Parental Grief Following Pregnancy Loss: The Influence of Social Support.

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Julie McDonald

Research into death and grief has grown steadily during the latter half of the twentieth century. In the past, family, neighbours and priests dealt with death and bereavement. However within the last decade, death and the associated grief and bereavement have also included the medical profession (Payne, Horn, & Relf, 1999). For many years the psychological profession has been involved in developing models that describe grief and how best to treat it. The most predominant feature proposed by most traditional theories of grief relates back to Freuds original work that revolves around the patient participating in "grief work" in order to get over the death and resume a normal life (Freud, 1957). The most recognised models of grief are based on the phasic or stages of grief that were first introduced by Bowlby (1969). Other theorists such as Kubler-Ross (1969) and Worden (1991) have used these theories as a basis to develop their own models of grief. Recently research in the area of bereavement and grief has moved away from the stages and phases of grief and is in the process of defining new models of grief. Grief is an emotional response to the loss of someone or something. The loss leads to a state of bereavement, the factual nature of a loss, which is ultimately expressed in a process of mourning.

1.1 Bereavement

Bereavement is the situation a person finds himself or herself in after having lost someone or something significant. This is a general term that is used to incorporate the emotions, experiences, and changes that take place as a result of that loss (Sanders, 1999). The term bereavement is commonly understood to refer to the actual situation after having experienced the death of someone significant in their lives (Stroebe, Hansson, Stroebe , & Schut, 2001). The length of time that a person spends in this state of bereavement depends of many factors that include how important the deceased was, and the nature of the attachment to the deceased. The circumstances in which the deceased died, was it sudden, a long illness or an unexplained death? Personal factors, such as their personality type, how previous losses were dealt with, and the degree of support they perceive around them to help them cope with the situation (Worden, 1991). Whilst bereavement is the state a person finds themselves in after the death of a loved one, grief is the particular emotional state experienced by the bereaved while in that state (Sanders, 1999).

1.2 Grief

Parkes (1995) describes grief as "essentially an emotion that draws us towards something or someone that is missing. It arises from an awareness of a discrepancy between the world that is and the world that should be" (p242).

Grief is a typical reaction to a loss and involves responses that manifest in many different forms. Cognitively, the grieving person may suffer from lack of concentration and attention and become preoccupied with thoughts of the deceased. Behaviourally they may cry continuously, become irritable and restless and may withdraw socially. Physiologically they may feel fatigued and in

some cases become physically ill (Payne, Horn, & Relf, 1999). These factors are all part of grief but the most important aspect of grief is the emotion. Grief, as an emotional response, can manifest as sadness, anger and rage, guilt and loneliness (Payne, Horn, & Relf).

Hogan and Schmidt (2002), define grief as having two core variables; despair and detachment. The pain of missing a person that has died brings on despair. It is the feelings of longing for that person. There is an experience of feelings of helplessness and hopelessness about how to cope now that their loved one is no longer in their life. Detachment refers to the feelings of confusion and the loss of confidence in who they are. There is a sense of a loss of control of their life and a feeling their identity has changed as a result of the loss of a loved one. Those who are grieving go through a period of deep introspection and become preoccupied with thoughts and feelings associated with the lost loved one. As for bereavement, the length of time that a person spends dealing with these factors is directly related to how important the loss was to the bereaved, the type of loss and the situation surrounding the loss (Sanders, 1999). Whilst grief is the emotional response to the loss of someone or something, mourning is the overt expression of grief and bereavement and is heavily influenced by cultural expressions of death experiences (Kalish, 1985).

1.3 Mourning

Although mourning is a term that is often used interchangeably with grief, it is defined here as the behaviours that the bereaved engages in that are the social expressions or acts that are performed after death (Stroebe et al. 2001). Mourning consists of culturally defined expressions of grief; the dressing in black or white, attendance at funerals and crying, or drinking and laughing as is the case at a wake. Different cultures and societies have different mourning customs. In western society mourning is on a small scale and often personal and private but there are still general rules that are expected to be followed. For example, it is customary for the bereaved to arrange a funeral ceremony followed by a burial or a cremation allowing family and friends to pay their respects to the deceased (Sanders, 1999). In the past, mourning practices such as wearing black by widows, were well defined and gave clear instructions of how to mourn for all members of the community. In modern western society the public rituals are now limited to the funeral ceremony leaving the bereaved to cope with the death of a loved one without public mourning rituals (Aries, 1985; cited in Malacrida, 1997).

1.4 Traditional Theories of Grief

1.4.1 Freud

Freud was the first to discuss grief in 1917 in his book Mourning and Melancholia. He pointed out the similarities between grief and depression (Freud, 1957), and argued that emotional expression

is directed towards people or objects that are in a position to satisfy the individuals needs. Freud argued that attachment to a person or object involves using an individuals "libidinal energy" *. If the person or object is lost the libidinal energy, in the form of thoughts and memories of the attachment felt for that person, continues to be invested in that person or object (Freud, 1957). According to Freudian theory, grieving is the outcome of a dilemma between wanting to relinquish the relationship with the person who is no longer with them, so that they can regain the energy that is invested there, whilst still being able to maintain the bond with the person. Freudian theorists see the psychological function of grief as being the process of freeing the individual from the bond to the deceased (Stroebe, & Schut, 2001). “Grief work” is the term coined by Freud to describe the process of accepting the reality of the loss, withdrawing the emotional energy from the lost person to finally redirect it to another more appropriate source (Payne, Horn, & Relf, 1999).

1.4.2 Bowlby

Bowlby (1986), in the third volume of his series on attachment and loss, Loss Sadness and Depression, relates the grieving process to his attachment theory. He argued that when a person experiences the loss of something or someone, an innate motivational system is activated that compels them to search for the lost object and they will do anything possible to regain proximity to this object. When this is not possible, as is the case when the lost object is a deceased loved one, the person experiences profound sorrow and despair. The way a person deals with this despair is to emotionally work through a series of four phases, shock; yearning and protest; despair; and finally, recovery. Working through these phases helps the individual to reorganise the way they look at the world in order to then resume normal activities and seek out new relationships with other potential objects of attachment.

1.4.3 Kubler-Ross

Kubler-Ross (1969) developed a model of grief that was specifically designed for those who were experiencing terminal illness and dealing with thoughts of dying. The five stages of grief outlined by Kubler-Ross were widely accepted by the medical profession and were used not only for those who were dying but also for those who were experiencing the death of a loved one. The stages include denial and isolation, anger, bargaining, depression, and finally acceptance. The medical profession adopted these stages seeing them as stages that everyone must go through if they were to avoid pathological grief.

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* Libidinal. The adjective form of libido. Libidinal energy- unconscious psychological energy derived from the id (Reber, 1995)

Kubler-Ross should be commended for bringing the subject of death out into public discussion, yet her model is based on a particular population of people, dying in a particular way, and is organised around the authors' clinical experiences, not on empirical data (Corr, 1993).

1.4.4 Worden

Using a combination of the psychodynamic theory of Freud (1957), and the phasic models of attachment theorists (Bowlby, 1986), Worden (1991) proposed four tasks involved in dealing with the grief associated with the loss of a loved one. Worden describes mourning as adaptation to a loss and requires the individual to work through four tasks before being able to properly proceed with life. The first task is to accept the reality of the loss. The opposite being denial of the loss. Denial can take various forms ranging from denying that the death has occurred to denying the meaning of the loss, saying that the loss was not as important when it is. Denial of the loss can sometimes see people remaining for an extended period of time at the first task of the grieving process. The second task involves progressively addressing the pain of grief, followed by the third, adjusting to an environment that no longer has the deceased in it. The fourth and final task is being able to relocate the deceased. Not necessarily forget the deceased, but learning to live with the memories while continuing on with life (Worden, 1991).

This brief review of some of the traditional theories of grief show a common thread of stages and phases that a person needs to progress through to resolve and "get over" their grief, to return to a state before the loss occurred. Whilst these theories have been widely accepted in the past, new theories of grief have been developed in an attempt to explain the kind of grief reactions that clinicians are observing in their practice (Stroebe, Van Den Bout, & Schut,1994).

1.5 Recent Models of Grief

Traditional theories view grief as something that needs to be cured and overcome. There is an implicit assumption that the bereaved must return to a positive state of mind and well being as soon as possible. The danger with this type of reasoning is that human suffering, an integral part of grief, will be considered as a negative reaction (Stroebe & Schut, 1999). Recent theories of grief do not attempt to categorise grief into stages that a person must progress through. Its focus is on how to help the person cope with the experience.

Stroebe and Schut (1999) have developed a new model of grief, they call Dual Process Model (DPM). Instead of talking about stages that will lead to a cure for grief, this model focuses on describing the ways people come to terms with the loss of a loved one. Grief is described as a complex process combining the confrontation of the loss with avoidance of the loss. The model identifies two stressors: loss versus restoration orientation.

Loss oriented stressors are based on attachment theory, where the bereaved concentrate on what they have lost and work through the process of dealing with the areas in their life that are most

affected by the deceased who is no longer a part of it. Restoration orientation refers to the individual trying to restore their life to something that they are happy with, and includes learning to live without the deceased. These two processes are not followed in a stage or phase pattern. Rather, the individual oscillates between the two. At times they will actively confront the issues that surround the loss and at other times they will avoid it. The same applies to the tasks of restoration. The dual process model argues that it is necessary for the individual to move back and forth between the two processes if they want to achieve adaptive coping (Stroebe, & Schut, 2001).

Adapting to the loss of a loved one is not the same as expecting the bereaved to return to a positive normal state. This model accepts that the person will possibly never be the person they were before the loss. However, through the processes of the DPM they will eventually learn to cope with life without the loved one, and possibly change their perception of life.

Grief can be viewed as an experience that can lead to a new appreciation for life. The grief to personal growth model (Hogan & Schmidt, 2002) outlines a journey through the experience of grief that leads to personal growth. Unlike traditional models that focus on a return to normality, this model views grief as a time for the individual to be "transformed by the experience in essential ways that result in their creating a new identity and revising their worldview" (Hogan & Schmidt: 619).

This model suggests that because of the loss, the bereaved are able to see life from a new perspective and with time can gain a new appreciation for life, ultimately leading to personal growth. This stage is often not achieved because the bereaved allow themselves to become submerged in their grief and are unable to learn the lessons this experience is teaching. Based on the traditional idea of phases of grief, this model differs in its expected outcome of grieving. Rather than the process of grief returning an individual to normality, this model argues that the bereaved must work through the despair and detachment which at times include avoiding everyone and becoming preoccupied with grief until they become transformed by the experience. Bereavement is seen as a time to reconstruct a world that does not contain their loved one, finding new meaning and purpose in their permanently altered lives (Hogan & Schmidt).

Personal growth is made possible by the bereaved discussing their feelings as they reconstruct their life now that the loved one is no longer a part of it. This process requires those people around the bereaved to have an understanding of the impact this loss has had on them and the importance of being able to talk freely about it.

1.6 Disenfranchised Grief

Often the bereaved are left to experience their grief in a state of isolation because the sense of loss is not socially recognised. Societies have sets of norms in relation to grieving, and these norms specify when, where, how long, and for whom people should grieve. The rules of society may not always correspond with how an individual is feeling after the death of a loved one, indeed, society may not recognise the degree of attachment felt for the deceased. Doka (1989) refers to this as

disenfranchised grief. People who experience disenfranchised grief are usually not given the right to grieve and receive little support from those around them. Expressions of sympathy, forms of help such as time off work and the opportunity to talk about the loss are generally not offered to the bereaved in these circumstances.

Doka (1989) proposes three main reasons why a person may experience disenfranchised grief in western society. The relationship may not be recognised. An example of this is homosexual relationships and extramarital affairs where the partners of the deceased may not be given the same respect and support as for partners in recognised relationships. Secondly the griever's experience may not be recognised as grief, with the bereaved perhaps being left out of grieving rituals because it is presumed that they will not experience grief in the same way as others. This is often the case for children, the very old, the disabled, and the mentally ill. Thirdly the death may not be recognised as a significant legitimate loss. This occurs when the death is not viewed as legitimate as is often the case for abortion, miscarriage and stillbirth.

1.7 Loss of a Pregnancy

Ectopic pregnancy, miscarriage, stillbirth, and neonatal death (see Appendix C for definitions) are often not recognised as a legitimate loss for parents (Nicol, 1997). Mulkay (1993) coined the term ‘social death’ to describe " the cessation of the individual person as an active agent in others' lives" (Mulkay, p33). It refers to the loss of an individual to the community, to society and to living others (Mulkay).

When a baby dies before it has begun its life outside the womb it is not considered to have been known to society and therefore is not considered as a 'social death' (Malacrida, 1997). The baby is only really known as an entity to the parents, and it is argued that even they have not had enough time to form a strong attachment to the baby. Therefore, the loss may not be viewed as important in comparison to other deaths.

However, studies now claim that the process of attachment begins well before the birth of the infant, challenging the belief that attachment only begins at the time of birth (Peppers & Knapp, 1989, cited in Robinson, et al., 1999).

Attachment to the unborn baby can be achieved through routine ultrasound scans allowing the parents to visually bond with the baby. Fetal movements connect the baby and parents in a physical sense allowing interaction with their unborn baby (Heidrich & Cranley, 1989, cited in Robinson, et al., 1999). Attachment to an unborn child is also achieved through the emotional investment in the pregnancy. The hopes and dreams of a future life with an unborn child create a bond just as close as those created with children outside the womb (Robinson, Baker, & Nackerud, 1999).

The length of time the baby has spent in the womb, referred to as the gestational age, may have an influence on the emotional investment in the pregnancy and the overall level of attachment felt by the parents, but it is not the only determining factor. The personal significance of the loss, to

the parents, is often a better indicator of the level of attachment felt than the length of the pregnancy (Kohner, 1995).

1.8 Gestational Age of Baby

It is a generally accepted view that the shorter the length of the pregnancy the less painful the loss is to the parents (Goldbach et al, 1991). Research into the effect of gestational age on level of grief has produced mixed findings (see Goldbach, et al.,1991, for review). Some researchers hypothesise that there are no significant differences in the levels of grief between women who had experienced either early or late losses (Peppers & Knapp, 1980, Leppert & Pahlka, 1984). Rather than having an influence on the level of grief, gestational age may affect the amount of support available to the parents. The shorter the pregnancy, the less opportunity there is for the unborn baby to be known by anyone other than the parents and therefore the less likely support will be offered (Conway & Russell, 2000).

It has also been argued that the level of attachment to the baby is greater for the mother than the father in the early stages of gestation. Because the father does not carry the baby, he may not feel as intense an attachment as the mother (Borg & Lasker, 1989). As the father feels fetal movements and he has viewed the ultrasound pictures of his child, level of attachment is not that different to that of the mothers by the time of birth (Peppers & Knapp, 1980).

1.9 Gender Differences and Grief

The type of attachment felt by mothers and fathers to their unborn baby have been found to be quite different. Most fathers report that while they felt an attachment to the fetus, they believed that is was not as strong as for the mother and baby (Worth, 1997). This may explain the finding that fathers level of grief may not be as intense as for mothers immediately after the death of the baby. However the differences in grief subside one to two years post loss (Goldbach, Dunn, Toedter & Lasker, 1991).

These findings do not mean that men do not experience feelings of grief, rather, it may suggest that they are not given the opportunity to show their grief. Women display their grief more openly than men as reported in females high scores on the active grief scale of the Perinatal Grief Scale (PGS) (Lasker & Toedter, 1991). The gender differences in grief may be explained by the socially accepted behaviours available to mothers and males and the roles they are expected to play. It is socially acceptable for women to express their grief openly through crying and talking about their loss, alternatively, men are expected to carry on and to be strong, keeping their feelings to themselves while supporting others (Stinson, Lasker, Lohman & Toedter, 1992).

Matin and Doka (2000), identified two styles of grieving, instrumental and intuitive, which have been found to relate to masculine and feminine tendencies. The intuitive style is associated with women and is focused on the emotional aspects of grieving. It involves the person seeking out support and social surroundings in which they are able to openly grieve. In contrast, the instrumental

style of grieving revolves around cognitive and problem solving activities. It is often solitary and is focused on solving the problems faced, now that the loved one is no longer in their life. This latter style is more often associated with men. These two styles are extremes of a continuum and there is often a blend of them both, although the major finding appears to be that women deal with grief more intuitively and men deal with grief more instrumentally. Moreover, two styles can create conflict because those who cope by seeking support and are concerned with the emotional aspects of the loss find it hard to understand those who focus on the cognitive problem solving aspects of dealing with the loss, and visa versa (Martin & Doka, 2000). The instrumental style gives outsiders the impression that they have 'moved on' and are 'over' their grief in a relatively short period of time, whilst those who use the intuitive style can be viewed as submerged in their grief and encouraged to resolve it.

1.10 Temporal Issues and Grief

The commonly held view that time will heal the experience of grief is an important concept that is related back to the traditional theories of grief. The stage theories of grief proposed that there was a time limit in which the bereaved were expected to recover from the loss. Within a relatively short time, six months was often recommended, the bereaved were expected to progress through the various stages that lead back to a normal life (Parkes,1995). It is now accepted that the time needed to grieve varies between individuals and a standard time limit to grief is hard to define (Janssen, Cuisinier, & Hoogduin, 1996). To an outsider, the bereaved may appear to be functioning normally within a few weeks but the experience of grief can linger on for years, and in some ways an important loss will always remain with the bereaved (Kalish, 1985). However, longitudinal studies on bereaved parents who have experienced the death of a loved one have demonstrated that levels of grief decline over the two years following the loss (Lasker & Toedter, 1991; Vachon, 1988). These findings are not surprising in relation to the models of grief discussed. As the time goes on the bereaved person adapts to the death of the loved one. This does not mean that the bereaved has forgotten the deceased, rather they have learned to adapt to life without them. Anniversaries and special celebrations, or anything that sparks a reminder of the deceased can produce a wave of grief similar to that experienced at the time of the death (Kalish, 1985). It is in times like these that the bereaved continues to need the understanding from those they look to for support.

1.11 Social Support

Social support has been defined in numerous ways with some researchers basing their definition on the structural aspects of support and others on the emotional aspects. Most recent research in social support is concerned with both the type of support provided and the adequacy of this support for the individual. Based on these ideas, researchers have defined social support in terms of its four functions, esteem, informational, instrumental and social companionship. Esteem support refers to others promoting the individual's sense of self esteem and being valued by others.

Informational support is the useful or necessary information provided by social contacts. Instrumental support is the financial or material support from others, and social companionship is spending time with others in recreational activities (Cohen & Wills, 1985). These four functions have been simplified by some researchers (Power, Champion & Aris, 1988), into two types of support; emotional support which includes both esteem and informational support; and practical support including instrumental support and social companionship

Social support can come from many different sources and some researchers (Singer & Lord, 1984), have distinguished between three specific categories of social contact. Formal support which can come from organisations such as sporting clubs and church groups, personal support which is usually provided by family and friends, and professional support from counsellors, doctors, and support groups. These three sources of support may provide different functions for the person but there is often an overlap between the three depending on the individual and the circumstances that surround their need for support (Singer & Lord).

Research into social support has shown the beneficial effects it can have on a persons health and well being. The availability of social support has been associated with a reduced risk of mental illness (Cohen & Wills, 1985), an increase in general wellbeing (Lu, 1995) and reduced mortality (Blazer, 1982).

Generally two models of social support have been used to support the claim that social support has an effect on an individuals health. The stress buffering model (Cohen & Wills, 1985), suggests that social support protects or buffers the individual from a stressful event by providing emotional and practical support to help the individual cope with the situation. This model of social support is best measured by qualitative measures that look at the significance and meaning of relationships and the different functions of support (Dolbier & Steinhardt, 2000). The main effect model suggests that social support has an effect on well being regardless of whether an individual is experiencing a stressful situation or not. The main effect is best measured in a quantitative way that focuses on the structural nature of the social relationships and the number of people in the individuals social network (Dolbier & Steinhard).

There is no definitive way to measure the exact benefit of a specific support attempt, although this is often determined subjectively by the individual who is receiving it (Vachon & Stylianos, 1988). Measurement of social support is usually based on measures that assess the individuals perception of either the availability of others who provide the support or the actual receipt of support. Self-report measures are usually used to gather information on social support, and usually done by asking individuals to rate the level of support they receive and from whom. The results from these studies can be misinterpreted as reporting the amount of received social support when in fact they are reporting the individuals perception of the amount of support they receive (Dunkel-Schetter & Bennett, 1990). Continuous observation of the individuals interactions with those around them is the only way

to report actual received support. As this alternative is not available, most studies rely on the self report of the perception of received social support.

1.12 Social Support and Pregnancy Loss

Studies using the perinatal grief scale (PGS) have shown that regardless of the measure used to assess the amount of social support from family and friends, the greater the perceived social support the lower the grief scores on the PGS (Toedter, Lasker, & Janssen, 2001). Social support has been shown to help the bereaved with their grief after the death of a spouse (Kaunonen, et al., 1999), and in adolescents who have experienced the death of a sibling (Hogan & DeSantis, 1994). Socially sharing the experience of losing a loved one enables the bereaved to construct a social narrative which gives the death and its consequences more reality (Pennebaker, Zech & Rime, 2001). Sharing of emotional experiences can also facilitate and maintain close personal relationships and provide the bereaved with social support. However, in the case of pregnancy loss, socially sharing the experience of the death of their baby is not often available to parents.

The death of a baby is not always perceived as a 'social death' (Mulkay, 1993), and the usual network of support may not be perceived as being available. Past research has suggested that there are certain circumstances where support is not as readily available (Dunkel-Schetter & Bennett, 1990), due to the sensitive nature of a situation or the discomfort it creates in others. However, it is these very situations when support is perhaps most needed (Dunkel-Schetter & Bennett). In a situation such as the loss of a baby an individual's support network may not be as willing or capable of providing the support needed (Dunkel-Schetter & Bennett). Those closest to the bereaved person may feel threatened or uncomfortable about the death. They may deal with this by avoiding any conversations that are related to the loss (Pennebaker, 1990). Others may feel they are unable to be supportive for fear of saying or doing the wrong thing (Riches & Dawson, 2000). Often the main source of support is from their partner because they are often the only ones who have an understanding of the intensity of the grief (Cecil, 1994).

Having the opportunity to talk freely to a supportive person who is willing to listen with empathy and without judgment can help the bereaved to emerge from their grief with a new understanding of life (Hogan & Schmidt, 2002). Parents who are grieving the death of a baby are often not given access to this type of support from those around them. Due to this lack of support and understanding it is possible that they will experience ‘complicated mourning’, a period of extended bereavement that can lead to additional psychiatric and emotional distress and subsequent withdrawal from social interaction (Rando, 1992, p.44). The people in an individual’s social network may not be as supportive due to the emotional reactions that they are experiencing due to the stressful situation they are faced with.

Stressful situations often cause people to display emotional reactions such as fear, discomfort, frustration and embarrassment (Dunkel-Schetter & Bennett, 1990). Most people, when asked how

they would respond to a hypothetical situation requiring them to support someone, would be able to suggest an appropriate response. However, in a real situation when they are faced with what to say or do while experiencing feelings of anxiety, they often resort to automatic responses (Lehman, Ellard, & Wortman, 1986).

It is common for parents who have experienced the death of a baby to be subjected to platitudes such as "its for the best", and "you're young, you can have another baby", because they are unsure what to say (McDonald, 2002). Comments such as these can have a negative affect on the bereaved parent making them feel isolated in their grief because those around them have not acknowledged that they have experienced a legitimate loss (Doka, 1989). Even though these statements are said with the intention of helping, they can often have a detrimental effect on a persons psychological well being. (Lehman, Ellard, & Wortman, 1986; Revenson, Schiaffion, Majerovitz & Gilsofsky, 1991). What is important to remember when measuring social support is that it is the individuals' perception of how beneficial it has been to them. However, other factors may influence this perception, such as their personality.

Discussion

The results show that the level of Perceived Support from significant others in an individual's life does have an influence on the reported level of grief as measured by the Perinatal Grief Scale (PGS). Significant differences in the scores of the PGS and the reported level of Perceived Support were found for males and females. With females reporting higher levels of both grief and support. Significant differences were also reported in the level of Perceived Support between parents who had experienced an early loss of pregnancy compared to a late loss. Those experiencing the death of a baby between the gestational age of 2-20 weeks reported lower levels of Perceived Support than those who experienced the death of their baby between 21 weeks and 28 days after birth. A significant relationship between the total PGS score and the discrepancy score was reported suggesting that the higher the discrepancy reported between Perceived and Ideal Support, the higher the level of reported grief. The time since the death of the baby significantly explained some of the variance in scores on the PGS. Although contrary to what was hypothesised, the longer the time since death of the baby the higher the reported level of grief.

5.1 The Influence of Support on Level of Grief.

The hypothesis that higher levels of Perceived Support from the four sources of support, would predict lower levels of grief was supported. Social support has a beneficial influence on the level of grief of parents who have experienced the death of a baby. Support from the individual's partner had the greatest influence on the level of grief, with those who lack support from this source experiencing more grief. This is not surprising, as has been found previously partners are often the main source of

support when a baby dies (Cecil, 1994) and a strong marital relationship has been found to decrease scores on the PGS (Lasker & Toedter, 1991). What is surprising is that support from partners was the only significant predictor on all subscales of the PGS. Support from friends and family did not significantly contribute. This is interesting considering the findings of Toedter et al., (2001) in their comparison of 22 studies that used the PGS. They found that the perception of support from family and friends, despite the use of various measures of social support, were consistently related to lower PGS scores.

The results from this study may be explained by the recruitment procedures of this sample. The majority of the sample (88.1%), consisted of volunteers recruited from the Internet, and most (73.9%) were, or had been, members of a support group. Previous findings (Toedter et al., 2001) have reported that people who were members of support groups or volunteered through the Internet were often people that were more troubled by the loss. Often these people have found little satisfaction with the support from family and friends and have sought out others who have had a similar grief experience in support groups to help them (Schwab, 1996). That participants in this sample are reporting that family and friends are having no significant influence on their level of grief suggests that support groups were sought out for this reason.

Of the subscales of the PGS the influence of social support was greater on Difficulty Coping and Despair than for Active Grief. Explanations for this may lie in the interpretation of each subscale. Active Grief is associated with the sadness of missing the baby, and overt emotional responses such as crying (Potvin, et al., 1989). Difficulty Coping contains items that relate to the parent not being able to get along with others or to cope with daily life, (eg. " I can't keep up with my usual activities", Potvin, et al.). Despair is measured using items such as " I feel unprotected in a dangerous world since my baby died" and is associated with feeling of hopelessness and insecurity (Potvin, et al.). Based on the definitions of these subscales it is reasonable to assert that Difficulty Coping and Despair could be influenced to a greater extent by social support than Active Grief.

Active Grief revolves around feelings of sadness which support from others may not be able to change. However, with supportive people being available the bereaved parents may feel better equipped to manage issues related to coping with everyday life. This support may also help when interacting with others who do not have an understanding of the grief. Support may also be beneficial in showing bereaved parents that they are not alone and thereby ease the sense of insecurity. If the bereaved parents have a perception that they are receiving support from those around them then it can influence the level of grief by decreasing it. However, problems may arise when the level of Perceived support is different to the level of support that they consider they require.

A measure of discrepancy between Perceived support and Ideal Support was calculated to give an indication of the satisfaction with the level of support. The hypothesis that the higher the level of discrepancy the higher the level of grief was supported. There was a positive relationship between

the level of discrepancy and the level of grief. This score indicates parents are not satisfied with the level of support they are receiving. The mean for the ideal rating was six out of a possible score of seven, which corresponded with expecting support always. This suggests that their ideal level of support may be unrealistically high, expecting to have support available to them from all sources of support almost all of the time.

5.2 Influence of Time Since Death of the Baby, on Level of Grief

Support was not found for the hypothesis that as time progressed the level of grief would decrease. Unlike the inferences of the common phrase "time heals", the results of this study suggest that as Time Since the Death of a baby progressed the level of grief increased. Time Since the Death of the baby was found to have a greater influence than social support on the level of grief.

More Particularly, Time Since the Death had greater influence on the subscales of Active Grief and Difficulty Coping than for Despair. Active Grief and Difficulty Coping may not subside as Time Since the Death of the baby progresses because of a continued need for the social network to acknowledge the death as a significant loss. When a death is viewed as a 'social death' (Mulkay, 1993), the bereaved are recognised and their grief is validated by society. Validation of the loss by those who associate with the bereaved provide them with access to support. Being able to talk openly and freely about the loss to others can help facilitate the grief process and the bereaved can go on to achieve personal growth (Hogan & Schmidt, 2002).

In the case of pregnancy loss, personal growth may not be achieved because the death of a baby may not have been accepted as a legitimate death and therefore parents' grief is not recognised. The opportunity to openly express grief with others and to rely on the support from others in dealing with coping with everyday life may be limited. This may lead parents to become submerged in their grief and unable to adapt to life without the baby.

Feelings of Despair may not increase over time as strongly as Active Grief and Difficulty Coping because of the initial reactions of grief. Despair is a feeling of worthlessness and fear that other traumatic events will happen. As time progresses a parent's feelings of insecurity may be challenged, and shown to be unfounded, leading to reduced levels of Despair.

5.4 Gender Differences in level of grief and support.

The hypothesis that females would report higher levels of grief, and social support was supported. Females reported higher scores on the total PGS and the subscales of Difficulty Coping and Despair. Interestingly, males reported higher levels of Active Grief, which is contrary to previous findings (Lasker & Toedter, 1991). The higher levels of Active Grief reported by males may be due to the sample that consisted mainly of parents who were from support groups. It has been reported (Toedter, et al., 2001), that men are much less likely to participate in studies of this nature, (as has

been demonstrated by the reduced number of males in comparison with females for this study), or to join support groups. This suggests that those males who do participate and are members of support groups are more likely to be affected by the death of a baby. These men may also feel more comfortable disclosing the extent of their Active Grief knowing that they are replying anonymously and were not constrained by the social norms that are placed on a man and the way he grieves (Stinson, et al., 1992).

5.5 Influence of Gestational Age on Level of Support

Parents who had experienced the death of their baby within the first twenty weeks of gestation (early loss), reported lower levels of Perceived Support than for those who had experienced a later loss (21weeks - first 28 days of life). This supports the findings of Conway and Russell, (2000), that the longer the gestational age of the baby the more opportunity there is for others, apart from the parents, to invest emotionally in the pregnancy. Support will more likely be offered to the parents if those around them have a concept of the significance of the loss.

5.6 Qualitative data

Acknowledgment was the main theme of the qualitative questions. This was true for both helpful and unhelpful comments and behaviours. Validation of the grief and the recognition of the significance of the loss was viewed as being helpful in dealing with grief. These parents wanted to be extended the same courtesies other bereaved people are given after the death of a loved one. To be acknowledged as a parent regardless of whether they had any living children made parents feel accepted as a parent and therefore permission to grieve the death of their baby was afforded to them. To accept their grief as legitimate validated the existence of their baby. Parents spoke of wanting people just to listen, providing them with an outlet to talk about their thoughts and feelings. This supports the claim by Hogan and Schmidt, (2002) that talking about grief facilitates the grief process. However, for any benefit to be gained, the person who is willing to listen must also be accepting of the extent of the grief experience.

Parents were asked what other people had said to them and done for them that they had found especially helpful in dealing with their grief? Comments from participants that illustrate the themes and are presented in Table 20.

Acknowledgment

One of the most important themes that came out of the answers was that of Acknowledgment. Parents wanted to be acknowledged as parents even if they didn't have any other living children. They also appreciated it when the baby was acknowledged as a baby and treated as any other baby would be treated. Many of the comments identified how good it made them feel to have their baby referred to by name the same way as a living baby.

Permission to grieve

Many of the helpful comments revolved around the parents being given Permission to Grieve by those around them. This is similar to acknowledging the loss of the baby but it is more focused on people around them recognising that they had experienced a loss and that they had a legitimate reason to grieve.

Contact with similar others

Talking with others who had experienced a similar loss was found to be helpful to many of these parents. They found understanding and acceptance of their loss amongst those people who had also experienced the death of a baby. Hearing the stories of others that were experiencing the grief associated with losing a baby helped the parents to understand the feelings they were having as normal.

Just saying sorry

Another common phrase that many parents found helpful was just saying sorry. Incorporated in this theme was the honesty of people who expressed that they did not know what to do or say but that they were sorry and would try and be there for them in any way that they could. By just saying sorry it was conveyed to the bereaved parents that they acknowledged that they had experienced a tragic loss.

Spiritual Beliefs

This theme focused on the helpful nature of religious or spiritual comments. To know that their baby was with God or in a better place gave them a sense of peace. Many talked about their babies being in heaven with other members of their family or friends that had died. The perception that their baby was not alone and was looking down on them was a source of great comfort.

Gifts and Memorials.

The most common theme of helpful behaviours was the gifts and memorial that people gave to bereaved parents. To receive gifts from others in memory of their baby assured parents that their baby was recognised as a baby and family and friends had acknowledged the loss.

Remembering Anniversaries and Special Days

Many of the parents wrote about how helpful it was when others remembered their babies' birthdays and anniversaries and on special occasions such as Christmas. This gave parents a sense that the baby had not been forgotten by others and that their baby had been given the same respect

as a living child. However, it was often the case that the people who remembered these special days were parents who had also experienced the death of a baby, thereby indicating that common experiences may be an important issue in the support of a grieving person.

Listening and Understanding

It was important to many of the parents to have someone to listen to them. Comments centred on parents wanting to be listened to with understanding and sensitivity. They needed to be able to tell their story and talk freely about their experience without being made to feel uncomfortable or judged.

Keeping in Contact

Parents found it helpful when people around them kept in contact with them even after the initial death. Those people who called frequently and made the effort to visit provided immense support to the bereaved parents. It was especially helpful to many when the contact continued months and years after the death of their baby. Regular contact helped the parents to know that they had not been forgotten.

Practical Help

Practical help in the form of provision of meals and baby sitting services were found to be helpful to these parents. This kind of help allowed parents time alone to grieve without the hassle of everyday duties.

Table 20 Themes that Illustrate Helpful Comments and Behaviours.

Theme	Comments
Acknowledgment As Parents	" …… congratulated my husband and I on becoming parents for the first time, which was really important to us as we felt such a strong connection to him and wanted to celebrate him as much as mourn him". (# 313)
	"A few people acknowledged us as parents on mothers & fathers day even though we did not have a living child. Such acknowledgement has decreased with each passing year & with the birth of our living son making the few gestures that are made even more special." (#198)
	"mostly its just that they recognize that I am still a mother even though Sidney died and will always be one…… they do recognize that she did exist even though she never took a breath outside the womb." (# 113)

Acknowledging babies existence	" that they were real people - despite not making it into my arms - they were still a part of me and always will be " (# 119). " allowing me to brag like a proud mommy" (# 124). "Asking " do our later children look like the baby we lost?" Just general conversational things that people would ask in a normal situation". (# 250).
Permission to Grieve	"That I can deal with my grief in my own time and way. That I don't have to "arrive at acceptance of my sons death or get over it" that he and his life and death is a part of me and goes with me throughout my life." (# 220) "You never get over grief. You just learn to deal with a little better each day." (#188) "Let me grieve my way without judging, so many want to fix you, but they can't. " (#314)
Contact with Similar Others	"The people who have come forward and shared their losses with me have been most helpful. The honesty in the reflection that it never hurts less, you just learn to deal with it and live around it, is the best advice". (#41). "……..when she recounted what had happened to her and shared her reactions and feelings with me it helped a lot. It "normalised" the way I was feeling. Prior to that I thought I was losing my mind".(#33).
Just Saying Sorry	There was very little anyone could think of to say. The people I appreciated most didn't say anything but "I'm sorry." (#13) " the most helpful comments have been ones where people honestly said they were sorry and did not follow it up with a comment intended to make themselves feel better (such as: he's in a better place, isn't it nice to know he'll be waiting for you and you'll see him again)." (#110) "I had a couple of friends who called and just said "I'm so sorry, I don't know what to say… it must have been horrible." NOT trying to make sense of it and just grieving with me was helpful." (#139)

Gifts and Memorials	"…..that my baby's are in heaven with my grandmother, and she is probably enjoying them, and someday I will see each precious baby when I also see her. "(#183) "Being Jewish, I was told by a rabbi that our belief is that a stillborn baby had the purest soul of all as it has never sinned. Therefore there is a special place in heaven for them as they are so special. This I found a very comforting thought." (#275) "I find it very comforting when people tell me that my son is in a better place and he is watching over me, guiding me through life." (#291) "Friends of ours gave us a silver baby cup engraved “In Celebration of Isabella.” They had it made even after her passing, which meant a lot to me. By doing so, they acknowledged her name and her life – they even “celebrated” it." (#28) "My mom also made a special memory frame for Clayton with his obituary, footprints, and ultrasound picture. That meant so much to me because she did it on her own and spent some time on it. Then I knew for sure that she missed him and really wanted to remember him too, and that she accepted him, as we do, as our REAL child. " (#59) "a friend had a porcelain doll made to the size & weight that my Phoebe was at the time she died (19 wks gestation). the hospital also gave me a special box with small mementos so I didn't leave empty handed." (#119) "They gave me presents for him that they had bought for him before they knew he would die. It was lovely to get these things even though they were a reminder of his absence. These gifts also reminded me that he was a real baby who was and always will be a part of our family" (#143)
Remembering Anniversaries and Special Days	"My parents & sisters all have special candles in memory of our son & light these on family occasions such as birthdays & Christmas. "(#198) "I have some absolutely wonderful friends. Not one single family member has remembered (or at least mentioned) my son’s birthday, or ever talks about him. Every year at least one of my friends sends me a card on his birthday, calls to see how I’m doing, or in some way lets me know they’re thinking of me, and of my son. That means so much, to know he’s not forgotten, and to know they care." (#304)

	"One person sends me a card for her anniversary every year. It is nice when people remember her. That is only one person, though. And this close friend had also lost a baby at about 24 weeks gestation. Others who never lost, including close relatives and friends do not acknowledge her or her day." (#254) "Many of my friends and family are also very good about remembering his birthday. They always send cards and flowers, which is great, it lets me know that he touched other people's lives too. My biggest fear is that people will forget about him, but when I get things for his birthday it lets me know that people remember." (#57)
Listening and Understanding	"Listened to us talk without trying to give their own opinions." (#312) "Listening quietly as the best thing anyone did for me. You can only listen to so much advice from people who have not been there before you lose your temper. But talking is like a release. Even when you don't realize all that you feel, talking will help you sort it out." (#13) "Just being there and listening no matter how many times they hear the same stories over and over. I only have a certain amount of memories of my sweet babies, so those are what I talk about. In the beginning, I just needed someone to shut-up and just cry with me. " (#80)
Keeping in Touch	"Close friends have insured that I have not become isolated. When I don't return their calls they just keep trying until I am forced to get back to them. They don't take it personally and make every effort to stay in contact and ensure that I am kept in the loop." (#160) "One friend of mine still gives me a card periodically just to let me know she hasn't forgotten my baby-that has meant more to me than anything, especially when it feels that everyone else has forgotten. " (#189)
Practical Help	"Our neighbor organized a meal for our family each night for about two weeks after Marlene had died. Friends took our two boys for playdates so we could get everything ready for the Angel Mass and Funeral and have some quiet time for ourselves. We asked one person out of each group of friends to let the other people know what had happened, so we did not have to tell our story over and over again." (#45) "my children's school brought meals for 2 weeks. Set up playdates every day

for my boys to give me time alone so I could grieve. Certain friends and most family members call almost daily to see how I am doing. Everyone close to me speaks of our daughter often and how much she was loved an is missed." (#47)

4.10.3 Unhelpful comments and behaviours

Unhelpful comments and actions focused on the lack of acknowledgment of grief and the disrespect shown to the baby. Most parents spoke of being subjected to insensitive Platitudes. These responses were perceived to be more a benefit to alleviate the discomfort of the people around them than to provide support to the parents. There was a need for many people in the social network of the bereaved to rationalise the death of the baby in the belief that if they could provide a good reason for the death it would make the parent feel better and thus to "get over it". Avoidance by others was common with many parents perceiving that they were not permitted to express their grief. Family and friends were often more motivated to rationalise the death and encourage recovery because of the effect it was having on their own relationship with the bereaved (Lehman et al., 1986). In this instance the support they were providing was centred on easing their own discomfort.

Questions three to seven asked about specific things people had said and done that had been unhelpful to them in dealing with their grief. Each question focused on different aspects such as making them angry, had been upsetting or had been offensive. Table 21 presents some of the common themes identified in these questions and comments from participants that illustrate them.

Not Acknowledging the Loss

Many felt that people around them did not Acknowledge the significance of their loss. It was reported that people made insensitive comments that referred to being able to easily replace the baby that had died (#137) or that the baby was not a real baby and therefore the parents had no reason to be so upset (#223).

Not acknowledged as a parent

This theme involved parents feeling upset and angry that because they did not have a living child they were not considered as a parent (#137). Most parents talked about the confusion they felt on days such as mother's and father's day when they felt they had a right to be celebrated as a parent yet those around them failed to do this (#35).

Rationalisation of the Death

Many spoke of how family and friends searched for explanations as to why the death had occurred and had tried to justify the death with simple remarks . Comments such as "things happen

for a reason", or "there must have been something wrong with the baby so it is just as well it died", were made under the assumption that this was helping the parents with their grief (#313). Many of these explanations revolved around religious beliefs, that it was God's plan and that the baby was now in a better place (#216).

Platitudes

Parents also spoke about being subjected to a barrage of Platitudes. Comments that minimised the significance of the grief being experiencing were upsetting, offensive and often made the parents feel angry (#107).

Discomfort when baby is mentioned

Most parents spoke of being made to feel uncomfortable when speaking about their baby. They could often sense that those around them were uncomfortable with the conversation and felt that they were not given the opportunity to speak openly (#17). Often the people that these parents felt would be the most supportive were the ones with the least understanding and were responsible for the feelings of discomfort. Not having an opportunity to speak openly about their experience created a sense of isolation and disappointment in those around them (#145).

Avoidance

Avoidance was another area that parents indicated as being unhelpful. The death the baby was often ignored completely or was 'brushed aside' when the conversation was brought up by the parent (#10). This was thought to be because the person wanted to avoid his or her own discomfort derived from talking about the death (#36). Some parents (#28) felt that the subject was avoided in an attempt to spare the parent from painful memories. Parents felt the avoidance was a sign of disrespect to their baby and were deeply hurt by this (#140).

Not Permitted to Grieve

Some parents considered that they were not given the right to grieve for their babies. For many they were told that they should "get over it"(#59). For most, they felt that to "get over it" would be disrespectful to their baby and was something they did not want to do (#175). They were often told that they should be over their grief and that they should be concentrating on moving on with their life (#17).

Table 21 Themes that Illustrate Unhelpful Comments and Behaviours.

Theme	Comments
Not acknowledging the loss	"It" wasn't a real baby. Your lucky "it" happened early. It's not like you became attached to "it". Or that you loved "it". (#3)
	"that you can have another, like you had dropped an ice cream or something equally mundane. " (#119)
	"You can always have another one". What a pile of rot! Of course we can have another one, but the implication that we can just replace our son with another baby is absolute rubbish! " (#137)
	"General lack of acknowledgment that we have experienced a death and general trivialisation of the matter." (# 176)
	"some people have said something like "You'll have another opportunity..." They don't understand that OUR SON is the one that won't have the opportunity. We suffer for him, not for us." (#162)
	"Another thing that really hurt was that my husband's work never acknowledged our baby, but sent flowers to a casual employee the next week, when a family member died, I think that sums it up!! Our loss is insignificant because people never knew the person." (#115)
	"Most people don't even want to talk about your loss because for most of them the baby was never a human being to start with and they won't even address the baby by his or her name. " (#223)
	"I have found that it bothers me a great deal that some people avoid me altogether, won't even look at me, and there are others like my mother-in-law and brother-in-law that never acknowledge that my wife and I had a child at all." (# 218)
	"she (mother) told me to NEVER include Joylynn as a part of our family because she is dead. I no longer speak to my mother." (#305)
Not acknowledged as a parent	"One of the hardest things is that people don't validate your right to be considered a parent, because you have never raised a child. Just because I am not able to hold him in my arms does not mean I am not a parent! " (#137)

	"It also greatly angers me that some people do not consider me (or my husband) to be a parent because my child died in utero. I still had to give birth to my son; he didn't disappear once he died. Society needs to be more sensitive regarding this point. " (#145)
Rationalisation of the Death	"May be it is a blessing that you lost your baby, because there might have been something wrong with it, it might not have been healthy and a burden for you later." (# 45) "I have found that people feel the need to explain the death of our baby as being natures way or gods way etc really frustrating as it implies to me that my babies death should be willingly and instantly accepted and with little fuss, all because they say that my babies life wasn't meant to be. In reality I think that this is peoples strange way of making themselves feel better about the loss of innocent life that is considered socially unacceptable to talk about or acknowledge. " (#313) "Trying to spiritualise and relate my loss to some kind of "higher plan". In most cases, they are trying to relate my loss to <u>their</u> understanding and belief of the way the world is." (#56) "Using religion as a reason for my loss. This has caused me to question my faith a great deal in the last two years. People who have told me "this is God's way" or "God has his reasons" really is frustrating. Why would God do this to me and my husband." (#216) "He's in a better place. Yes I believe in Heaven, and yes I believe Heaven is a better place than earth and yes I believe my son is there. But I am his momma and there is no better place for my son than in my arms." (#17)
Automatic Platitudes	"Those who have said "I know how you feel" have no idea. The one thing nobody knows is how I feel. Also those who have said "It is one of those things" and "it will make you stronger" have no idea either. Generally any of those throw away lines like that really hurt. If they only realise that by using such a trivial statement they are trivialising the whole thing they may realise how insensitive they are being. I know they are trying to help but those who have not experienced that sort of pain have no way of sympathising." (#107) "you're young…you will have another… it was god's will…. etc..etc..etc…. all the usual platitudes." (#113)

	”It was God’s will” , “It was meant to be”, “Maybe she would have had something wrong with her”, “Everything happens for a reason” , “You’ll have other babies”, “You’re so strong; you’ll be okay” (#139) "it is probably for the best” “you’re young – you can have more” “at least you can have another to replace him” “I know how you feel”(from those who don’t) “aren’t you over that yet?”(after 1 month) I could go on and on.: (#191)
Feelings of Discomfort	"…… speak before they think about what they are actually saying and whether they truly believe what they are about to say. All the tiresome cliches…”it was meant to be”…”its Gods will”…”You can have another one”…”These things happen for a reason” All the words that are nothing but hot air and a cover for their own uncomfortableness. (I believe that a deep level most people do care, they just don’t bother to educate themselves/have a fear about death and expressing themselves about death to others. I acknowledge that it certainly isn’t always easy." (#220) "Making me feel as if I did something wrong by talking about him and keeping his memory alive." (#25) "……. Shut up. Let me talk when I need to. Don’t tell me you don’t want to talk about it because it makes YOU uncomfortable and you don’t know what to say. Say nothing. Hug me and let me know that you love me and care about me. That’s all I ask." (#17) "I am made to feel that I shouldn’t mention my baby in the presence of certain people because they don’t want to deal with it and think I should be over it, or at least not talk about it anymore. That has been very disappointing to me – that my family, the very people that I thought I could rely on to provide me with love and support, have been the very people that have let me down the most. I have been emotionally crushed by the lack of understanding I have received from my family. I know they care and have been concerned about me, but they just don’t want to talk about it because it is too painful for them. I feel isolated, ignored and even more alone. " (#145) "My brother in law (husbands brother) refused to come to our daughters funeral because "he didn't think he could cope" how did he think we were coping!!! His and his wifes complete inability to accept our loss still makes me angry." (#172)
Avoidance	"Roll their eyes when Elijah’s name comes up, walking away from me or “removing themselves” from my presence when the topic comes up, judging me and suggesting I should move on …" (# P10)

"I think it is the lack of reaching out and avoiding me that upsets me." (#128)

"Not talk about the baby and pretend that the pregnancy did not happen. (true of co-workers who I think are uncomfortable with the situation, or think that by bringing it up it would hurt me)" (#23)

"People avoid mentioning that anything ever even happened so as to not upset me. I notice it more when people are obviously avoiding the issue and pretend that I was not pregnant two months ago and lost a baby. It is always on the top of my mind, especially since it happened so recently, so I feel very uncomfortable when people ignore it. " (#28)

"Some of my “friends” were totally unsupportive because they say they did not know what to do. They thought we needed time to ourselves so they just stayed away. This was not what we wanted but they were uncomfortable so they did this to make themselves feel better." (#36)

"Friends at work told people not to say anything to me when I came back to work. No one talked to me for 3 months." (#124)

"People had avoided me, avoided talking about the loss of our babies, if you don’t talk about it, it won’t hurt…ha! I would be the one to have to bring up the subject, for I needed to talk! " (#221)

"The majority of people ignore my “situation”. Their silence hurts me more than they can know." (#140)

"It has been hard because everyone has stopped calling or coming over. I have friends who avoid me, because I tell them I still hurt and they don’t want to be around me. I want them to call and to help me out when I am so down and depressed that I feel like I can barely cope with my day. I need them more now than I did after I lost my little girl." (#142)

"They have not talked about her or acknowledged our loss, except in the period immediately afterward. I suppose they think they are being helpful by not dredging up memories & letting us “get on” with our lives, but it hurts very much to feel like our child has been forgotten by everyone except us." (#177)

Not Permitted to Grieve

"Four years? Aren’t you over it by now?” “There must be something wrong with you. Have you tried a good therapist?” " (#108)

"you need to put the past behind you and get on with your life (six weeks later), my mother once asked me (about 3 weeks after) why I was so down in the dumps on this particular day. " (#252)

"Snap out of it. You should be over this by now." (#282)

"They had no understanding how debilitating my grief was. You need to move on. It's been 2 months now, life goes on you have to snap out of it." (#314)

"So many people tried to fix me and didn't understand that what I was feeling and doing was normal " (#314)

"Expecting me to get over it right away, since I never really "knew" my baby." (#59)

"Assuming that enough time has passed and I should be "over it". I may look fine on the outside, and I may be able to get on with my life, but I never want to be "over" her." (#175)

"it gets better with time. Whoever first said this obviously never buried their child. It does not get easier. It gets different. You are better equipped to cope with his 2nd birthday because you've been through his 1st. And so on. But, easier? No. It's never easy." (#17)

"You need to get over it and move on with your life. I go to work every day. Work a 40 hour work week. I cook dinner every night for me and my husband. I clean house, I do laundry. What's your definition of getting on with your life? I am living my life…..I'm just living it with an tremendous loss and with grief more painful than anyone can ever imagine " (#17)

"I am made to feel that I shouldn't mention my baby in the presence of certain people because they don't want to deal with it and think I should be over it, or at least not talk about it anymore." (#218)

"You shouldn't have to grieve . . after all it wasn't really a baby yet" (#181)

"Telling me that it was time to stop grieving for her. I didn't know there was a time limit on grieving." (#16)

4.10.4 Hypothetical Support

Question 8 asked participants to hypothetically comment on what they would say and do if they had a friend who had experienced the death of a baby. Most responses were a replication of what had been stated in the previous questions. They spoke of acknowledging the baby and the parents and of listening in a non judgmental way to them talk about their experience. Giving the bereaved parent a sense of 'not being alone' appeared to be an important aspect of most comments of hypothetical support.

Allowing the bereaved parent to guide the person how to help was also deemed important along with remembering the baby with the bereaved.

Table 22 Comments on Hypothetical Attempts of Support

	Comments
Hypothetical Support Attempts	"I would hug them and tell them that I am so sorry and that this is wrong, it shouldn't happen to anyone. It's okay to cry and grieve. I would hold them as long as they needed to be held. I would tell them to love their baby with a mother's fury, to hold on to that baby and not let anyone tell them that they should forget, get passed it or just let it be. I would offer to help them in anyway that I can. I would offer to help with funeral, burial, clothes anything. I would cook and clean their home if that's what they needed. I would help them; not try and protect them from the pain. You can't protect anyone from the anguish. The anguish will come regardless, but at least I would try to help them through it because unfortunately they are not alone. I've already been there and I'm still there. I would help them even if it means I say or do nothing. Sometimes silence is comforting, just knowing that that person is near is enough. But I would never let them feel alone." (#70) "Tell them I am very sad for them and sad for their baby. Listen to what they have to say and give them my full attention. Not offer answers or reasons or try to "fix" things. Let them express themselves and their expressions of grief in whatever way they wished, crying, talking, yelling. Allow them to talk about their child and share memories such as photos with me. Allow them as much time as they need for this expression and for themselves. Answer any questions they may have honestly and assist them ,if requested, to find answers to questions they may have. In a situation that I'm unsure about something I wish to do for ,or talk with the parent about, I ask how they feel about it beforehand. Ensure that their baby is remembered and included at special celebration times (Christmas) ,anniversaries/birthdays and milestones (first day of school), but only to do so if that was what the parent wished. Maintain contact with the parent at regular intervals and ensure that I contact them when I said I would." (#220).

The way that society deals with death and the non -status of the unborn baby often means that the death of a baby is not given enough significance to allow parents to express their grief. Members of their support network often have difficulty providing the support needed because they may feel threatened themselves and uncertain about how to help (Dunkel-Schetter & Bennett, 1990). The lack of significant influence that support from family, friends and professionals had on the level of grief reported by the parents in this study may be due to a lack of understanding. Motivated by a need to "fix" the problem and take away the pain the parents are feeling, support people often neglect to try and understand the needs of the grieving parent. Understanding is found by talking to others who have experienced the death of a baby and is of great comfort to these people. However, the responses to the qualitative questions indicate that it is understanding from those who love and care for them that is most needed. Parents are hurt when the people they depend on for support fail to see the magnitude of their loss and try to encourage them to "move on". The comments from these parents clearly indicate that to "move on" implies that they should forget their baby, which is something they are not willing to do.

5.7 Limitations

The majority of parents in this study were currently, or had been members of a support group. It would be interesting to have recruited more parents from different sources to investigate if there were differences in the level of grief and support between those parents who feel comfortable in a support group and those who manage their grief without being part of a group. It could be that those people who join support groups experience their grief differently to other bereaved parents. It might be that support groups encourage parents to become obsessed by their grief and not able to adapt to the death of their baby. This would be an interesting aspect to investigate in the future.

5.8 Conclusion

Grief associated with the death of a baby can be influenced by support from others. Surprisingly, according to this study, the bereaved parents family and friends do not have an influence on grief. It may be possible that family and friends are too close to the bereaved and have difficulty in providing support due to their own grief after the death of a baby. Information that informs family and friends of how they can provide appropriate support while dealing with their own grief may be beneficial. The comments from bereaved parents indicate that as time progressed those who are close to the bereaved may become frustrated and feel that the support they are providing is inadequate. Comments from participants suggested that they were pressured by family and friends to recover from their grief. Their comments to the bereaved indicated that they felt that the bereaved had spent long enough grieving and encouraged them to 'move on'.

Unlike the common assumption that time heals, bereaved parents reported increased grief as time progresses. Further research into the influence of time of grief would be an interesting continuation of this study. Further support from this hypothesis may lead to a new direction in the provision of support. Comments from participants indicated that there was a time limit to how long they were permitted to grieve, although this was not viewed as sufficient to most parents. Possibly temporal issues can be explained by the reliance on theories of grief that involve stages and phases. The more recent models that do not promote that the bereaved should recover from grief but should learn to adapt may better explain the experience of grief.

Research into support groups and how they facilitate adaptation to a loss may be an interesting area of future study. It may be possible that the support group environment is a useful resource for a bereaved parent. Talking with others who have had a similar experience may in fact be how the bereaved learns adaptive coping skills. However, answers to issues such as this are far beyond the scope of this study but provide interesting possibilities for future studies in the area of bereavement and grief.

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