefrustreerd gemaak?

_____

_____

Afdeling G: Houding teenoor ondersteuning/ondersteuningsgroepe

1. Watter reaksie van ander persone het u die meeste waargeneem? Beskryf en verduidelik asseblief?

_____

_____

_____

_____

_____

_____

2. Wat is u gevoel rakende 'n ondersteuningsgroep? Dui asseblief aan.

Ek het 'n ondersteuningsgroep bygewoon in my area.	
Daar was nie 'n ondersteuningsgroep beskikbaar in my area nie.	
Ek het gehuiwer om 'n ondersteuningsgroep by te woon.	
Ek het nie gedink dit is nodig om 'n ondersteuningsgroep by te woon nie.	
Ek sal vir ander persone wat dieselfde situasie ervaar aanbeveel om 'n ondersteuningsgroep by te woon.	

Dankie dat u die tyd geneem het om hierdie vraelys en onderhoud te voltooi. U bydrae word hoog op prys gestel en sal 'n waardevolle bydrae maak tot hierdie studie, sowel as vir toekomstige maatskaplike werk-dienslewering aan ouers wat 'n perinatal verlies gehad het.

Mev. M. Human

Appendix C1 - Participant information and consent form –English

PARTICIPANT INFORMATION AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Psychosocial implications of stillbirth: a crisis intervention approach.

REFERENCE NUMBER: N10/09/313

PRINCIPAL INVESTIGATOR: Melanie Human

ADDRESS: Department of Obstetrics & Gynaecology, P.O. Box 19063, Tygerberg, 7505

CONTACT NUMBER: 021-938 4748

Statement of Research
It is a basic ethical principle that a participant who is to participate in the research must give his or her informed consent to such participation. This consent must be based on the understanding of the nature and risks of the research. This document provides information important for this understanding. If you have any questions please ask. Research projects include only participants who choose to take part. Please take your time to make your decision. If at any time you have questions, please ask.

What is this study about?
The purpose of this study is to look at the long term effects of the loss of a baby before birth or at the time of birth. The loss of a baby can have many effects for the mother and her family. The researchers hope to learn about the long term effects of the loss of a baby in order to provide better help to women that lose a baby before or at the time of birth in the future.

How many people will be part of the study and where will the study take place?
This study will take place at Tygerberg Hospital and Bishop Lavis Day Hospital in the comfort of the social worker's office. Approximately 30 women who have lost a baby more than six months ago will be part of the study.

What will happen during this study?
During this study, you will take part in one interview. This interview will last about 1 hour. During the interview you will be asked questions about basic information for example your age, marital status, whether you are working or not and stresses in your life.

You will also be asked questions about how the loss of your baby has affected your own life, your marital relationship, your children and who is supporting you through this period.

Why am I being asked to take part in this study?
You have been asked to take part in this study because more than 6 months ago, you lost a baby before birth or at the time of birth.

Will you benefit from taking part in this research?
You will receive information about dealing with grief after the loss of a baby. Because of the emotional nature of the topic of discussion, the social worker will be available to talk to anybody that needs further support after completion of the interviews. If you become very emotional and need to be helped even further, you will be referred to a Psychiatrist at Tygerberg Hospital. You may also benefit from being able to reflect on your loss and share your emotions and feelings with someone aside from your family and friends. Information collected during this research may help future parents deal with the loss of a baby.

Are there in risks involved in your taking part in this research?
Some of the questions about your loss might be disturbing to you. If this is the case you must inform the researcher about this in order to give you the proper support and counselling that is needed. The researcher will assess your situation and in acute cases where the participant presents with signs of severe emotional distress or indicates that she has suicidal thoughts, an immediate referral will be made to the Registrar of Psychiatry on call at Tygerberg Hospital as was arranged with liaison psychiatrist, Dr. B. Chiliza. In non-acute cases a referral will be made to the Psychiatric Clinic at Tygerberg Hospital at J-lower ground, contact number (021 938 5120) or to the Psychiatric nurse, Mr. N. Kiewiets at the Community Clinic in Bishop Lavis, contact number (021 934 6050).

Will information about me be kept confidential?
The records of this study will be kept private. Information collected during this study does not become part of your medical record and will be stored in a separate research file by the researcher. Information obtained for this research study will be accessible only by researchers directly involved with this study. You will not be identified in any report about this research. We will not share your name. The information collected will be identified by a number on the study records and not by name. Several people may look at this information including: the individuals from the National Institutes of Health, the Health Research Ethics Committee of Stellenbosch University, the Advisory and Safety Monitoring Board appointed by the United States government, the data coordinating center, and researchers that are part of the project.

We may need to report information about you to health care providers and/or local authorities if we suspect that you may harm yourself or others.

If you do not agree to take part, what alternatives do you have?
If you do not agree to take part in the study, but is in need of support and counselling after the loss of your baby the following organisations can be contacted:

- **Compassionate Friends: Contact person is Alta Volschenk (021 8560717) or Cynthia Lasson (021 553 0038)**

- **Lifeline – 24 hours counselling service – 021 461 1113**

Will I be paid to take part in this study?
No, you will not be paid to take part in the study but transport will be provided as well as coffee/tea and a sandwich after the interview.

Will it cost me anything to take part in this study?
There will be no costs involved for you, if you do take part in this study.

Who is funding this study?

Stellenbosch University and Mrs. Melanie Human are not receiving any payments to conduct this study.

Can I be removed from the study?
If we feel that having you continue in the study would not be good for you, we may remove you from the study.

What are my rights as a participant?
Taking part in this study is voluntary. You have the right to:

- Refuse to participate in this study.
- Skip any questions or stop any interview before it is finished.
- Withdraw from the study at anytime. If you choose to withdraw, you may contact Mrs. Melanie Human at tel 021 938 4748 or mail your request to mhuman@sun.ac.za

If you decide not to take part or withdraw from (quit) the study, your decision will not affect your current or future medical care.

The Health Research Ethics Committee, Faculty of Health Sciences, Stellenbosch University, has approved recruitment and participation of individuals in this study on the basis of:

- Guidelines on Ethics for Medical Research of the South African Medical Research Council;
- Declaration of Helsinki;
- International Guidelines: Council for International Organisations of Medical Sciences (CIOMS);
- Applicable South African legislation.

Is there anything else that you should know or do?

- You can contact **Mrs. Melanie Human** at tel **021 938 4748** if you have any further queries or run into any problems.
- You can contact the **Health Research Ethics Committee** at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this consent form for your own records.

Declaration by participant

By signing below, I _____ agree to take part in the study entitled “Psychosocial implications of stillbirth: a crisis-support approach”.

I declare that:

- I have read or had read to me this consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressured to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interest, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ……..…….. 2011.

_____

Printed name of participant

....

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.

- I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2011.

Signature of investigator **Signature of witness**

Appendix C2 - Participant information and consent form – Afrikaans

DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM

TITEL VAN DIE NAVORSINGSPROJEK: "Psychosocial implications of stillbirth: a crisis-support approach

VERWYSINGSNOMMER: N10/09/313

HOOFNAVORSER: Melanie Human

ADRES: Department Verloskunde en Ginekologie, Posbus 19063, Tygerberg, 7505

KONTAKNOMMER: 021-938 4748

Navorsingsverklaring

Dit is 'n basiese etiese beginsel dat 'n deelnemer wat beoog om deel te neem aan navorsing, ingeligte toestemming moet verskaf. Toestemming moet gegee word gebaseer daarop dat 'n deelnemer bewus is van die aard en risiko's van die studie. Indien u enige vrae het rakende die studie moet u asseblief vra. Neem asseblief u tyd om u besluit te neem.

Wat behels hierdie studie?

Die doel van hierdie studie is om die langtermyn invloed van die verlies van 'n baba voor geboorte of tydens geboorte te verken. So 'n verlies kan 'n effek hê op die ma van die baba en haar familie. Die navorser hoop om meer te leer oor die uitwerking van so 'n verlies op die moeder sodat beter ondersteuningsdienste aan hierdie moeders verskaf kan word.

Hoeveel persone gaan aan die studie deelneem en waar gaan die studie plaasvind?

Hierdie studie gaan plaasvind by die Safe Passage studie se kantore in Tygerberg Hospitaal en Bishop Lavis Dag Hospitaal in die gemak van die maatskaplike werker se kantoor. Ongeveer 30 deelnemers wat 'n stilgeboorte/miskraam meer as ses maande gelede gehad het, sal deel wees van hierdie studie.

Wat gaan tydens die studie gebeur?
U sal gedurende hierdie studie deelneem aan een onderhoud. Die onderhoud sal ongeveer een uur duur. Tydens die onderhoud sal u vrae gevra word oor basiese inligting soos u ouderdom, huwelikstatus ens.

U gaan ook vrae gevra word oor hoe die verlies van u baba 'n invloed gehad het op u eie lewe, u huweliksverhouding, u kinders en oor watter ondersteuning beskikbaar is vir u. Beide onderhoude kan ook gesamentlik plaasvind.

Hoekom word ek gevra om deel te neem aan die studie?
U word gevra om deel te neem aan die studie omdat u meer as ses maande gelede 'n baba verloor het voor- of tydens geboorte.

Sal u baatvind daarby om deel te neem aan die studie ?

U sal inligting ontvang oor die rouproses nadat u baba gesterf het. Omrede dit 'n emosionele onderwerp is wat bespreek word, sal berading aangebied word na afloop van die onderhoude. Indien u baie emosioneel raak en verdere hulp benodig, sal u na 'n psigiater by Tygerberg Hospitaal verwys word. Alhoewel die bespreking emosioneel van aard gaan wees mag dit moontlik positief vir u wees om te

reflekteer oor u verlies en dit met iemand te deel. Daar sal voordele wees vir toekomstige ouers wat ‘n baba verloor, omrede riglyne vir beter maatskaplike werk intervensie geïdentifiseer word.

Is daar enige risikos aan my deelname in hierdie studie verbonde?

Sommige vrae mag moontlike ontstellend wees vir u. Indien dit die geval is, moet u die navorser hiervan inlig sodat verdere hulp aan u verskaf kan word. In baie ernstige gevalle waar u moontlik selfmoordneigings toon, sal 'n onmiddelike verwysing na die Registrateur van Psigiatrie aan diens by Tygerberg Hospitaal gemaak word. In minder ernstige gevalle sal u verwys word na die Psigiatriese Kliniek by Tygerberg Hospitaal by J-Laer grond, kontaknommer (021 938 5120) of die Psigiatriese Verpleegkundige, Mnr. N Kiewiets by die Gemeenskapsgesondheidsentrum in Bishop Lavis, kontaknommer (021 934 6050).

Sal inligting oor my konfidensieël gehou word?

Enige rekords van hierdie studie sal privaat gehou word. Enige inligting wat tydens hierdie studie verkry is, sal nie deel vorm van u mediese rekord nie en sal in 'n aparte navorsingslêer gestoor word. Inligting wat verkry word sal toeganklik wees vir navorsers wat direk betrokke is by die studie. U naam sal glad nie op enige papier aangebring word nie. Die inligting wat verkry word sal volgens nommer geïdentifiseer word. Persone wat toegang het tot hierdie inligting is: individue van die Nasionale Instituut van Gesondheid, Mediese Navorsings Etiese kommittee van Universiteit Stellenbosch, die Raadgewende en Veiligheidsmoniteringsraad aangestel deur die Verenigde State, die data-koördineringssentrum en navorsers wat deel is van hierdie studie.

Indien ons vermoed dat u moontlik uself kan beseer, sal ons wel u inligting moet oordra aan toepaslike mediese rolspelers.

Wat is die alternatiewe indien u besluit om nie deel te neem aan die studie nie?

Indien u nie aan die studie wil deelneem nie, maar wel ondersteuning benodig met die verlies van u baba, kan die volgende organisasies gekontak word:

- Compassionate Friends: Kontakpersoon is Alta Volschenk (021 856 0717) of Cynthia Lasson (021 553- 0038)

- Lifeline - 24 uur beradingsdiens - 021 461 1113

Is daar betaling om deel te neem aan die studie en is daar koste aan verbonde?

Nee, u sal nie betaal word om deel te neem nie. Vervoer sal wel verskaf word deur die studie en na afloop van u onderhoud sal koffie/tee en ‘n broodtjie aan u verskaf word.
Is daar enige kostes om aan die studie deel te neem?
Daar is geen koste aan verbonde as u aan die studie deelneem nie.

Wie befonds hierdie studie?

Universiteit van Stellenbosch en Mev. Melanie Human ontvang geen betaling om hierdie studie uit te voer nie.

Kan ek van die studie verwyder word?

Indien die navorser voel dat dit tot nadeel sal wees vir u om voort te gaan met die studie, kan u deelname gestaak word.

Wat is my regte as deelnemer aan hierdie studie?

Deelname aan die studie is vrywillig. U het die reg om:

- Te weier om deel te neem aan die studie.
- Die onderhoud te stop voor dat dit voltooi is of 'n sekere vraag oor te slaan.

- Enige tyd uit die studie te onttrek. As u wil onttrek, mag u Mev. Melanie Human kontak by 021 938 4748 of 'n e-pos stuur aan mhuman@sun.ac.za

Indien u besluit om nie aan die studie deel te neem nie, sal dit nie u toekomstige mediese versorging beïnvloed nie.

Hierdie navorsingsprojek is deur die Komitee vir Mensnavorsing van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van:

- Die Internasionale Verklaring van Helsinki
- Die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).
- Internasionale Riglyne: Raad vir Internasionale Organisasies van Mediese Wetenskappe (International Guidelines for International Organisations of Medical Sciences (CIOMS)
- Toepaslike Suid-Afrikaanse Wetgewing

Is daar enigiets anders wat u moet weet of doen?

-
- U kan **Mev. Melanie Human** kontak by tel **021 938 4748** indien u enige verdere vrae het of enige probleme ondervind.
- U kan die **Komitee vir Mensnavorsing** kontak by 021-938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur u studiedokter hanteer is nie.
- U sal ’n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.
-

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek, …….....……...…….. om deel

te neem aan ’n navorsingsprojek getiteld "Psychosocial implications of stillbirth: a crisis-support

approach"

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in ’n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te *(plek*) .....……. op *(datum*) ……...…….. 2011.

....

Handtekening van deelnemer **Handtekening van getuie**

Verklaring deur navorser

Ek *(naam)* ……..…… verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan

  …….....……..

- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Geteken te *(plek*) .....……. op *(datum*) ……...…….. 2011.

....

Handtekening van navorser **Handtekening van getuie**

Appendix D - Approval letters from Safe Passage Study, Ethical Committee Tygerberg Hospital and Department of Health

DM-STAT
DATA MANAGEMENT & STATISTICAL CONSULTING

One Salem Street
Suite 300
Malden, MA 02148
Phone: 781-395-4523
Fax: 781-395-4968

December 14, 2010

Mrs. M Human
Department of Obstetrics and Gynaecology
2nd Floor, Golden Lane
Room 27
Tygerberg Hospital

RE: Prenatal Alcohol in Sudden Infant Death Syndrome and Stillbirth (PASS) Network Steering Committee approval of follow-up study on psychosocial implications of stillbirth

Dear Ms. Human and Prof S. Green:

This letter is to inform you that on October 22, 2010, the PASS Network Steering Committee approved your request to conduct a follow-up study on psychosocial implications of stillbirth on participants in the Safe Passage Study. The purpose of the follow-up study is to gain a better understanding of the psychosocial implications of stillbirth for the mother and her family in order to provide guidelines for intervention by the social worker from the crisis intervention perspective. The key investigator on this study will be Ms. Melanie Human under the supervision of Professor Sulina Green. In addition, the following PASS Network investigators will serve as co-investigators on the study: Professor Hein Odendaal, Dr. Coen Groenewald, Dr. Hannah Kinney and Dr. Amy J. Elliott. This approval is contingent Ms. Human obtaining review and approval of the study protocol and informed consent form from the Stellenbosch University Health Research Ethics Committee.

Please feel free to contact me if you have any questions or require any additional information.

Sincerely,

Idania Ramirez

Idania Ramirez, MPH
Vice President of Operations
DM-STAT, Inc.
DM-STAT Innovative Solutions, Inc.
619-684-1415
Idania.Ramirez@dmstat.com

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
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23 November 2011 **MAILED**

Mrs M Human
Department of Obstetrics and Gynaecology
2nd Floor, Golden Lane.
Room 27
Tygerberg Hospital

Dear Mrs Human

"Psychosocial Implications of Perinatal Loss: A Crisis-Support Approach."

ETHICS REFERENCE NO: N10/09/313

RE : PROGRESS REPORT

At a review panel meeting of the Health Research Ethics Committee that was held on 9 November 2011, the progress report for the abovementioned project has been approved and the study has been granted an extension for a period of one year from this date.

The latest participant informed consent form was evaluated and approved.

Please remember to submit progress reports in good time for annual renewal in the standard HREC format.

Approval Date: 9 November 2011 Expiry Date: 9 November 2012

Yours faithfully

MRS MERTRUDE DAVIDS
RESEARCH DEVELOPMENT AND SUPPORT
Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za
Fax: 021 931 3352

DEPARTMENT of HEALTH
Provincial Government of the Western Cape

Tygerberg Academic Hospital and
Mitchells Plain & Tygerberg Oral Health Centres

lbinde@pgwc.gov.za
tel: +27 21 938-5752 / fax: +27 21 938-6698
Private Bag X3, Tygerberg, 7505
www.capegateway.gov.za

REFERENCE : Research Projects
ENQUIRIES : Dr M A Mukosi

Date: 26 JAN 11

ETHICS NO: N10/09/313

Dear Prof Odendaal

Ref: Psychosocial implications of perinatal loss: A crisis-support approach.

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

DR D ERASMUS
CHIEF DIRECTOR: TYGERBERG HOSPITAL
21.01.2011